

# ALPORT UK

England & Wales · Charity number 1154774

## Details

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**Status** Registered

**Legal form** CIO

**Registered** 2013-11-27

**Register** [View on the Charity Commission register](#)

## Contact

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**Address** PO Box 329  
Cirencester  
GL7 9JA

**Phone** 01793 847264

**Email** [info@alportuk.org](mailto:info@alportuk.org)

**Website** [alportuk.org](http://alportuk.org)

## Activities

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**Objects:** THE OBJECTS OF THE CIO ARE THE RELIEF OF SICKNESS AND THE PROMOTION OF HEALTH OF THOSE PEOPLE SUFFERING FROM ALPORT SYNDROME, IN PARTICULAR, BUT NOT EXCLUSIVELY BY: (A) THE ESTABLISHMENT AND FACILITATION OF A SUPPORT NETWORK FOR ALPORT SYNDROME PATIENTS, CARRIERS, THEIR FAMILIES AND CARERS; (B) THE PROVISION OF INFORMATION ON ALPORT SYNDROME; (C) THE SUPPORT OF RESEARCH INTO ALPORT SYNDROME BOTH IN THE UK AND INTERNATIONALLY;(D) THE SUPPORT OF A RESEARCH REGISTRY IN THE UK AND AN INTERNATIONAL ALLIANCE OF NATIONAL REGISTRIES.

**Activities:** Working in partnership with patients and the scientific community we will:- Facilitate a support network for individuals and families- Be a conduit for high quality, accessible information- Raise the profile of Alport Syndrome- Contribute to the international research agenda- Collaborate on the development of a UK patient registry and alliance of international patient registries.

## Classification

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- **How:** Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups

## Geography

- Throughout England And Wales

## Finances

| Period end | Income   | Expenditure | Assets | Employees |
|------------|----------|-------------|--------|-----------|
| 2025-08-01 |          | -           | -      | -         |
| 2024-08-01 | £154,267 | £155,496    | -      | -         |
| 2023-08-01 | £92,190  | £93,858     | -      | -         |
| 2022-08-01 | £37,443  | £47,756     | -      | -         |
| 2021-08-01 | £60,067  | £28,327     | -      | -         |
| 2020-08-01 | £60,067  | £28,327     | -      | -         |

## Trustees

| Name                           | Role  | Appointed  |
|--------------------------------|-------|------------|
| Professor Frances Anne Flinter | Chair | 2025-04-11 |
| Alice Turner                   |       | 2025-05-06 |
| Amanda McLean                  |       | 2025-05-09 |
| Professor Daniel Gale          |       | 2025-04-29 |
| Professor Neil Turner          |       | 2025-04-29 |
| Professor Rachel Lennon        |       | 2025-04-11 |
| Susie Gear                     |       | 2025-06-30 |

**ALPORT UK**

England & Wales - Charity number 1154774

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# Accounts

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# ANNUAL REPORT AND ACCOUNTS



For the year ended 31 July 2024

## Trustees' Annual Report for the period

|      |   |                   |      |    |    |   |                 |  |  |
|------|---|-------------------|------|----|----|---|-----------------|--|--|
|      |   | Period start date |      |    |    |   | Period end date |  |  |
| From | 1 | 8                 | 2023 | To | 31 | 7 | 2024            |  |  |
|      |   |                   |      |    |    |   |                 |  |  |

### Section A Reference and administration details

Charity name

Other names charity is known by

Registered charity number (if any)

Charity's principal address

#### Names of the charity trustees who manage the charity

|    | Trustee name    | Office (if any) | Dates acted if not for whole year | Name of person (or body) entitled to appoint trustee (if any) |
|----|-----------------|-----------------|-----------------------------------|---------------------------------------------------------------|
| 1  | Colin Baigent   |                 | Whole year                        |                                                               |
| 2  | Julia Skelding  |                 | 01 August 2023 – 21 May 2024      |                                                               |
| 3  | Susie Gear      | Chief Executive | Whole year                        |                                                               |
| 4  | Frances Flinter |                 | Whole year                        |                                                               |
| 5  | Rachel Lennon   |                 | Whole year                        |                                                               |
| 6  | Neil Turner     |                 | Whole year                        |                                                               |
| 7  | Danny Gale      |                 | Whole year                        |                                                               |
| 8  | Tim McLean      |                 | Whole year                        |                                                               |
| 9  | Amanda McLean   |                 | Whole year                        |                                                               |
| 10 | Alice Turner    |                 | Whole year                        |                                                               |

#### Names of the trustees for the charity, if any, (for example, any custodian trustees)

| Name | Dates acted if not for whole year |
|------|-----------------------------------|
| n/a  |                                   |
|      |                                   |
|      |                                   |

## Names and addresses of advisers (Optional information)

| Type of adviser                                                                 | Name                               | Address                                                                                                                                                                          |
|---------------------------------------------------------------------------------|------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Medical – paediatric nephrologist</b>                                        | Professor Rachel Lennon            | Royal Manchester Children's Hospital, Oxford Road, Manchester M13 9WL                                                                                                            |
| <b>Medical – adult nephrologist</b>                                             | Professor Neil Turner              | University of Edinburgh Renal and Autoimmunity Group, MRC Centre for Inflammation, Queen's Medical Research Institute, Little France, Edinburgh, EH16 4TJ                        |
| <b>Medical – adult nephrologist</b>                                             | Professor Daniel Gale              | Department of Renal Medicine, University College London                                                                                                                          |
| <b>Geneticist</b>                                                               | Emeritus Professor Frances Flinter | Emeritus Professor of Clinical Genetics, Guy's & St Thomas' NHS Foundation Trust<br>Genetics Department, 7th floor Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT |
| <b>Physiologist – hearing</b>                                                   | Professor Dan Jagger               | University College London, UCL Ear Institute, 332 Gray's Inn Rd, London, WC1X 8EE, United Kingdom                                                                                |
| <b>Eye specialist</b>                                                           | Dr Omar Mahroo                     | St Thomas' Hospital Campus, 3rd Floor South Wing Block D, Westminster Bridge Road, London SE1 7EH                                                                                |
| <b>PR, Communication and Marketing</b>                                          | Jane Keightley                     | JK Branding and Communications Limited                                                                                                                                           |
| <b>Accountant</b>                                                               | David Cuthbertson                  | Shilton Accounting Services Ltd                                                                                                                                                  |
| Name of chief executive or names of senior staff members (Optional information) |                                    |                                                                                                                                                                                  |
| Susie Gear, Chief Executive                                                     |                                    |                                                                                                                                                                                  |

## Section B Structure, governance and management

### Description of the charity's trusts

|                                                                     |                                                                                                               |
|---------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| Type of governing document<br>(eg. trust deed, constitution)        | Constitution                                                                                                  |
| How the charity is constituted<br>(eg. trust, association, company) | Charitable Incorporated Organisation                                                                          |
| Trustee selection methods<br>(eg. appointed by, elected by)         | Appointed for a term of 3 years by a resolution passed at a properly convened meeting of the Charity Trustees |

### Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Policies and procedures for the induction and training of trustees

- Provided with a guide for how the charity operates – this now includes a set of policies on topics such as expenses, relationship with pharmaceutical companies, sponsorship etc.
- Disclosure and Barring checks
- Given a briefing on the charity and engaged in activities to enable them to participate fully in the decisions of the charity.

Organisational structure of the charity and wider network

- We are a small charity and so have a very flat organisational structure.
- Day-to-day activities are run by one of the trustees – Susie Gear with two part-time employees and a number of volunteers. All day-to-day decisions are jointly taken with at least one of the other Trustees eg Alice Turner, Amanda McLean, Emeritus Professor Frances Flinter or Professor Rachel Lennon. If we need to check any of the decisions, we involve the other trustees - who are less involved in the day-to-day activities and so provide excellent challenge and objectivity.
- Our closed Facebook page, Alport Warriors, is moderated day-to-day by one of our volunteers – Wilma Calderwood – with back up from Hannah Russell and Susie Gear and with any specific medical questions answered by our medical advisory team – see list above.
- Our public facing social media eg Facebook and Instagram pages are run by Susie Gear, Hannah Russell and some of the younger Alport Warriors.
- Alport UK's Scientific Advisory Committee provide expert medical input and advice as required: Professor Colin Baigent (Strategic direction of research and Clinical trials), Emeritus Professor Frances Flinter (Clinical and particularly Genetics and diagnoses), Professor Danny Gale (Rare Renal Database RaDaR and Clinical trials), Professor Rachel Lennon (Paediatric Nephrology, Podocyte research and clinical guidelines) and Professor Neil Turner (Adult Nephrology and RaDaR).
- Alport UK's international Workshop Organising Committee is made up of a wide range of 40 experts – researchers, clinicians and Alport patients – with representation from Australia, Belgium, Brazil, Canada, China, Croatia, Cyprus, France, Germany, Hong Kong, Israel, Italy, Japan, Lithuania, Poland, Russia, Singapore, Spain, Thailand, UK, USA.

Trustees' consideration of the major risks & procedures to manage them:

- **Support** – as we support patients and family members living with Alport Syndrome, there can be specific questions or situations that require medical advice or input. For the majority of questions, it is

Alport UK's policy to encourage patients and their families to partner with their own clinicians to explore their questions and concerns together. This is because the questions often require a detailed clinical history, which a patient's own clinician is best-placed to support with. Where this is not possible or for more general questions, we have a scientific advisory committee which is available, with 24-hour turnaround, to provide expert medical input, signposting and advice to patients and their families. All committee members are practising/retired clinicians in the NHS and are recognised internationally for their experience and expertise. We also have a wider network of international experts from whom we can get additional opinions, as required. As we support a number of young adults and vulnerable adults, we have a Safeguarding Officer, who we consult if there are any safeguarding concerns. Mental health is an ongoing challenge for patients living with a life-long condition where the health declines, so we encourage patients to seek professional help from the NHS and help them access the necessary services often through renal units or Kidney Care UK.

- **Information** – all published information and recommendations published on our website, [alportuk.org](http://alportuk.org), is reviewed by members of our scientific advisory committee.
- **Research** – all projects we embark on are reviewed by members of our scientific advisory committee and we get input from a wider network of international experts and patients, as required. This includes assessing clinical trials and although, as a charity, we never recommend participation in a trial, we direct patients to discuss clinical trials with their own clinicians and provide as much information as possible to support patients' decisions on participating in a trial. If we have concerns with a trial, we publish views in international publications, as necessary.
- **Collaboration** – is a core way of working for our charity. We collaborate with other national patient organisations and an international scientific community interested in research into Alport Syndrome. We run monthly conference calls and a series of international workshops for all involved to keep in touch with progress. Funds for these international research activities are kept in a separate bank account so that the international expenditure is transparent – and separate from the UK funds - to maintain the open collaborative working environment. To ensure all appropriate risks are managed related to this international collaboration, we have an international Workshop Organising Committee to ensure there is a balance of work and information across different countries or continents. Our aim is to collaborate with an increasingly diverse community to remove bias.
- **Fundraising, finances and projects** – As a small charity, we fundraise for specific projects and these funds are kept in separate bank accounts 'ring-fenced' for each project. The majority of our fundraising is through applications to larger charities that support small charities, such as ours, with funds allocated for specific activities, such as the information days or international workshops undertaken by alport uk. Increasingly, we also seek funding for work from biotech and pharmaceutical companies. We aim to raise collaborative funding for any project, so we are not reliant on one company for project funding which also means Alport UK is not associated with one company for one particular project.

## Section C

## Objectives and activities

Summary of the objects of the charity set out in its governing document

The objects of the CIO are the relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- The establishment and facilitation of a **support network** for Alport Syndrome patients, carriers, their families and carers;
- The **provision of information** on Alport Syndrome;
- The **support of research** into Alport Syndrome both in the UK and internationally;
- The **support of a research registry in the UK** and an international alliance of national registries

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

### Public benefit – statutory declaration by Trustees

The Trustees have paid due regard to the Charity Commission's guidance on public benefit in deciding what activities the charity should undertake. alport uk recognises and welcomes the need to carry out its charitable activities to the benefit of those affected by Alport Syndrome, and retains this aim at the centre of its strategic planning.

**alport uk is a patient-led organisation** dedicated to facilitating a support and information network for all those affected by Alport Syndrome.

**Alport Syndrome** is an inherited condition that can cause kidney failure, deafness and eye abnormalities. Those who inherit it will probably require a kidney transplant when they are young adults. It can impact a large number of people in a family. It is the second most common form of inherited kidney disease. Meet Sam to understand the impact it has on an individual: <https://www.youtube.com/watch?v=fMrtfUV8GOI>.

**Our Vision** is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life.

**Our Mission** is to work in partnership with individuals, families and the scientific community to:

- Facilitate a **support** network for patients and families
- Be a conduit for high quality, accessible **information**
- **Raise the profile** of Alport Syndrome in the scientific community
- Contribute to the international **research** agenda
- **Collaborate** on the development of a UK patient registry and alliance of international patient registries.

### alport UK fund four key areas of activity

1. **Support** – Provide support for UK patients and families through a support network, website and information days.
2. **Information** – Work with clinicians, individuals and families to educate them on more effective diagnosis and treatment, for example national and international guidelines for diagnosis, treatment and the best care for children, teenagers and adults.
3. **Research** – Work with other national patient organisations (eg USA, across Europe and Asia) to:
  - a. Facilitate and drive the design, development and maintenance of an international research strategy and plan for Alport

Syndrome using a programme of international workshops – online and in-person.

- b. Grow a global network – of patients, clinicians, laboratory scientist and pharma companies – the Alport Syndrome Alliance. The aim of the Alliance's global network is to advance treatments and knowledge.

- 4. **Collaboration** – Bring together the scientific community to work across the different clinical disciplines that specialise in kidneys, ears, eyes, mental health, other rare disease areas with similar issues etc. and work with the national patient organisations or other rare renal disease groups to share best practice with developed and developing countries.

The activities of alport uk are grounded in the local communities across the UK as we aim to connect up regional groups of individuals and families that are affected by Alport Syndrome. As a possible few thousand individuals impacted in the UK, it is a small population of those living with Alport Syndrome if looked at on their own. This requires alport uk to work internationally with other national patient organisations and clinicians to co-ordinate activities and research across a far bigger group of patients, particularly those with 100,000+ patients in countries such as China and USA.

## Additional details of objectives and activities (Optional information)

### Contribution by volunteers

**alport uk had two part-time employees over this period. The Chief Executive, leading the performance and achievements, is a volunteer. alport uk relied on voluntary help to run the activities over this period as for the previous nine years.** With the growth of our community over Covid, we took steps to grow the number of volunteers in our team as we received more queries than we could respond to with the size of our team. Many volunteers come to us initially asking for support and then offer their many skills to help others as they see how they benefited.

**Our community often reflect and remark on the journey we've been on and the remarkable progress alport uk makes and their ability to support patients and deliver professional international events that appeal to all stakeholders.**

**We are incredibly grateful to the many volunteers for this remarkable progress, especially for the many contributions from the following key and very motivated people:**

- **Saira Bhatti** for her work on ERKNet Alport patient journeys, and for spending time educating us on how to design websites to suit patient needs, with accessible content.
- **Kimya Bungler** for participating in The 2024 International workshop on Alport Syndrome in Cyprus and for writing up the notes and supporting Tom Oates with the scientific publication.
- **Wilma Calderwood** for her day-to-day moderation on our closed Facebook page, Alport Warriors.
- **Sam Clarke** whose 4,776-mile cycle ride in 2019 allows us to use the funds raised for the 'Don't Wait Fund' to support patients with Alport Syndrome take up a new activity or hobby.
- **Dan Jagger** for participating in both the patient days in Liverpool and at The 2024 International workshop on Alport Syndrome in Cyprus and sharing his instructive info and videos about hearing.
- **Dan Long** for running the production of our online workshops.
- **Amanda McLean** for welcoming all the participants of The 2024 International Workshop on Alport Syndrome in Cyprus, and ensuring it ran smoothly.
- **Tom Oates** for participating in The 2024 International workshop on Alport Syndrome in Cyprus and for drafting the content for the scientific publication to summarise the workshop.
- **Louise Oni** for hosting the Alport information day in Liverpool.
- **Alice Turner** for her continuing enthusiasm and fundraising work, ideas and help with running alport uk.
- **Archie Walker** for running the production of our online workshops.
- **Patrick Walker** for moderating our online workshops and engaging young adult patients at the in-person workshop in Cyprus and the information day in Liverpool.
- **Heidi Zealey** for helping The 2024 International Workshop on Alport Syndrome in Cyprus run smoothly and professionally. Also thanks to Heidi for continuing to represent Alport UK with European patient groups such as FEDERG and ERKNet EPAGs, including working on European clinical guidelines for Alport Syndrome.

- **Aura Zealey Smith** for moderating our online workshops and taking time out of her studies to join the information day in Liverpool.

**Grateful thanks to all those who raised money for us this year – every penny makes a difference. Particular thanks go to:**

- **Margaret and Sam Maidment** and their family and friends who raised over £4,000 hosting an afternoon tea in August 2023.

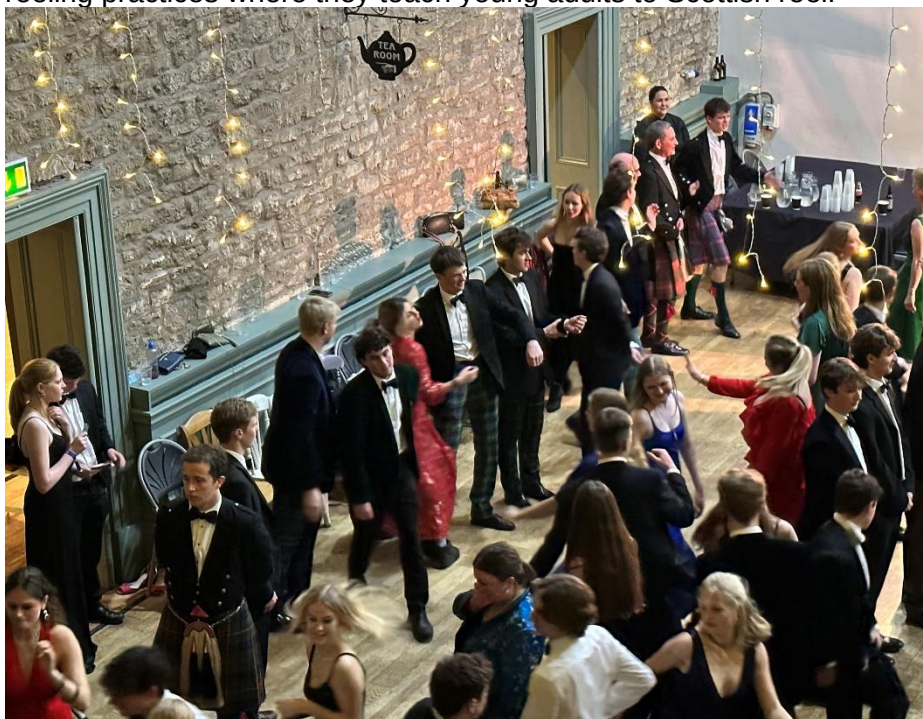


- **Disa Hunter**, who raised £2,580 and raised awareness of Alport Syndrome and Alport UK at her pop-up shop in Shetland in November 2023. Her family, friends and the Shetland community donated clothes, toys and other items, which Disa sold in her pop-up shop.



- **Sarah Forrester and her organising committee** at the Cirencester Kick Up your Heels Gathering in December 2023 (an annual reeling event) that raises vital funds for Alport UK and other charities.

Particular thanks go to **Jamie Walker** for organising a huge reeling party and raising the funds through tickets sales and by running reeling practices where they teach young adults to Scottish reel.



Some of the young people reeling in aid of alport uk, December 2023.

- **The Reis family in Cornwall** – to celebrate the wedding of Rowan Williams and Sam Reis.
- **Those who donated funds raised from funerals** of loved ones. Particular thanks go to the family of Mike Gear - Gears, Farrows and Walkers - who raised £6,640 in Mike's memory, to help diagnose and support people who do not yet know they have Alport Syndrome. Alport Syndrome was hugely important to Mike Gear as his wife Sal was diagnosed with Alport, in her 20s in the late 1960s. Mike was so positive in supporting Sal through over 30 years of dialysis and two kidney transplants. Alport Syndrome also impacts many other members of the family.

**And those who generously provided alport uk with a grant:**

- **Amelia Chadwick Trust**
- **D'Oyly Carte Charitable Trust**
- **Dyer's Company and other livery companies**
- **Farrer-Brown Trust**
- **Kidney Care UK**
- **Kidney Research UK**
- **Liverpool Charity and Volunteer Services**
- **Stoneygate Trust**
- **Commercial companies** – Calliditas, Biotronic Ltd (Cyprus), Enyo, C. Georgiou Lab Supplies (Cyprus), Nefronitda Nephrology Center (Cyprus), Regeneron, Travere and Visterra who sponsored either patient days in Liverpool or The 2024 International Workshop on Alport Syndrome in Cyprus.

**And a number of people who wish to remain anonymous** but to whom we are very grateful for their support and encouragement.

**We wish to thank our Scientific Advisory Committee** for continuing to spend so much time this year advising and supporting support the community as the pandemic continued its hold whilst they were all also very busy on clinical wards helping with renal issues. They answered all queries within 24 hours, ensuring the community remained as calm as possible at such a worrying time for renal patients. We are so very grateful to the scientific community for their help to answer all questions and emails as and when they arose from patients or other scientists. Very many thanks to our UK Scientific Advisory Group:

- **Emeritus Professor Frances Flinter**
- **Professor Danny Gale**
- **Dr Thomas Hiemstra**
- **Professor Dan Jagger**
- **Professor Rachel Lennon**
- **Dr Omar Mahroo**
- **Professor Neil Turner**
- **Professor Colin Baigent.**

**Alport online workshops** – Patients, patient families and clinicians continued to volunteer for alport uk. Thanks to **Patrick Walker** and **Aura Zealey-Smith** for their



Aura Zealey Smith moderating a workshop online

excellent moderation and broadcasting skills quizzing the scientists to make each production so much more engaging for the online audiences - see Alport Workshops on YouTube channel: <https://tinyurl.com/y9cuhgby>. Thanks also to **Dan Long** and **Archie Walker** for managing the productions behind the scenes, doing the rehearsals with scientific teams all over the world and training people up to deliver some outstanding workshops.



Patrick Walker moderating an online workshop

Thank you to **Patrick Walker** for his excellent video-editing work that makes each Podcast so professional when loaded onto YouTube. We are so grateful for the ongoing inspiration from this group who help run the very professional **Alport online workshops** featuring the latest Alport research, using Zoom, which were provided for the international Alport community (patients and scientists) by alport uk and with set up costs kindly funded by Kidney Research UK. Volunteers who helped with the workshops, acting as moderators or contributors telling their stories also included **Katie Brown, Sam Clarke, Dan Long, Patrick Walker, Heidi Zealey, Aura Zealey-Smith**

We wish to thank those involved in growing **Alport Avengers**, an invaluable WhatsApp group specifically aimed at 18–35-year-olds, joining and sharing their experiences to help others. This included **Katie Brown, Sam Clarke, Emmy Peters, Jamie Walker, Patrick Walker** and **Aura Zealey-Smith**.

We are also very grateful to our colleagues who run the other national patient organisations and collaborate with alport uk, such as **André Weinstock** (Alport Syndrome Foundation, USA), **Maria José Cacharron** (Spain), **Jessie Zhang and Mr Cai** (China), **Christof Finkler** (Germany), **Dave Blatt** (Australia).

Huge thanks to the inspiration of many volunteers around the world – each Alport experts in both their scientific area and geography - that made up the **Workshop Organising Committee for The 2024 International Workshop on Alport Syndrome in Nicosia, Cyprus: Dr Marina Aksenova**, Veltischev Research and Clinical Institute for Pediatrics of the Pirogov Russian National Research Medical University, Moscow, Russia  
**Assistant Professor Moumita Barua**, Toronto General Hospital, Toronto, Canada  
**Dr Agnė Čerkauskaitė**, Division of diagnosis and treatment of Rare Kidney and Metabolic Diseases, Nephrology Center, Vilnius University Hospital Santaros Klinikos, Vilnius, Lithuania  
**Professor Constantinos Deltas**, University of Cyprus, Molecular Medicine Research Center, Nicosia, Cyprus  
**Professor Jie Ding**, Department of Pediatrics, Peking

University First Hospital, Beijing, China  
**Professor Frances Flinter**, Emeritus Professor of Clinical Genetics, Guy's and St Thomas' NHS Foundation Trust, London, UK  
**Professor Daniel Gale**, Department of Renal Medicine, University College London, UK  
**Professor Danica Galešić-Ljubanović**, Department of Pathology University of Zagreb School of Medicine, Head of Department of Nephropathology and Electron Microscopy, Dubrava University Hospital, Zagreb, Croatia  
**Professor Oliver Gross**, Department of Nephrology and Rheumatology, Georg-August-Universität Göttingen, Germany  
**Professor Julia Höfele**, Institute of Human Genetics, Munich, Germany  
**Professor Hirofumi Kai**, Graduate School of Pharmaceutical Sciences, Kumamoto University, Japan  
**Professor Bertrand Knebelmann**, Necker Hospital, Paris, France  
**Associate Professor Ron Korstanje**, The Jackson Laboratory, Bar Harbor, USA  
**Professor Rachel Lennon**, Wellcome Trust Centre for Cell-Matrix Research, University of Manchester, UK  
**Associate Professor Beata Lipska**, Department of Biology and Medical Genetics, Medical University of Gdańsk  
**Dr Laura Massella**, Division of Nephrology, Dpt. of Pediatric Subspecialties, Bambino Gesù Children's Hospital - IRCCS, Rome, Italy  
**Professor Julian Midgley**, Department of Paediatrics, Alberta Children's Hospital, Canada  
**Professor Jeffrey Miner**, Washington University in St. Louis, USA  
**Associate Professor Laura Perin**, Saban Research Institute, University of Southern California, USA  
**Professor Judith Savige**, University of Melbourne, Australia  
**Professor Roser Torra**, Fundació Puigvert, Barcelona, Spain  
**Professor Neil Turner**, Professor of Nephrology, University of Edinburgh and Consultant Nephrologist, Royal Infirmary of Edinburgh, UK

**Patient representatives:**

**Dave Blatt**, Alport Foundation of Australia  
**Maria José Cacharron**, Spain  
**Christof Finkler**, Alport Selbsthilfe, Germany  
**Susie Gear, Amanda McLean, Heidi Zealey**, alport uk  
**Julia Schifter**, Alport Foundation Israel  
**Andre Weinstock**, USA  
**Jessie Zhang and Mr Cai**, Chinese patient group, China

Our special thanks to **all members of the Lennon Lab of Manchester University** who are based at the Wellcome Centre for Cell Matrix and led by the inspirational **Professor Rachel Lennon, also responsible for**



Professor Rachel Lennon being filmed by patient Sam Clarke

**running Stoneygate Trust and Kidney Research UK's Alport Research Hub.** The team all volunteered and worked very closely with alport uk on a number of different events and projects over the year including The 2024 International Workshop on Alport Syndrome and are doing some amazing basic science research and collaborations with the Alport community around the world. The Lennon lab research work is internationally recognised as leading edge and helping us better understand what happens in the kidneys with Alport Syndrome. They also are always on hand to support alport uk with explaining scientific terms, helping design workshop agendas and generally engaging with the patient community. It is unusual for patients to be so engaged in research and we have the Lennon lab and Rachel Lennon to thank for this exciting collaboration that is leading to new ways of working.



Bernard Davenport and Rachel Lennon talking about the Alport Research Hub at the information day in Liverpool.

When we organise **Alport information days**, such as the one in Liverpool (July 2024), we work with local kidney doctors and their teams to volunteer, help us find suitable venues and engage the local patient

community. To update people on the latest Alport research, we also rely on Alport experts including geneticists, hearing experts and the Alport Research Hub employees to give up a Saturday and to travel across the country to come and present their latest research. For the information day in Liverpool (July 2024) we are very grateful to the following, who volunteered to come to give presentations and answer questions: **Austin Chukwu, Bernard Davenport, Frances Flinter, Dan Jagger, Rachel Lennon, Louise Oni.**

The international workshops on Alport Syndrome also require a local team in that country to organise the local aspects of the workshop. For **The 2024 International Workshop on Alport Syndrome**, grateful thanks go to co-organisier and host **Professor Constantinos Deltas**, and the **Biobank.Cy team**, especially **Ioanna Christodoulou**.



Professor Constantinos Deltas and Ioanna Christodoulou being presented with gifts from representatives of the China Alport patient group.

There are also a number of people we would like to recognise for their contributions to our projects. Although we pay them for the project work they do, each has given way more time and ideas than they charge us for. Their continued support we very much appreciate:

- **Jane Keightley** – for her marketing advice and on-going support to build the brand of Alport UK to raise its profile along with communicating and engaging people in our aims and objectives and core activities. We also very much appreciate Jane's writing and editorial advice that sets the written tone for all our communications.
- **Robina Newman** – for her continued work on our brand and design and generally helping us to create a bright and distinctive identity that sets the visual tone for our activities including some lovely branded merchandise which helps our patients be proud of their Alports and of our community.



- **Paul Heaps** – who kindly took photos of the Liverpool patient day, to share what we do, celebrate our special team, and photograph all who participated.
- **Sam Clarke** – for his excellent videos that make our work come alive and enable alport uk to share the important work we do. This year Sam filmed:
  - Some more powerful short documentaries of people Living with Alport Syndrome shown at the Liverpool information day: Mark Thomas: <https://youtu.be/OzYP42oXTAg>  
Pippa Thomas – a ‘partner’s perspective’: <https://youtu.be/WJmCEqjUFYM>
  - The 2024 International Workshop on Alport Syndrome: <https://youtu.be/qtLCY2Yg8o8>
  - A couple of videos celebrating 10 years of Alport UK and ideas for the future:  
Alport Syndrome Alliance 10 years on: <https://youtu.be/vAk9HgxEJ-Y>  
Ideas for Alport research, looking ahead to 2034: <https://youtu.be/qtLCY2Yg8o8>



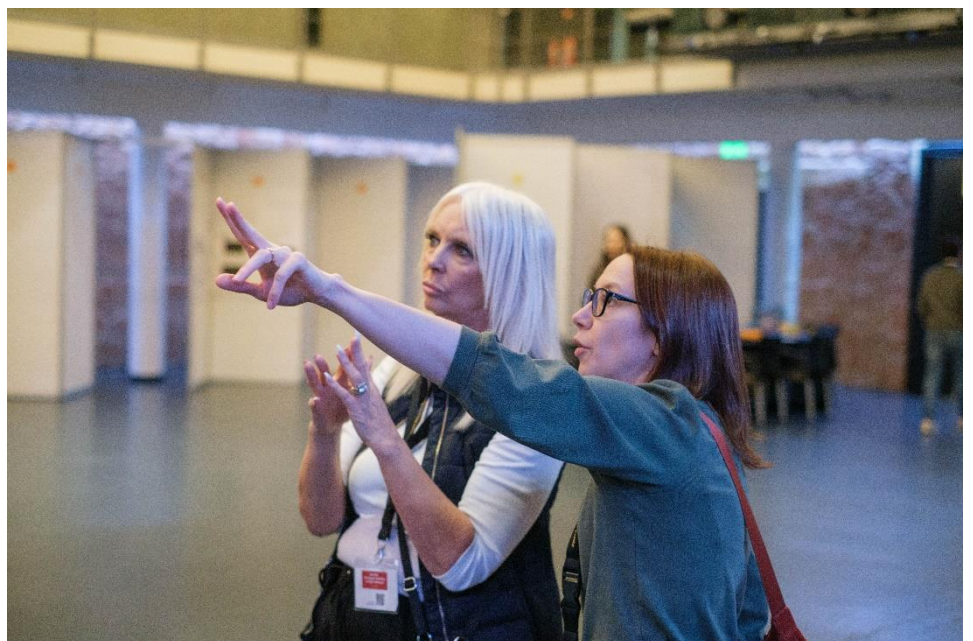
Sam Clarke filming at The 2024 International workshop on Alport Syndrome in Nicosia, Cyprus. See links above for examples of the 2-minute videos he makes.

- **Hannah Russell**, Engagement Director, initially became a volunteer for alport uk soon after her daughter Florence was diagnosed with Alport Syndrome. Hannah’s role, initially as Fundraising and Engagement Manager, was formalised and became a paid part-time role in 2023. With her understanding of the journey that newly-diagnosed families go on, means Hannah sensitively supports those who can find the initial diagnosis challenging. Hannah does this selflessly and with great compassion helping them adjust to their situation and connect with others living with Alport Syndrome. Hannah enjoyed working with the Alport UK team, volunteers, clinicians, researchers, other charities and pharma to collaboratively deliver the patient day in Liverpool, and the international workshop in Cyprus.



Hannah Russell introducing her story to the international group of patients gathered for the patient day ahead of The 2024 International workshop on Alport Syndrome in Nicosia, Cyprus.

- Jayne Perrin**, Operations Director, joined alport uk in June 2023, initially as an Administrator. With Jayne's background in corporate governance, she has mastered processes to run events and manage alport uk operations. Jayne's first big event was The 2024 International workshop on Alport Syndrome in Cyprus in March, which ran incredibly professionally thanks to Jayne's tireless efforts. Jayne thrives off the everyday challenges alport uk sets her, has set up new processes to keep the charity running smoothly, and is a greatly valued part of the team. Jayne keeps us smiling and reminds us we achieve a lot as three part-time women running the charity with so much help from the incredible networks of amazing volunteers.



Jayne Perrin and Hannah Russell getting things organised for the smooth running of The 2024 International workshop on Alport Syndrome in Nicosia, Cyprus.

### Summary of the main achievements of the charity during the year

The achievements of Alport UK this year build from last year and are summarised under the headings of our key objectives and areas of activity below. **Overall, our main outcome is to create a more positive and brighter future for individuals and families living with Alport Syndrome.** Being a rare and therefore small community, we aim to deliver sustainable strategic change for Alport Syndrome, using virtual networks and the limited resources to effectively support patients and develop treatments for Alport Syndrome. Positivity and engagement are the main ingredients for all the support we offer – we aim to inspire and encourage people living with Alport Syndrome to be optimistic and explore their own individual route to a brighter future.

### The philosophy that underpins our performance

The Six Pillars of Wellbeing – long established as a framework to think about mental health and wellbeing - is a useful structure to encourage positive outcomes for individuals and families living with Alport Syndrome. The Six Pillars that inspire our activities:

- **Stress management** – keeping the community calm and informed with the latest information, so they can become more independent, strong and resilient over time
- **Nutrition** – inspiring the community to eat healthily to protect their kidneys for as long as possible and when on restricted diet, explore new foods they can eat
- **Community** – connect to reduce the feeling of isolation caused by having a rare disease that few others either know or understand
- **Sleep** – ensure the community members can have a routine with good sleep to enable them to deal with the rollercoaster journey that some individuals and families face as part of living with a rare disease and coping with critical events along the way, such as hearing declining, kidney failure and eye issues.
- **Exercise** – we know cardiovascular exercise is good for the kidneys. It is also vital to rebalance the chemical impact brought on by the feeling of anxiety that overwhelms some people living with the fact that their or their children's kidneys may fail and hearing might decline at some unknown time in the future
- **Meaningful activity** – encourage individuals, families, and researchers to connect around a shared objective of helping our community in some way, whether it be volunteering for our community, advocating, fundraising, collaborating on research or useful information or sharing stories to help others living with Alport Syndrome.

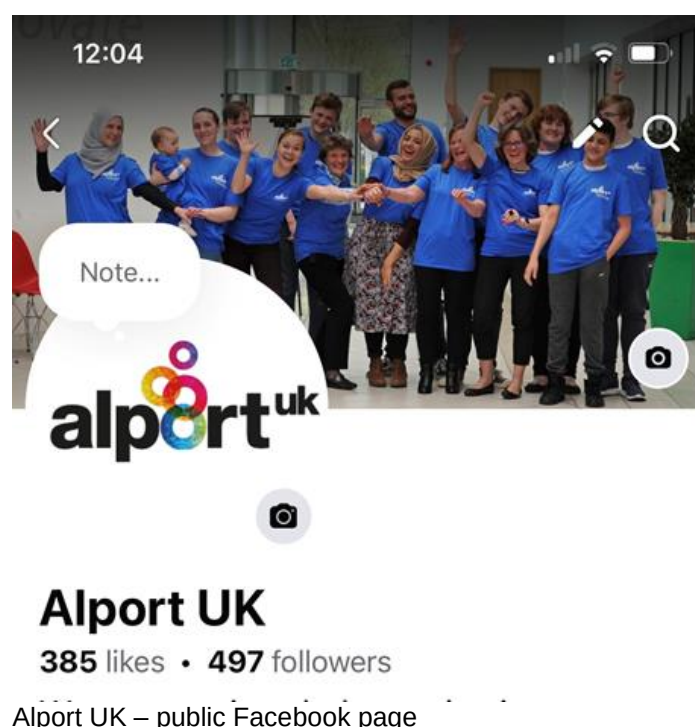
### As a tiny charity we are very clear what we can do

Supporting a rare disease is a challenge as there are few people who have Alports, or who want to research it or to fund it. So as a charity we aim to think wisely about how we use our strengths, capabilities, and resources and how to collaborate to complement these. Our volunteers have strong capabilities in delivering commercial innovation and collaboration across virtual networks of international stakeholders around the world. Some examples of the principles that guide what we do in our five key areas of work:

1. **Support network:** with a small, isolated patient community with such differing needs, we like to deliver **personal support in a timely way that delivers practical advice** and solves practical issues. alport uk's role is to empathise, understand the needs/issues, advocate for patients (and researchers) and support delivery of solutions through a virtual organisation with minimal overheads. The power of the internet and social media provide us with very economical tools such as our closed Facebook community page, **Alport Warriors** and our public **Alport UK Facebook page**. With our limited resources, this often means facilitating patient/researcher access to resources. For example, alport uk facilitates patients getting the right diagnosis via genetic testing, understanding treatment options or facilitating the grant application process for holiday breaks via Kidney Care UK's grant system. alport uk also writes letters of support for researchers to facilitate grant applications for Alport research.



Alport Warriors – private Facebook page



Alport UK – public Facebook page

2. **Provision of information:** with a diverse community and a very complex condition to explain, we try out different ways to provide information in a **variety of formats that suit different stakeholders**. With many of the community facing critical medical decisions as young adults, increasingly we use a combination of **in-person Information Days with short videos, social media and engaging activities to enable the patient community to engage in formats and content they find valuable**. For example, we encourage young adults to become our 'media team' at events, to engage in content, choose what is important and create videos and social media content themselves. Sam Clarke made additional videos about Living with Alport Syndrome to illustrate the positive attitude patients have despite facing health challenges – see one of the videos here that was filmed about a patient's experience of a clinical trial: <https://youtu.be/67w3zY-c0Zk>. We also publish **scientific information in the appropriate international journals so that it builds consensus across our community and is peer reviewed and globally available** for researchers, clinicians and patients.
3. **Support research:** with limited funds and fundraising capability, we choose to focus our efforts to **inspire and facilitate collaborative behaviours such as information and resource sharing to facilitate and accelerate innovative ways of working and the development of new treatments and knowledge**. For example, alport uk continues to facilitate **the international research community coming together as the Alport Syndrome Alliance – a global network to advance treatments and knowledge for Alport Syndrome. alport uk organise in-person and online workshops to share and exchange ideas**. This strategy aims to create a vibrant international research community that attracts more researchers and pharmaceutical or biotech companies interested in developing new treatments. These activities deliberately complement the strengths and activities of our colleagues in organisations such as:
  - Kidney Research UK – who raise money to fund specific UK Alport and kidney research projects eg elements of Rachel Lennon's lab based at Manchester University.
  - Alport Syndrome Foundation in the USA – who have more recently focused on very specific areas of Alport research that they prioritise eg relationships of aneurysms to Alport Syndrome, hearing and other topics at an early stage of development.
4. **Continued support of a UK research registry:** with significant investment made by Kidney Care UK and Kidney Research UK into The **National Registry of Rare Kidney Diseases (RaDaR)** – the UK Kidney Association's (UKKA) initiative designed to pull together information from patients with certain rare kidney diseases - alport uk support this vital project by **encouraging patients, clinicians and kidney units to upload long-term clinical data into this database to enable natural history studies in the future to progress Alport Syndrome research**. This will give a much better understanding of how Alport Syndrome affects people. It will also speed up research. The value for:
  - Alport patients:
    - Access to their clinical data online which records blood and urine results, medications and clinic letters.
    - Ability to be contacted about future potential research studies or patient information events

- Contribute to the increase in knowledge about their condition.
  - Clinicians:
    - Share knowledge with other colleagues
    - Use RaDaR as part of a research study or clinical trial.
5. **Fundraising:** with a small number of people in the UK (compared with other countries with much larger populations) impacted by Alport Syndrome, awareness of the condition is limited and traditional fundraising by the public typically focuses on the key health areas of cancer, heart conditions etc. **We heartily encourage individuals and families living with Alport Syndrome to fundraise when inspired to do so, by providing support, encouragement and new branded merchandise** (eg t-shirts, badges, wrist bands, shaking tins etc) to enable them to achieve whatever challenge motivates them. This means that **we raise significant funds for each major project (eg an international workshop or a new website) or a programme of activities (information days) by applying for grants from larger charities or from pharmaceutical companies.** We specifically support large fundraising events each year eg a dinner with an auction, a major activity eg swimming the channel or cycling round Europe etc.

## Highlights: achievements and performance this year

### Engaging our community in the diverse locations with greatest need

To be taken seriously as a rare disease community, by the pharmaceutical and biotech companies who develop treatments, we need an engaged patient community who understands the need for treatments and how vital engaging in clinical trials is for the development of treatments for generations to come. We have a number of different ways in which people living with Alport Syndrome engage across the UK and across the world. We specifically focus on and engage the larger



Learning about healthy kidneys – diet and exercise - at the Liverpool information day.

communities in the UK and abroad, informed by statistics such as the population tables below which show a) the locations of largest groups of Alport patients across the UK and b) the countries that have the largest

group of Alport patients, if you assume that 80% of patients (typically with x-linked inheritance pattern) account for a prevalence of 1 in 10,000 in any population. The reality is that recent research by Gibson et al (2022) suggests the prevalence of the Alport gene COL4A5 (x-linked inheritance) is closer to 1 in 2,300 in any population which obviously increases the market size for treatments as indicated by the tables below:

#### A) Table showing locations of largest groups of Alport patients across the UK, based on prevalence in a city

| Location            | Approx Current Population 2024 | 1 in 1000<br>0.0001 | 1 in 2300 | Reference<br><a href="https://worldpopulationreview.com/countries/united-kingdom-">https://worldpopulationreview.com/countries/united-kingdom-</a> |
|---------------------|--------------------------------|---------------------|-----------|----------------------------------------------------------------------------------------------------------------------------------------------------|
| UK                  | 69,273,616                     | 69,273              | 30,118    | As below                                                                                                                                           |
| London              | 9,748,030                      | 974                 | 4,238     | As below                                                                                                                                           |
| Manchester          | 2,811,760                      | 281                 | 1,222     | As below                                                                                                                                           |
| Birmingham          | 2,684,810                      | 268                 | 1,167     | As below                                                                                                                                           |
| West Yorkshire      | 1,942,470                      | 194                 | 844       | As below                                                                                                                                           |
| Glasgow             | 1,708,150                      | 170                 | 742       | As below                                                                                                                                           |
| Southampton         | 959,202                        | 959                 | 417       | As below                                                                                                                                           |
| Liverpool           | 922,871                        | 922                 | 401       | As below                                                                                                                                           |
| Newcastle Upon Tyne | 828,712                        | 828                 | 360       | As below                                                                                                                                           |
| Nottingham          | 813,078                        | 813                 | 353       | As below                                                                                                                                           |
| Sheffield           | 751,303                        | 751                 | 326       | As below                                                                                                                                           |
| Bristol             | 617,280                        | 617                 | 268       | As below                                                                                                                                           |
| Leicester           | 508,916                        | 508                 | 221       | As below                                                                                                                                           |
| Edinburgh           | 464,990                        | 464                 | 202       | As below                                                                                                                                           |
| Leeds               | 455,123                        | 455                 | 197       | As below                                                                                                                                           |

Data reference <https://worldpopulationreview.com/countries/united-kingdom-population>

These figures guide our UK engagement. A practical example of this, is that we prioritise running information days in UK cities where there are the greatest potential number of Alport patients for example systematically **prioritising locations to date: London, Birmingham, Liverpool, Glasgow, Edinburgh, Cardiff, Manchester.**

#### B) Table showing countries with the largest groups of Alport patients across the world, based on prevalence in a country population

| Alport UK Population - Global October 2024 |                                |             |      |            |           |                                                                                                                                                       |
|--------------------------------------------|--------------------------------|-------------|------|------------|-----------|-------------------------------------------------------------------------------------------------------------------------------------------------------|
| Location                                   | Approx Current Population 2024 | Growth Rate | Rank | 1 in 10000 | 1 in 2300 | Reference: United Nations population estimates and projections -<br><a href="https://worldpopulationreview.com">https://worldpopulationreview.com</a> |
| Global                                     | 8005176000                     |             |      | 800517     | 3480511   |                                                                                                                                                       |
| India                                      | 1450940000                     | 0.4119      | 1    | 145094     | 630,843   | As below                                                                                                                                              |
| China                                      | 1419320000                     | -0.1006     | 2    | 141932     | 617,095   | As below                                                                                                                                              |
| United States                              | 345427000                      | 0.06        | 3    | 34542      | 150,185   | As below                                                                                                                                              |
| Indonesia                                  | 283488000                      | 0.0719      | 4    | 28348      | 12,325    | As below                                                                                                                                              |
| Pakistan                                   | 251269000                      | 0.1225      | 5    | 25126      | 10,924    | As below                                                                                                                                              |
| Nigeria                                    | 232679000                      | 0.1526      | 6    | 23267      | 10,116    | As below                                                                                                                                              |
| Brazil                                     | 211999000                      | 0.0269      | 7    | 21199      | 92,173    | As below                                                                                                                                              |
| Bangladesh                                 | 173562000                      | 0.0669      | 8    | 17356      | 75,461    | As below                                                                                                                                              |
| Russia                                     | 144820000                      | -0.0244     | 9    | 14482      | 62,965    | As below                                                                                                                                              |
| Ethiopia                                   | 132060000                      | 0.108       | 10   | 13206      | 57,437    | As below                                                                                                                                              |
| Mexico                                     | 130861000                      | 0.035       | 11   | 13086      | 56,896    | As below                                                                                                                                              |
| Japan                                      | 123753000                      | -0.0202     | 12   | 12375      | 53,805    | As below                                                                                                                                              |

Data reference <https://worldpopulationreview.com/countries/united-kingdom-population>

These country populations focus our international engagement activities. alport uk invested time and engagement efforts to engage patients from China, Indonesia, Nigeria, Brazil, Russia, Japan. alport uk do this through clinical contacts in the countries, or social media and in-person international workshops in countries with larger populations of Alport patients. **To date we have patients and clinicians engaging in person or online from 66 countries.** Thanks to alport uk's initial investment in 2014 to support patients engaging in China, the Chinese patients have now set up their own **Chinese Alport Syndrome Parents Association** which today is now one of the largest patient organisations in the Alport global community connecting so many diverse people across Asia and

significantly reducing their feeling of isolation. alport uk continue to support and collaborate with this vital community of people living with Alport Syndrome.

### **Support network proactively increased**

Before the charity existed in 2013, it was typical that a family diagnosed with Alport Syndrome would never meet nor talk to anyone outside their own family impacted by the condition. There was no support network and no mechanism for connecting individuals and families. People felt isolated. Through regular annual **national Alport Information Days**, our **web site** and closed Facebook page - **Alport Warriors** - and other social media pages (Instagram, X formerly Twitter), support networks developed and each year the community feels stronger, more connected and able to deal with issues as they arise and particularly as we work through challenges together. People don't feel alone anymore. This infrastructure proved invaluable in supporting patients through the unknown stages of the pandemic and as we emerged beyond.

The closed Facebook community – **Alport Warriors** – is one of the ways alport uk proactively encourages peer support – people living with Alport Syndrome helping others in a similar situation. The carefully moderated group continues to grow and now numbers over 1000 members from all over the world, trusting and appreciating the excellent advice we get from our colleagues in the UK's NHS. In 2019, there were 350 members. Each year we are contacted by more and more people from around the world as they are diagnosed with Alport Syndrome. We provided advice specifically relating to COVID and the impact on kidney patients. As we work as a 'virtual' organisation anyway, alport uk was able to easily respond, during Covid, to the increase in requests and with more of the community online – patients and researchers – more people were able to help each other. This engagement from the wider community was valuable for all and so alport uk thrived in a really positive way, despite the pandemic. It was an opportunity for more to engage and more got value from this engagement.

One practical way of supporting patients is with the **Don't Wait Fund** – a fund that people living with Alport Syndrome can apply to for a grant of up to £250 to start a new activity: Over this year, we funded 6 people living with Alport Syndrome, including:

- **A contribution to a new bike for a young man going on a cycle tour after receiving a kidney transplant.**
- **A girl received support for the start-up fees for gymnastics.**



Amaya received support for starting gymnastics lessons.

## Key support network achievements this year

On Saturday 21 October 2023 we hosted and facilitated a webinar on **'The missing variants in Alport syndrome'**, in collaboration with Professors Judy Savage (Australia) and Julia Höfele (Germany). Topics included: how to improve coverage by whole exome sequencing; detecting splicing variants; synonymous changes; and mosaicism. This informative, in-depth webinar had participation from geneticists, researchers and clinicians across the world. It is reassuring for patients who have been diagnosed with variants of unknown significance, or who have symptoms and family history of Alport but a negative genetic test, that research is ongoing, working to find answers to these questions.

Finding the missing variants in Alport Syndrome (Alport podcast)



Professor Julia Höfele and Professor Judy Savage moderating discussion at the online workshop.

## Delivered an Alport information day in Liverpool (July 2024)



Austin Chukwu talking about kidney-friendly diet and the value of good cardiovascular exercise at the Liverpool information day.

| Participant numbers           | Liverpool, July 2024 |
|-------------------------------|----------------------|
| Adults                        | 32                   |
| Young adults                  | 18                   |
| Older children and teens, 12+ | 1                    |
| Younger children, 0-11        | 5                    |
| Total                         | 56                   |



Introductions at the Liverpool information day.

These in-person Alport Information Days, advertised via our social media and email, combine a mix of information (from experts), social networking and getting to know the city we are in. The information days are organised around the country to attract diverse groups impacted by Alport Syndrome and target specifically the larger cities with large populations. The days particularly attract newly diagnosed individuals and families and connect them with others on similar journeys, whether as individuals, parents, young adults or children. We combine the activities with social activities particularly aimed at the young adults. The information day agendas are designed specifically to create a safe space for people to ask any questions they may have of the experts, to connect with others and engage in understanding Alport better. The days are 'immersive', designed to support and attract a diverse group of people. Professional childcare is a key element of the day, so both parents and children get their questions answered and they have the opportunity to connect and meet with others impacted by Alport Syndrome.



Shaista Dagia and Aura Zealey Smith recording videos at the Liverpool information day.

Sam Clarke's filmed stories of *Living with Alport Syndrome* are a key feature at the workshop. In Liverpool, we watched two new short films, featuring Mark and Pippa: <https://youtu.be/OzYP42oXTAg>, <https://youtu.be/WJmCEqjUFYM> When asked to comment on the value of the weekend in Liverpool to family and friends, the people living with Alport Syndrome commented:

"Amazing day, thank you so much everyone who spoke or organised the day, we have learned loads and really enjoyed meeting so many families."  
"Fantastic weekend love our Alports family lovely to meet new people and find out more information 😊"  
"Thank you to everyone for making us feel included and very supported. Our very first time coming to these events and we learnt so much! 😊"

**alport uk's private Facebook page - Alport Warriors** - provides support to a group that increased to over 1000 members. Membership is supported by Wilma Calderwood whose steady hand ensures the group remains in a well-protected, safe space. Discussions are initiated by both regular and new contributors and cover such subjects as kidney donation, hearing, sight, drug trials, transplant successes, successes at the annual Transplant games, fundraising opportunities, celebrating birthdays, links from other Alport Facebook sites, fundraising activities, and a range of questions about Alport Syndrome, its' symptoms, treatments and their side effects. Connection with others who are in a similar situation is clearly valued by some people in the Alport community. Connection is not valued by all, so we aim to provide support for individuals or families in other ways to suit their needs.



Dan Long, one of our young adult volunteers and part of the Alport Avengers (young adult) group, participating at the Liverpool information day with his son.

One woman living with Alport Syndrome commented:

"Having such a rare disease can be really isolating... Knowing there are others, all at different stages in this group that you can check in with is so reassuring when facing all the different milestones of this disease such as being pregnant with alports, then having a child with alports, being advised that your young child should start meds, watching your child get hearing aids for the first time... just some of the scary bits we have faced so far... and managed. It's great to have a private, safe space to have

your 'wobbles' while you work through stuff. Many thanks for all the support and advice that everyone offers."

A large percentage of patients with Alport Syndrome face Chronic Kidney Disease (CKD) in their late teens or early 20s and will require dialysis or a transplant. The exact details of prognosis for the genetic mutations of these young adults are not yet known, so the young adults face an emotional 'waiting game' for their kidney function to start declining. Some describe it as a 'timebomb'! The young adults find it most helpful to connect with young people of their own age – peers who provide information from their own personal experience - so they can learn from and mentor each other when facing these particularly challenging times such as declining kidney failure and transplants. This is one of the roles of the **Alport Avengers group** – a group of 18–35-year-olds that emerged and was set up on WhatsApp. If a young adult has a question or a parent of a young adult raises a question, alport uk offer membership of this vital group.

We arranged the fourth social event for the Alport Avengers in Liverpool to meet in person which they found incredibly valuable. They spent time variously talking, sightseeing and getting to know each other and, importantly, sharing experiences of Alport Syndrome.



The Alport Avengers – young adult group living with Alport Syndrome - met and re-connected at the Liverpool information day for a social.

We continued the dissemination of information and offering support for both patients and carers, including:

- **Answering enquiries emailed to alport uk** at [info@alportuk.org](mailto:info@alportuk.org) and phone calls sent to our landline number of 01793 847264 and putting people in touch with experts to answer their questions, writing letters to support children's needs at school or putting people in touch with other families to share stories and experiences.
- **Sending out information electronically** – there was a high number of enquiries about newly diagnosed children living with Alport Syndrome, about hearing and about transplantation experiences.

### Provision of information

With the help of our scientific advisors, alport uk continue to offer information and expert advice on our closed Facebook page – **Alport Warriors** - to the community to answer queries as they arise. This

approach - informing people to enable them to take control and build resilience - is vital as our community has so many differing needs, many different age groups, at differing stages of kidney failure, undergoing different types of kidney replacement therapy and many patients and family members from other countries seeking advice. We are very proud of the alport uk team, how they anticipate queries, source expert advice and information to enable people to stay as calm as possible during challenging times when newly diagnosed etc, including sourcing food banks and writing letters to employers to explain the needs of their employees with Alport Syndrome. We are incredibly proud of the patients, their positive and pragmatic approaches to looking after themselves and helping each other across the community.

As mentioned above in the 'Support' section, the **Alport Avengers** group (18-35 year-olds) on Whatsapp continues to grow and the young adults share the information they've learned from their individual journeys. The group is monitored to make sure the information is accurate and relevant.

**Young woman:** "I like the fact that it doesn't feel too formal. It's a group of friends, where you can ask questions, compare symptoms, discuss struggles, but also have a laugh! Without the group I think people could potentially feel more isolated and not have that space they can easily access! Sometimes posting on a social forum feels intimidating, so this is a nice balance :)"

**Young man:** "For me mainly, I love that we all feel comfortable sharing how we feel in real time, knowing that we're going to get a quick response from someone who fully understands the challenges we might be facing. It provides a level of reassurance and understanding that I (and I know many others!) never got while growing up."

With this young adult group, as the most critical group facing declining kidney function just at the time they are trying to leave home, build careers etc, their feedback increasingly indicates that short videos are the most useful way of sharing information. We now use short videos to explain Alport Syndrome and to share patient stories. Our most shared videos include four filmed and produced for alport uk by filmmaker, Sam Clarke who is also a young person living with Alport Syndrome:

- **My Only Antidote:** Sam Clarke, cycled round Europe raising funds for people living with Alport Syndrome and filming his experiences: <https://youtu.be/1A1adCj-cvo> We use this video for newly diagnosed patients as it explains the real challenges of living with Alport Syndrome. Sam also ably inspires patients with the fun activities that he does such as sky diving, cycling and generally having fun. These are such important messages for young patients.
- Sam also helps alportuk by filming a **series of 2-3-minute documentaries about Living with Alport Syndrome**. These short films document the highs and lows of living with Alport Syndrome. The films are invaluable communication materials that engage the wider community in what it is really like to live with Alport Syndrome. We are very grateful to the following people that Sam filmed about their journeys and living with Alport Syndrome:  
**Mark and Pippa** - <https://youtu.be/OzYP42oXTAg>,  
<https://youtu.be/WJmCEqjUFYM>  
**Ryan Wicks** - <https://youtu.be/67w3zY-c0Zk>  
**Professor Colin Baigent** - <https://youtu.be/whFRZfBUDs0>  
**Katie Brown** - <https://youtu.be/DJTKNLWQfmo>  
**Lesley Forrest** - <https://youtu.be/RoDWE-8Ck60>

**Jospeh McLean** - <https://youtu.be/4bz5-tK6m6w>.

- **Patients inspire Alport Syndrome research**, a collaboration between alport uk and University of Manchester: <https://www.youtube.com/watch?v=77p7nzKz6nc>
- **Highlights from The 2019 International workshop on Alport Syndrome**, Siena, October 2019: <https://youtu.be/QH8mDTmKaVU>
- **Highlights of Podocyte 2021**, a film made by young patients who have podocyte-related kidney conditions, Manchester, July 2021: <https://youtu.be/3-ZDm2CR8Ow>
- **Alport Syndrome Alliance 10 years on:** <https://youtu.be/vAk9HgxEJ-Y>
- **Highlights from The 2024 International workshop on Alport Syndrome**, Cyprus, March 2024: <https://youtu.be/HnwKsDMms8A>

We are very grateful to patient Sam Clarke for making these upbeat and very professional videos and all the incredible people who agree to be filmed and share their thoughts and stories. Sam is exemplary in that he also is willing to collaborate with other Alport patients on the content and editing. Sam himself gets a lot of value from meeting members of the Alport community and he talks openly about how it helps his own mental health and living with the 'timebomb' of when his own kidneys would fail. The work on these videos means we have a very engaged young adult group who feature on the videos telling their stories and sharing their opinions, plus doing some of the interviews to create the content. The success of content and style of these videos is because they are designed and filmed by people living with Alport Syndrome for people living with Alport Syndrome. As a result, the videos are often watched by clinicians and researchers and admired for their inspiration. In addition to being excellent providers of information, the videos also inspire many others who watch them. The videos demystify what it is like to live with Alport Syndrome and why patient/research scientist collaboration on Alport research is so important. In addition to being good information providers, the videos are excellent emotive marketing tools to potential funders and give a lot of positive hope for the community and people who want to find out more about it.

A number of years ago, a very successful **series of two-minute animated videos were written, illustrated and produced by a group of our young people with Alport Syndrome for their peers**, some in collaboration with University of Manchester. The writing of the videos and working with the clinicians to make them scientifically accurate was a valuable process for the young people to engage in understanding Alport better as sometimes they can be in denial about what is important to keep them healthy or sources of support. We continue to use these videos, pasting the links onto Facebook when questions are raised by patients, carers and their families about Alport. Topics included:

- Why Alport research is important <https://youtu.be/TU0m6gGvTFY>
- Alport Community <https://www.youtube.com/watch?v=5qJEtmhcCIU>
- Alport Syndrome: Know your numbers <https://www.youtube.com/watch?v=jtkmJdwG0nE>
- Kidney transplants and Alport Syndrome <https://www.youtube.com/watch?v=Gd4yB9PVnM0&t=52s>
- Update on clinical trials and potential treatments for Alport Syndrome (written in English and translated into Italian, German and Chinese by

the young patients with Alport Syndrome) at The 2019 International workshop in Siena, Italy <https://youtu.be/JRsJtUu8Lh8>

When someone is diagnosed with Alport Syndrome, some of the regional genetics units e.g. at Bristol Genetics lab and some of the paediatric kidney units e.g. at Manchester University Hospital, have a small leaflet giving some summary details about the condition and our alport uk leaflets. Beyond this, there is an array of information one can find on the web, but it is hard to decipher what is medically correct or up to date. On our website is:

- **A summary leaflet for Alport UK** to encourage people to get in touch with us – this is now handed out at the genetics units when people are newly diagnosed with Alport Syndrome. It was also sent out, along with laminated posters with our contact details on, to all the main adult and children's kidney units around the country to advertise where to find out information about Alport Syndrome
- **A dictionary of scientific terms** to help patients learn more about the biology of Alport Syndrome, so when their clinicians explain things, they understand a bit more about what they are talking about as it is so hard to pick much up in a short clinic appointment.
- **Definitions of related rare renal diseases** – Nephrotic Syndrome, IgA Nephropathy, Membranous Nephropathy and Focal Segmental Glomerular Sclerosis (FSGS) that sometimes overlap with Alport Syndrome or people can be diagnosed with more than one disease or if people are misdiagnosed.
- **Videos available through our website** ([www.alportuk.org](http://www.alportuk.org)), on our YouTube @alportuk channel, and a special section on Alport Syndrome on [www.healthtalk.org](http://www.healthtalk.org) (<http://www.healthtalk.org/peoples-experiences/long-term-conditions/alport-syndrome/topics>) of our key experts talking about specific aspects of Alport Syndrome. Topics are varied about all aspects of living with Alport Syndrome and include: Genetics, An introduction to Alport Syndrome, Hearing and hearing aids, caring for people with Alport Syndrome, medication, women with Alport Syndrome etc.
- **Our website remains an invaluable resource.** We are currently fundraising to improve our information on the internet. We intend to update [www.alportuk.org](http://www.alportuk.org) to make the information clearer and more accessible and to answer the questions we have received over the last few years or so through our closed Facebook page, Alport Warriors. The plan is to collaborate with the other national patient organisations and provide an international website for the most up-to-date information, research papers and clinical guidelines. We need to establish what information is critical to hold and update at the international level (eg simple explanations of Alport Syndrome, clinical guidelines etc) and what is specific to a national community, such as how to navigate the NHS in the UK to access treatment. This project will mean we will update [www.alportuk.org](http://www.alportuk.org) so as not to duplicate resources.
- **Information about new clinical trials** that patients can sign up to is shared through our website 'Latest news' section, through our closed Facebook page (Alport Warriors) and through directly emailing our database of patients. alport uk specifically do not recommend any trials, but signpost people to the most up to date information and encourage them to discuss it with their own clinicians who can discuss the relevance of the trial with them, knowing their personal situation.

## Supporting or driving research?

With limited funding available for rare kidney disease research, alport uk's strategy is use our small amount of funding to facilitate a virtual Alport research collaborative giving support, encouragement to scientists and to drive towards deadlines – what we call the '**oil to lubricate the Alport research ecosystem**' to accelerate research. Instead of funding a specific project we invest considerable time and our limited funds to get the research community together at international workshops to enable them to work together to set the research programme and create a vibrant and innovative research community that attracts more researchers and pharmaceutical companies interested in developing new treatments. The emerging innovative and vibrant global network – the Alport Syndrome Alliance - is advancing treatments and knowledge. **Over eight international workshops, the clinicians and laboratory scientists featured 370 new research projects. Many went on to publish their findings in international journals or forge new research collaborations.**

Alport UK is closely involved in an exciting new research development – the **Alport Research Hub**, a Manchester-based collaboration between Kidney Research UK and the Stoneygate Trust. The hub is directed by **Professor Rachel Lennon** from the University of Manchester, in collaboration with **Professor Daniel Gale** from University College London and **Professor Neil Turner** from the University of Edinburgh, all three of whom are Trustees of alport uk. The first hub meeting kicked off in January 2022 and was launched in June 2022, and aims to deliver a world leading research programme. Using patient data along with a new platform of technologies to test new treatments such as gene therapy, researchers aim to deliver major results within five years; this acceleration in research is extremely exciting for Alport patients, researchers and clinicians. Here is a short film that explains the Hub: <https://youtube.com/shorts/4SKzPemRYCU>.

As part of the need to provide people living with Alport Syndrome, with the most up to date information, we often provide links to the **series of over 36 international Alport online workshops**, which were run and moderated by our young adult Alport patients. The workshops are all listed on alport uk's YouTube channel @alportworkshops: <https://tinyurl.com/y9cuhgby>. **Subjects covered include: Transplantation experience, hearing, eyes, genetics and family planning**, and spotlights on labs around the world researching Alport Syndrome.

## Building on the Alport research indicators from 2019

In the 1990s, groups of leading clinicians, academics and scientists regularly met to discuss topics related to Alport Syndrome. They published a number of key papers about Alport Syndrome, but the regular meetings stopped. In 2012, alport uk commissioned a web audit of people publishing material on Alport Syndrome through to the current day and prepared a report on the status of research into Alport Syndrome. This report was used to identify the missing areas of activity and needs for research including:

- A shared international strategy and plan for Alport Syndrome research

- New research ideas and projects to develop new treatments and therapies and more research generally
- Ways to reengage the leading experts in Alport Syndrome
- Co-ordination of national patient registries
- The need to engage pharma industry in developing new treatments
- How alport uk could complement the current contributions of other national patient organisations, for example the Alport Syndrome Foundation who currently run an excellent programme of seed funding for Alport research, commissioning projects each year
- How Alport Syndrome is a model renal disease and that new treatments developed for Alport Syndrome could help other patients living with kidney disease.

In 2019, to check on the performance of our investment to get researchers together through these workshops, alport uk circulated a simple survey with the Workshop Organising Committee members and their research teams (ie not the full Alport research community, just some of the key members) to understand the impact of the international workshops, emphasis on collaboration and how much research is now being done. Overall, the numbers indicate a very healthy research community to whom we are incredibly grateful for all they do to help with the awareness and understanding of Alport Syndrome by delivering:

- 242 new research projects featured at four international workshops
- 131 publications with the majority in international journals
- 18 book chapters
- 38 major grants to fund the ongoing research.
- over 90% of the projects and publications were collaborative efforts.

These survey results confirmed to alport uk that our efforts to drive collaboration and accelerate research are delivering the results we need. Indeed, at the time of writing, **there are now over 400 new projects featured at international workshops since 2014.** The Alport research progress is accelerating and alport uk's strategy to use workshops to drive Alport research is the right approach to both drive research and engage new communities to join the global network.

### The 2024 International Workshop on Alport Syndrome, Cyprus



Participants at The 2024 International workshop on Alport syndrome in Cyprus.

To continue the collaborative international workshops in Oxford (2014) Göttingen, Germany (2015), Glasgow, Scotland (2017), Siena, Italy (2019), online (2021) and Calgary Canada (2022 – one-day hybrid format), alport uk delivered the seventh workshop in the series: **The 2024 International Workshop for Alport Syndrome, in Nicosia, Cyprus**. The 3-day workshop, organised in collaboration with Professor Constantinos Deltas and his team at the Cyprus Biobank, refreshed the Alport Syndrome Alliance's global network with their shared aim to advance treatments and knowledge. The planning started in earnest over the summer to get the workshop programme ready for the workshop in March 2024. alport uk restarted the conference calls with the international workshop organising committee to share progress, keep the researchers engaged in delivering the agenda in a number of key areas such as genetics, pathology (as there is an increasing interest in this area), clinical guidelines, registries, basic science and particularly new therapies.



Joint organisers of The 2024 International workshop on Alport Syndrome in Nicosia, Cyprus: **Biobank.cy** - Professor Constantinos Deltas and **Alport UK** – Susie Gear.

### **Highlights from The 2024 International workshop on Alport Syndrome**

14-16 March, Nicosia, Cyprus

Overall, **145 people participated in the workshop from 19 countries and featured 60 new Alport research projects** and included:

- 55 people living with Alport syndrome with local patients from Cyprus and Greece
- 45 clinicians, 39 laboratory scientists and 15 representatives from 7 pharmaceutical and biotech companies.

**There are at least 6 gene therapy ideas for Alport, in development in China, Cyprus, Israel, UK and USA.**

**The global Alport community now has over 25 pharmaceutical and biotech companies actively exploring new treatments** and some already active in clinical trials. These divide into two routes that deliver the global community's research strategy created in 2014:

1. **Alport specific (e.g. gene therapy)** - These can take years (can take 25 years) to develop, but with 6 progressing this is exciting news. The global community will need to effectively assess priorities, find funding for some and drive through pre-clinical studies and then clinical trials etc.
2. **Not Alport specific but protect kidneys for longer** and reduce time on dialysis/transplants. These take a shorter time to develop (10-15 years) so can protect kidney function in the meantime. A combination of these drugs (our USA patient colleague on the global committee calls it an **'Alportini' cocktail**) could potentially delay the need for dialysis for a lifetime, particularly for the milder forms of Alport which we now know are more prevalent in a population (1 in 200) than we first thought. As a community, we need to be careful that Alport is not 'used' by companies seeing us as an easy engaged and capable community to do easy general kidney trials that don't specifically benefit Alport kidneys but give the company safety data.

**We heard from a company that is treating children with gene therapy for sensorial deafness** – different cause from Alport – exciting evidence for how gene treatments can reach the ear. It was our Russian professor (children's kidney doc) who alerted us to this work.

With an increasing number of patients and patient families, who have relevant careers in pharmacology, rare disease clinical trial networks, medicine, research, mental health, global clinical trials and business, **our Alport research ecosystem has the right expert patient leadership to drive the innovations to deliver safe treatments in the next 10 years.**

**Huge thanks go to our global Workshop Organising Committee** (listed earlier in this report in volunteers section) who advise on the science and all aspects of the ecosystem. Their combined expertise and thinking drives the science and progress. The intellectual and political power of this group is invaluable. For example, Professor Roser Torra, recently elected as the new head of the European kidney association (ERA) and Associate Professor Beata Lipska-Ziętkiewicz chaired the development of European treatment guidelines for Alport so everyone with Alport across Europe (including the UK) has the right to safe treatments.

These are some of the many important elements of the research ecosystem for Alport that will attract additional researchers to choose to work in Alport and join our community in the next 10 years.

According to Professor Tobias Huber (President of the International Society for Glomerular Disease), one challenge we face is 'unless people participate in person, they don't experience the full value of the global community'.

#### **Feedback from workshop participants:**

97% felt that the intended outcomes were achieved. Outcomes for The 2024 International Workshop on Alport Syndrome:

- Understand the latest findings and new ideas – hearing, kidneys, basic science, new treatments, eyes, clinical trials and patient registries
- Collaborate with international colleagues in sessions on specific topics, e.g. genetics and gene editing, novel approaches to treatment
- Present your own research or case studies
- Hear patient perspectives

- Network with experts in related fields or related disease areas
- Be part of the future of Alport Syndrome research and treatment.



A younger participant at The 2024 International Workshop on Alport Syndrome gets to meet zebra fish who have 70% in common with human DNA and by studying them, we learn a lot about Alport Syndrome.

#### Comments and feedback we received about The 2024 International Workshop on Alport Syndrome:

'I'm really thankful for the opportunity to attend this workshop, and that you made my participation possible through the generous provision of travel expenses and accommodation. During my time at the workshop, I had the privilege of meeting numerous individuals who share similar journeys with Alport Syndrome. Interacting with them not only provided me with a sense of community but also allowed for the exchange of knowledge and personal stories, which greatly enriched my understanding of the condition. Moreover, the sessions and discussions facilitated at the workshop were enlightening, offering amazing insights into various aspects of Alport Syndrome, including its diagnosis, disease management, and ongoing research on new treatment methods. As I return from this workshop, I carry with me not only a wealth of newfound knowledge but also a renewed sense of purpose. I am inspired and motivated to utilize the knowledge and skills acquired during this event to make a meaningful difference in the lives of others affected by Alport Syndrome here in Croatia. In conclusion, I extend my sincerest thanks to the organizers, sponsors, and fellow participants of the Alport Workshop for their unwavering support and for creating a platform where individuals like myself can come together, learn, and be part of the change.' – Croatian patient

'This was a truly amazing experience for me as a basic scientist. The connection of patients, clinicians, pharma companies and basic scientists was exciting, educational and transformational for me. I wish there were many more meetings like this. I think this sort of gathering is invaluable for advancing treatment options for patients. As a basic scientist I now understand more about the type of research that I can do to provide more powerful insights into Alports. I'm also more motivated than ever. Thank you!!' – scientist, USA

'It was very helpful in meeting people (patients, nephrologists, researchers, ...) and getting an update on the scientific progress on Alport.' – pharmaceutical representative, France

'The scientific agenda was really satisfying and patient contributions was special. Thank you.' – laboratory scientist, Italy

'New advances in treatments were very useful to me and this is one of the only places where I could see all of this cutting edge information in one place. Tremendous.' – father and teenage son (patients), USA

'The gene therapy session was very good- encouraging to see several research groups contributing in the very challenging area.' – laboratory scientist, UK

'I was very impressed with the breadth of speakers' expertise, especially those who at first pass seemed to do work that was questionably related to Alport syndrome. I appreciated that the organizers thought outside of the box when planning the agenda and topics. Great work!' – clinician, USA



One of the Biobank.cy team from Cyprus presenting a poster to Dan Jagger, a hearing scientist, from the UK.

'I wanted to thank you for the great workshop in Cyprus. It was very well organized, interesting and engaging. We learnt a lot and were happy to meet this wonderful community you built.' – pharmaceutical representative, Israel

'I enjoyed and looked forward to participate to this Alport Workshop, as every other Workshop I attended in the past three years as I started my PhD research in Alport syndrome. Every time I leave the workshop excited and wiser.' – laboratory scientist, Cyprus

'The best conference/workshop experience ever. This workshop goes from strength to strength and it is incredibly effective and focussing our minds on the challenges in Alport' – clinician, UK

## Shining a light on Alport Syndrome: a one-day workshop for Asia



The poster features a background image of a modern building at sunset. It includes logos for NUS, Alport Syndrome Alliance, and National University Hospital. A cartoon illustration of two children is in the top right corner.

**NUS** National University of Singapore

**Alport Syndrome Alliance**

**National University Hospital**

Shining a light on  
**Alport Syndrome**

**A one-day workshop for Asia:  
20 August 2024, 9am-5pm  
Singapore**

Email: [workshops@alportsyndromealliance.org](mailto:workshops@alportsyndromealliance.org)

At the end of this reporting year, the Alport UK team, in collaboration with Associate Professor Ng Kar Hui and her colleagues at the National University Hospital, Singapore, started to plan in earnest for this one-day workshop in Singapore. Associate Professor Ng Kar Hui presented at the workshop in Cyprus in March 2024 on the management of Alport Syndrome in places with lower resources in South-East Asia, and was inspired to organise and host this workshop to engage others in the region.

## The 2025 International Workshop on Alport Syndrome, Beijing

To keep the momentum of research and the collaborative group, a date and location was agreed for the next international workshop on Alport Syndrome, which will be in Beijing in September 2025, hosted by and organised in collaboration with Professor Jie Ding, her colleagues at Peking University First Hospital and the Alport patient group in China.



The poster features a background image of the Great Wall of China at sunset. It includes logos for the Alport Syndrome Alliance, Peking University First Hospital, and alportuk.

**Organised by:**

**Alport Syndrome Alliance**

**The 2025 International Workshop on  
Alport Syndrome  
Beijing, China**

**4 September 2025 patient workshop  
5-7 September 2025 scientific workshop**

[www.alportsyndromealliance.org](http://www.alportsyndromealliance.org)

## Support of a UK research registry

In parallel to alport uk being set up, the then called UK Renal Association (now called UK Kidney Association - UKKA) established a working group

on Alport Syndrome, funded jointly by Kidney Research UK and Kidney Care UK (previously British Kidney Patient Association) to support the development of a national renal registry of patients, called RaDaR. RaDaR. Some of the trustees from alport uk contribute to the working group on an ongoing basis to devise ways of promoting RADAR to patients and clinicians across the UK to increase the number of patients and patient records online as this will provide invaluable data for research to understand the natural history of Alport Syndrome. At the time of writing, RaDaR has over 1,000 patients registered (compared with the 800 registered in the previous year) as having Alport Syndrome and with some clinical data going back 30 years. alport uk specifically contribute to the support of this UK research registry of patients and an international alliance of patient registries by:

- Promoting the importance of RaDaR to patients at Alport information days, along with information about the value of RaDaR to research.
- Making the research registry a central part of the national contribution to international efforts to collaborate on research coming out of the 2014, 2015, 2017, 2019, 2021, 2022 and 2024 International Workshops on Alport Syndrome and proposing to for there to be significant topics on it at the 2025 workshop.
- Supporting the enrichment of data as part of the programme of the Alport Research Hub, including chasing up the transfer of historical genetic data that transferred from Guy's Hospital to the Bristol genetic testing labs when they took on the testing service.
- Continuing the development of the UK's contribution to an international alliance of Alport Syndrome research. An 'alliance' is necessary as long-term there are not enough patients in the UK for Clinical trials and so pharmaceutical companies will want to do trials in a number of different countries to try new therapies. alport uk enlisted the help of designer Robina Newman to develop the branding for the Alport Syndrome Alliance and apply it to a website originally built by Alice Cooper to simplify the registration process for participants for The 2021 and 2022 International workshops on Alport Syndrome. The plans for the 2025 international workshop planned for September 2025 (in the next financial year) are to continue to increase the number of participants, compared with previous years, applying to join the international workshop and with the encouragement of other national patient organisations, especially across Europe to build the Alport Syndrome Alliance to help the Alport community act as one global network focused on advancing treatments and knowledge, with one voice.

### **Generation Study: Genomics England newborn screening programme**

Following successful advocacy from Alport UK trustees and patient representatives, Alport Syndrome was added to the list of conditions which Genomics England will test for in the Newborn Genomes Programme: <https://www.genomicsengland.co.uk/initiatives/newborns> Alport Syndrome was added as early diagnosis can lead to earlier management and better outcomes. Alport UK is preparing to provide support and information to parents of newly diagnosed babies.

If anyone reading this annual report is interested in more information or to get involved or support us with activities or fund raising, please email Susie Gear (Chief Executive) or Hannah Russell (Engagement Director) at [info@alportuk.org](mailto:info@alportuk.org) or call us on 01793 847264.

## Section E Financial review

### Brief statement of the charity's policy on reserves

Reserves from fundraising are kept in separate Barclays bank savings accounts, labelled for their specific use and to make sure restricted and unrestricted funds are used appropriately. For example, for:

- **Information days** (Alport UK Meetings)
- **UK Development of information, website and marketing material** (Alport UK)
- **Facilitating the International Workshops on Alport Syndrome** (Alport UK Research)
- **Supporting patients take up a new sport or activity** (Don't Wait Fund)

### Details of any funds materially in deficit

No funds in deficit

### Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

alport uk's principal sources of funds this year were again more diverse than in the previous year:

- Personal donations – limited this year
- Personal fund-raising activities, such as the afternoon tea and pop up shop.
- JustGiving pages for remembrance and for sponsorship of various activities that our community get involved in to raise funds for alport uk.
- Social media fundraising pages eg Facebook giving for birthdays
- PayPal donations to Alport UK
- Sales of Christmas cards and a wider variety of merchandise such as hoodies, t-shirts, water bottles etc
- Standing orders from a couple of very supportive patient families
- Customised shaking tins located in retail venues
- Donations from larger charities or foundations for specific activities and particular thanks to **The Stoneygate Trust, Kidney Care UK, Kidney Research UK, The Amelia Chadwick Trust, Liverpool Charity and Voluntary Services, the D'Oyly Carte Charitable Trust**
- Donations from **The Worshipful Company of Dyers**. With thanks to Alice and Sebastian Cooper.

Grants given by a number of pharmaceutical companies: alport uk are very grateful to the support from **Regeneron, Enyo, Calliditas, Visterra and Trave**.

As funds were all allocated to specific activities that support our key objectives this year, there was no opportunity for investment during this accounting period.

## Section F Other optional information

None

# Alport UK

## Report and Financial Statement For the year ended 31<sup>st</sup> July 2024

Charity number: 1154774

Shilton Accounting Services  
1<sup>st</sup> Floor, 1 The Clock House  
Brize Norton Road  
Carterton  
OX18 3HN

**Alport UK**  
**Charity number: 1154774**  
**Legal and administrative information**

|                                 |                                                                                                                                                                                                                 |
|---------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Charity name:                   | Alport UK                                                                                                                                                                                                       |
| Charity registration number:    | 1154774                                                                                                                                                                                                         |
| Type of organisation:           | Charitable Unincorporated Organisation                                                                                                                                                                          |
| Registered office and business: | PO Box 329<br>Cirencester<br>Gloucestershire<br>GL7 3PX                                                                                                                                                         |
| Trustees:                       | Professor Colin Baigent<br>Professor Danny Gale<br>Susie Gear<br>Emeritus Professor Frances Flinter<br>Professor Rachel Lennon<br>Amanda McLean<br>Tim McLean<br>Alice Turner<br>Emeritus Professor Neil Turner |
| Accountants:                    | Shilton Accounting Services<br>Certified Practising Accountants<br>1 <sup>st</sup> Floor, 1 The Clock House<br>Brize Norton Road<br>Carterton<br>OX18 3HN                                                       |

**Alport UK**  
**Charity number: 1154774**  
**Independent Examiner's report to the Trustees of Alport UK**

I report on the accounts of the Charity for the year ended 31<sup>st</sup> July 2024 which are set out below.

**Respective responsibilities of trustees and examiner.**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under section 43(2) of the Charities Act 1993 (the 1993 Act) and that an independent examination is needed.

It is my responsibility to:

- a) Examine the accounts (under section 43(7)(b) of the Act.
- b) To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 43(7)(b) of the Act.
- c) To state whether particular matters have come to my attention.

**Basis of independent examiner's report.**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence which would be required in an audit and consequently I do not express an audit opinion on the accounts.

**Independent examiner's statement.**

In connection with my examination, **no** matter has come to my attention

1. Which gives me reasonable cause to believe that in any material respect, the requirements of a) to keep proper accounting records in accordance with section 41 of the 1993 Act and b) to prepare accounts which accord with the accounting records and to comply with the requirements of the Act, have not been met.
2. To which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

David Cuthbertson – ICPA Cert Acc (Open)  
Shilton Accounting Services  
1<sup>st</sup> Floor 1 The Clock House  
Brize Norton Road  
Carterton  
OX18 3HN

**Alport UK**  
**Charity number: 1154774**  
**Director's report for the year ended 31<sup>st</sup> July 2024**

The trustees present their report and financial statement for the year ended 31<sup>st</sup> July 2024.

**Objects** – The relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- a) The establishment and facilitation of a support network for Alport Syndrome patients, carriers, their families and carers;
- b) The provision of information on Alport Syndrome;
- c) The support of research into Alport Syndrome both in the UK and internationally;
- d) The support of a research registry in the UK and an international alliance of national registers.

**Governing document** – the charity is governed by a constitution based upon a Charity Commission document that was adopted on 27<sup>th</sup> November 2013. A copy of the full governing document can be obtained from the charity.

**Trustees** - The overall responsibility of the organisation rests with the Board of Trustees. The selection of Trustees is designed to supplement the existing skills and expertise of the board and is governed by an informal skills assessment. The appointment of trustees is made in accordance with the constitution.

**Risk assessment** – Disclosure and Barring checks are carried out for all appropriate trustees, staff and volunteers. The Trustees have examined the major strategies, business and operational risks which the charity faces and confirm that systems have been established to enable regular reports to be produced so that the necessary steps can be taken to minimise these risks.

**Public benefit statement** – Alport UK is a patient-led organisation dedicated to facilitating a support and information network for all those affected by Alport Syndrome. Our vision is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life. This creates public benefits in health and community cohesion.

**Reserves policy** – The Trustees are actively trying to build reserves, with a view to being able to better support patients and facilitate international research collaboration. Minimum reserves are kept to cover 6-12 months of salaries and outgoings. In the event that reserves reach more than 24 months commitments, trustees will review.

This report was approved by the Trustees on 19 December 2024 and signed on its behalf by



**Susie Gear**

**Alport UK**  
**Charity number 115774**

**Statement of Financial Activities (including Income & expenditure Account)**  
**For the year ended 31<sup>st</sup> July 2024**

|                          | Restricted     | Unrestricted   | Total          | 2023           |
|--------------------------|----------------|----------------|----------------|----------------|
| <b>Income</b>            |                |                |                |                |
| Donations/Sponsors       | 837            | 121,994        | 122,831        | 87,060         |
| Delegate fees            | 22,499         | 2,050          | 24,549         | 3,011          |
| Fundraising/merchandise  |                | 3,685          | 3,685          | 2,119          |
| Other income             | 419            | 2,783          | 3,202          |                |
| <b>Total Income</b>      | <b>23,755</b>  | <b>130,512</b> | <b>154,267</b> | <b>92,190</b>  |
|                          |                |                |                |                |
| <b>Expenditure</b>       |                |                |                |                |
| Employee costs           |                | 42,969         | 42,969         | 30,241         |
| Bank & service charge    |                | 114            | 114            | 70             |
| Direct Events costs      | 21,135         | 163            | 21,299         | 9,223          |
| Branded goods            |                | 3,621          | 3,621          |                |
| Administration           |                | 1,044          | 1,044          | 2,700          |
| Travel & subsistence     | 316            | 61,309         | 61,625         | 37,466         |
| Internet/website         |                | 3,083          | 3,083          | 4,493          |
| Marketing                | 7,292          | 5,735          | 13,027         | 3,803          |
| Insurance                |                | 726            | 726            | 710            |
| Subscriptions            | 113            | 1,776          | 1,889          | 1,807          |
| Bursaries/grants         | 456            | 1,477          | 1,932          | 2,057          |
| Others                   |                | 2,879          | 2,879          |                |
| Accountants fees         |                | 1,288          | 1,288          | 1,288          |
| <b>Total Expenditure</b> | <b>29,312</b>  | <b>126,184</b> | <b>155,496</b> | <b>93,858</b>  |
|                          |                |                |                |                |
| <b>Net movement</b>      | <b>(5,556)</b> | <b>4,328</b>   | <b>(1,228)</b> | <b>(1,668)</b> |
|                          |                |                |                |                |
| <b>Transfers</b>         | <b>0</b>       | <b>0</b>       | <b>0</b>       | <b>0</b>       |
|                          |                |                |                |                |
| <b>Opening Balance</b>   | <b>26,325</b>  | <b>21,375</b>  | <b>47,700</b>  | <b>49,367</b>  |
|                          |                |                |                |                |
| <b>Closing Balance</b>   | <b>20,769</b>  | <b>25,703</b>  | <b>46,472</b>  | <b>47,699</b>  |

There are no recognised gains or losses other than in the Statement of Financial Activity.

**Alport UK**  
**Charity number 115774**

**Balance Sheet as at 31<sup>st</sup> July 2024**

|                                            | Notes    | 2024          | 2023          |
|--------------------------------------------|----------|---------------|---------------|
|                                            |          | £             | £             |
| <b>Fixed assets</b>                        |          | <b>3,075</b>  | <b>3,075</b>  |
| <b>Current assets</b>                      |          |               |               |
| <i>Cash at bank</i>                        | <b>4</b> | <b>44,397</b> | <b>47,048</b> |
| <b>Total Current assets</b>                |          | <b>44,397</b> | <b>47,048</b> |
| <b>Current liabilities</b>                 |          |               |               |
| <i>Creditors falling due within 1 year</i> | <b>5</b> | <b>1,000</b>  | <b>2,424</b>  |
| <b>Net current assets</b>                  |          | <b>43,396</b> | <b>44,624</b> |
| <b>Assets less liabilities</b>             |          | <b>46,472</b> | <b>47,699</b> |
| <b>Represented by</b>                      |          |               |               |
| <i>Restricted funds</i>                    |          | <b>20,769</b> | <b>26,324</b> |
| <i>Unrestricted funds</i>                  |          | <b>25,703</b> | <b>21,375</b> |
| <b>Total funds</b>                         | <b>6</b> | <b>46,472</b> | <b>47,699</b> |

**Signed on behalf of the charity's trustees**



**Susie Gear**

**Date: 19 December 2024**

**Alport UK**  
**Charity number: 1154774**

**Notes to the financial statements**  
**For the year ending 31<sup>st</sup> July 2024.**

**1. Accounting policies**

**a. Basis of accounting**

The financial statements have been prepared under the historic cost convention with items recognised at cost or transaction value unless otherwise state in the relevant notes to these accounts. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and reporting by Charities preparing their accounts in accordance with Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS102) issued on 16<sup>th</sup> July 2014 and the Charities Act 2011. The trust constitutes a public benefit entity as defined by FRS102.

**b. Going concern**

The trustees consider that there are no material uncertainties about the trust's ability to continue as a going concern.

**c. Fund accounting**

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

**d. Income resources**

All incoming resources are included in the statement of financial activities when the charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of financial activities when receivable.

Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes entitled to the grant.

Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by volunteers has not been included in these accounts.

Investment income is included when receivable.

Income resources from charitable trading activity are accounted for when earned.

**Notes to the financial statements**  
**For the year ending 31<sup>st</sup> July 2024.**

**e. Resources expended**

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

Costs of generating funds comprise of the costs associated with attracting voluntary income and costs of trading for fund raising purposes.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include accountancy and legal fees.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resources. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

**2. Staff costs**

The charity employed an average of two members of staff in the financial year.

**3. Trustee remuneration & related party transactions.**

The trustees all give freely of their time and expertise without any remuneration or other benefit in kind. Expenses incurred on behalf of the charity are reimbursed at cost.

**Alport UK**  
**Charity number: 1154774**

**Notes to the financial statements**  
**For the year ending 31<sup>st</sup> July 2024.**

**4. Cash at bank.**

|                                      |                  |
|--------------------------------------|------------------|
| Barclays General Account XXXXX405    | 18,242.51        |
| Barclays Research Account XXXXX642   | 1,594.29         |
| Barclays Don't wait Account XXXXX210 | 17,497.68        |
| Caxton FX                            | 5,295.01         |
| Paypal                               | 1,766.76         |
| <b>Total</b>                         | <b>44,396.25</b> |

**5. Creditors: Amounts falling due within one year**

Accounting fee accrual £1,000

**6. Movement in funds**

|              | Opening<br>balance | Incoming<br>resources | Outgoing<br>resources | Balance<br>31 <sup>st</sup> July 2024 |
|--------------|--------------------|-----------------------|-----------------------|---------------------------------------|
| Restricted   | £26,324            | 23,755                | 29,312                | 20,769                                |
| Unrestricted | £21,375            | 130,512               | 126,184               | 25,703                                |
| <b>Total</b> | <b>£47,699</b>     | <b>154,267</b>        | <b>155,496</b>        | <b>46,472</b>                         |

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# Accounts

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# ANNUAL REPORT AND ACCOUNTS



**a brighter future** for people living with alport syndrome

For the year ended 31 July 2023

| Trustees' Annual Report for the period |  |                   |   |      |    |  |                 |   |      |
|----------------------------------------|--|-------------------|---|------|----|--|-----------------|---|------|
| From                                   |  | Period start date |   |      | To |  | Period end date |   |      |
|                                        |  | 1                 | 8 | 2022 |    |  | 31              | 7 | 2023 |

## Section A Reference and administration details

|                                    |             |         |  |
|------------------------------------|-------------|---------|--|
| Charity name                       | alport uk   |         |  |
| Other names charity is known by    | n/a         |         |  |
| Registered charity number (if any) | 1154774     |         |  |
| Charity's principal address        | PO Box 329  |         |  |
|                                    | Cirencester |         |  |
|                                    |             |         |  |
|                                    | Postcode    | GL7 9JA |  |

### Names of the charity trustees who manage the charity

|   | Trustee name    | Office (if any) | Dates acted if not for whole year | Name of person (or body) entitled to appoint trustee (if any) |
|---|-----------------|-----------------|-----------------------------------|---------------------------------------------------------------|
| 1 | Colin Baigent   |                 | Whole year                        |                                                               |
| 2 | Julia Skelding  |                 | Whole year                        |                                                               |
| 3 | Susie Gear      | Chief Executive | Whole year                        |                                                               |
| 4 | Frances Flinter |                 | Whole year                        |                                                               |
| 5 | Rachel Lennon   |                 | Whole year                        |                                                               |
| 6 | Neil Turner     |                 | Whole year                        |                                                               |
| 7 | Danny Gale      |                 | Whole year                        |                                                               |
| 8 | Tim McLean      |                 | Whole year                        |                                                               |
| 9 | Amanda McLean   |                 | Whole year                        |                                                               |

### Names of the trustees for the charity, if any, (for example, any custodian trustees)

| Name | Dates acted if not for whole year |
|------|-----------------------------------|
| n/a  |                                   |
|      |                                   |
|      |                                   |

### Names and addresses of advisers (Optional information)

See table of Advisors over the page

| Type of adviser                                                                 | Name                               | Address                                                                                                                                                                          |
|---------------------------------------------------------------------------------|------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Medical – paediatric nephrologist                                               | Professor Rachel Lennon            | Royal Manchester Children's Hospital, Oxford Road, Manchester M13 9WL                                                                                                            |
| Medical – adult nephrologist                                                    | Professor Neil Turner              | University of Edinburgh Renal and Autoimmunity Group, MRC Centre for Inflammation, Queen's Medical Research Institute, Little France, Edinburgh, EH16 4TJ                        |
| Medical – adult nephrologist                                                    | Professor Daniel Gale              | Department of Renal Medicine, University College London                                                                                                                          |
| Clinical Geneticist                                                             | Emeritus Professor Frances Flinter | Emeritus Professor of Clinical Genetics, Guy's & St Thomas' NHS Foundation Trust<br>Genetics Department, 7th floor Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT |
| Eye specialist                                                                  | Dr Omar Mahroo                     | St Thomas' Hospital Campus, 3rd Floor South Wing Block D, Westminster Bridge Road, London SE1 7EH                                                                                |
| PR, Communication and Marketing                                                 | Jane Keightley                     | JK Branding and Communications Limited                                                                                                                                           |
| Accountant                                                                      | David Cuthbertson                  | Shilton Accounting Services Ltd                                                                                                                                                  |
| Name of chief executive or names of senior staff members (Optional information) |                                    |                                                                                                                                                                                  |
| Susie Gear, Chief Executive                                                     |                                    |                                                                                                                                                                                  |
|                                                                                 |                                    |                                                                                                                                                                                  |

## Section B Structure, governance and management

### Description of the charity's trusts

|                                                                     |                                                                                                               |
|---------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| Type of governing document<br>(eg. trust deed, constitution)        | Constitution                                                                                                  |
| How the charity is constituted<br>(eg. trust, association, company) | Charitable Incorporated Organisation                                                                          |
| Trustee selection methods<br>(eg. appointed by, elected by)         | Appointed for a term of 3 years by a resolution passed at a properly convened meeting of the Charity Trustees |

### Additional governance issues (Optional information)

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>You <b>may choose</b> to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> <li>• policies and procedures adopted for the induction and training of trustees;</li> <li>• the charity's organisational structure and any wider network with which the charity works;</li> <li>• relationship with any related parties;</li> <li>• trustees' consideration of major risks and the system and procedures to manage</li> </ul> | <p>Policies and procedures for the induction and training of trustees</p> <ul style="list-style-type: none"> <li>• Provided with a guide for how the charity operates – this now includes a set of policies on topics such as expenses, relationship with pharmaceutical companies, sponsorship etc.</li> <li>• Disclosure and Barring checks</li> <li>• Given a briefing on the charity and engaged in activities to enable them to participate fully in the decisions of the charity.</li> </ul> <p>Organisational structure of the charity and wider network</p> <ul style="list-style-type: none"> <li>• We are a small charity and so have a very flat organisational structure.</li> <li>• Day-to-day activities are run by one of the trustees – Susie Gear with one part-time employee and a number of volunteers. All day-to-day decisions are jointly taken with at least one of the other Trustees eg Julia Skelding, Emeritus Professor Frances Flinter or Professor Rachel Lennon. If we need to check any of the decisions, we involve the other trustees - who are less involved in the day-to-day activities and so provide excellent challenge and objectivity.</li> </ul> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

them.

- Our closed Facebook page, Alport Warriors, is moderated day-to-day by one of our volunteers – Wilma Calderwood – with back up from Hannah Russell and Susie Gear and with any specific medical questions answered by our medical advisory team – see list above.
- Our public facing social media eg Facebook and Instagram pages are run by Susie Gear, Hannah Russell and some of the younger Alport Warriors.
- Alport UK's Scientific Advisory Committee provide expert medical input and advice as required: Professor Colin Baigent (Strategic direction of research and Clinical trials), Emeritus Professor Frances Flinter (Clinical and particularly Genetics and diagnoses), Professor Danny Gale (Rare Renal Database RaDaR and Clinical trials), Professor Rachel Lennon (Paediatric Nephrology, Podocyte research and clinical guidelines) and Professor Neil Turner (Adult Nephrology and RaDaR).
- Alport UK's international Workshop Organising Committee is made up of a wide range of 39 experts – researchers, clinicians, academics and Alport patients – with representation from Australia, Canada, China, Croatia, Cyprus, France, Germany, Israel, Italy, Japan, Lithuania, Poland, Russia, Spain, UK, USA.

Trustees' consideration of the major risks & procedures to manage them:

- **Support** – as we support patients and family members living with Alport Syndrome, there can be specific questions or situations that require medical advice or input. For the majority of questions, it is Alport UK's policy to encourage patients and their families to partner with their own clinicians to explore their questions and concerns together. This is because the questions often require a detailed clinical history, which a patient's own clinician is best-placed to support with. Where this is not possible or for more general questions, we have a scientific advisory committee which is available, with 24 hour turnaround, to provide expert medical input and advice to patients and their families. All committee members are practising/retired clinicians in the NHS and are recognised internationally for their experience and expertise. We also have a wider network of international experts from whom we can get additional opinions, as required. As we support a number of young adults and vulnerable adults, we have a Safeguarding Officer, who we consult if there are any safeguarding concerns. Mental health is an ongoing challenge for patients living with a life-long condition where the health declines, so we encourage patients to seek professional help from the NHS and help them access the necessary services often through renal units or Kidney Care UK.
- **Information** – all published information and recommendations published on our website, [alportuk.org](http://alportuk.org), is reviewed by members of our scientific advisory committee.
- **Research** – all projects we embark on are reviewed by members of our scientific advisory committee and we get input from a wider network of international experts and patients, as required. This includes assessing clinical trials and although, as a charity, we never recommend participation in a trial, we direct patients to discuss clinical trials with their own clinicians and provide as much information as possible to support patients' decisions on participating in a trial. If we have concerns with a trial, we publish views in international publications, as necessary.
- **Collaboration** – is a core way of working for our charity. We collaborate with other national patient organisations and an international scientific community interested in research into Alport Syndrome. We run monthly conference calls and a series of international workshops for all involved to keep in touch with progress. Funds for these international research activities are kept in a separate bank account so that the international expenditure is transparent – and

separate to the UK funds - to maintain the open collaborative working environment. To ensure all appropriate risks are managed related to this international collaboration, we have an international Workshop Organising Committee to ensure there is a balance of work and information across different countries or continents. Our aim is to collaborate with an increasingly diverse community to remove bias.

- **Fundraising, finances and projects** – As a small charity, we fundraise for specific projects and these funds are kept in separate bank accounts ‘ring-fenced’ for each project. The majority of our fundraising is through applications to larger charities that support small charities, such as ours, with funds allocated for specific activities, such as the information days or international workshops undertaken by alport uk. Increasingly, we also seek funding for work from biotech and pharmaceutical companies. We aim to raise collaborative funding for any project, so we are not reliant on one company for project funding which also means Alport UK is not associated with one company for one particular project.

## Section C

## Objectives and activities

### Summary of the objects of the charity set out in its governing document

The objects of the CIO are the relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- The establishment and facilitation of **a support network** for Alport Syndrome patients, carriers, their families and carers;
- The **provision of information** on Alport Syndrome;
- The **support of research** into Alport Syndrome both in the UK and internationally;
- The **support of a research registry in the UK** and an international alliance of national registries

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

## Public benefit – statutory declaration by Trustees

The Trustees have paid due regard to the Charity Commission's guidance on public benefit in deciding what activities the charity should undertake. alport uk recognises and welcomes the need to carry out its charitable activities to the benefit of those affected by Alport Syndrome, and retains this aim at the centre of its strategic planning.

**alport uk is a patient-led organisation** dedicated to facilitating a support and information network for all those affected by Alport Syndrome.

**Alport Syndrome** is an inherited condition that can cause kidney failure, deafness and eye abnormalities. Those that inherit it will probably require a kidney transplant when they are young adults. It can impact a large number of people in a family. It is the second most common form of inherited kidney disease. Meet Sam to understand the impact it has on a family: <https://youtu.be/4vRuYBn6St4>.

**Our Vision** is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life.

**Our Mission** is to work in partnership with individuals, families and the scientific community to:

- Facilitate a **support** network for patients and families
- Be a conduit for high quality, accessible **information**
- **Raise the profile** of Alport Syndrome in the scientific community
- Contribute to the international **research** agenda
- **Collaborate** on the development of a UK patient registry and alliance of international patient registries.

## alport UK fund four key areas of activity

1. **Support** – Provide support for UK patients and families through a support network, website and information days.
2. **Information** – Work with clinicians, individuals and families to educate them on more effective diagnosis and treatment, for example national and international guidelines for diagnosis, treatment and the best care for children, teenagers and adults.
3. **Research** – Work with other national patient organisations (eg USA, across Europe and Asia) to:
  - a. Facilitate and drive the design, development and maintenance of an international research strategy and plan for Alport Syndrome using a programme of international workshops – online and in-person.
  - b. Grow a global network – of patients, clinicians, laboratory scientist and pharma companies – the Alport Syndrome Alliance. The aim of the Alliance's global network is to advance treatments and knowledge.
4. **Collaboration** – Bring together the scientific community to work across the different clinical disciplines that specialise in kidneys, ears, eyes, mental health, other rare disease areas with similar issues etc. and work with the national patient organisations or other rare renal

disease groups to share best practice with developed and developing countries.

The activities of alport uk are grounded in the local communities across the UK as we aim to connect up regional groups of individuals and families that are affected by Alport Syndrome. As a possible few thousand individuals impacted in the UK, it is a small population of those living with Alport Syndrome if looked at on their own. This requires alport uk to work internationally with other national patient organisations and clinicians to co-ordinate activities and research across a far bigger group of patients, particularly those with 100,000+ patients in countries such as China and USA.



Families connecting at the Newcastle information day (October 2022)



Children playing at the Cardiff information day (April 2023)

## Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grant making;
- policy programme related investment;
- contribution made by volunteers.

### Contribution by volunteers

**alport uk had one part-time employee over this period. The Chief Executive, leading the performance and achievements is a volunteer. alport uk mostly relied on voluntary help to run the activities over this period as for the previous nine years.** With the growth of our community over Covid, we took steps to grow the number of volunteers in our team as we received more queries than we could respond to with the size of our team. Many volunteers come to us initially asking for support and then offer their many skills to help others as they see how they have benefited.

**Our community often reflect and remark on the journey we've been on and the remarkable progress alport uk makes and their ability to support patients and deliver professional international events that appeal to all stakeholders.**

**We are incredibly grateful to the many volunteers for this remarkable progress, especially for the many contributions from the following key and very motivated people:**

- **Saira Bhatti** for spending the time educating us on how to design websites to suit patient needs and for reviewing a number of website ideas and designs for both Alport UK and the Alport Syndrome Alliance.
- **Katie Brown** for continuing to help us run the Alport online workshops and for moderating the young adult (18-35 year-olds) Whatsapp Group: Alport Avengers, even while her kidney function declined.
- **Kimiya and Frank Bunger** for their excellent notes taken at the international workshop and work on a website for the Alport Syndrome Alliance.
- **Wilma Calderwood** for her day-to-day moderation on our closed Facebook page, Alport Warriors, which saw the community double in size during the pandemic.
- **Sam Clarke** whose 4,776-mile cycle ride in 2019 allows us to use the funds raised for the 'Don't Wait Fund' to support patients with Alport Syndrome take up a new activity or hobby.
- **Mary Lou McCarthy** for kindly giving up a weekend (when she typically does wedding photography) to come and take photographs in Newcastle at our information day.
- **Dan Long** for running the production of our online workshops.
- **Alice Turner** for her continuing, enthusiasm and fundraising work, ideas and help with running alport uk and supporting fundraising activities post-pandemic and for her eternally positive attitude to fundraising. Alice also has a forensic knack of putting our annual accounts together and tracking down all receipts and invoices to make the accountant's role much easier as he prepares the annual accounts.
- **Archie Walker** for running the production of our online workshops.
- **Patrick Walker** for moderating our online workshops and engaging young adult patients at the in-person workshop at Calgary and other Alport Avenger social activities.
- **Heidi Zealey** for continuing to help us run the Alport online workshops and increasing responsibilities representing Alport UK with European patient groups such as FEDERG and ErKNET EPAGs.

- **Aura Zealey Smith** for moderating our online workshops and engaging young adult patients at the in-person workshop at Calgary.

**Grateful thanks to all those who raised money for us this year – every penny makes a difference. Particular thanks go to:**

- **Lauren Brand** for her plant sales generating funds for alport uk
- **Penny Calder and family - Hannah and Nicholas** - who raised money for alport uk in memory of their husband/Dad Nick Bundy. A big thank you to Battersea Choral Society (London) for choosing Alport UK as their charity for Christmas. Nick used to sing with the choir and they kindly donated their Christmas collection to Alport UK.



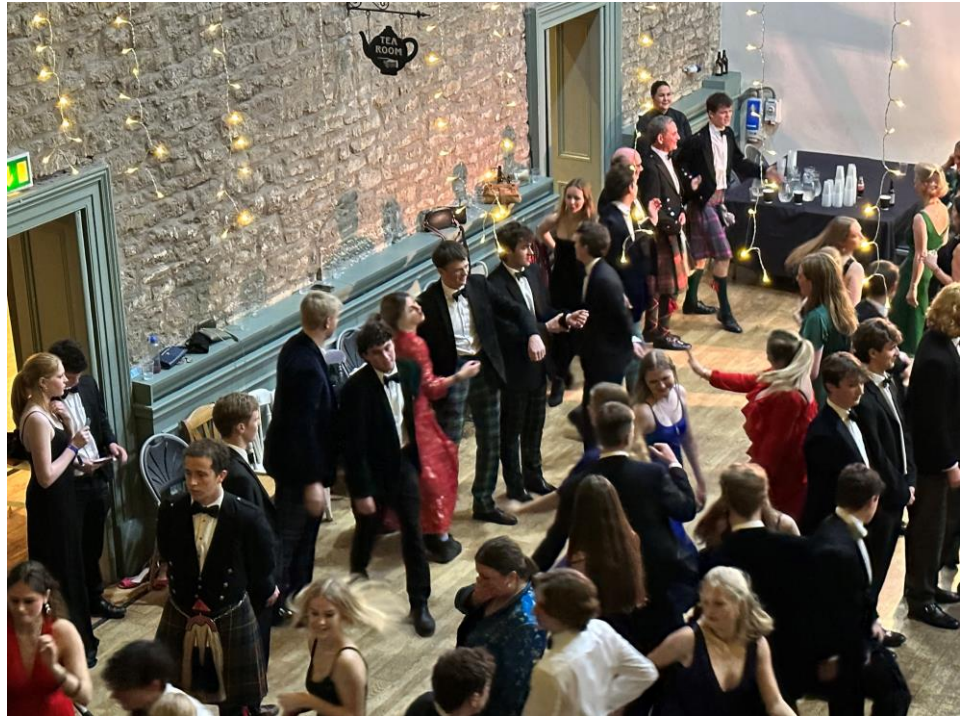
Hannah and Nicholas



Battersea Choral Society Christmas Concert in aid of Alport UK (December 2022)

- **Sarah Forrester and her organising committee** at the Cirencester Kick Up your Heels Gathering in December 2022 (an annual reeling

event) that raises vital funds for Alport UK and other charities. Particular thanks go to **Cece Vass** and **Jamie Walker** for organising a huge reeling party and raising the funds through tickets sales and by running reeling practices where they teach young adults to Scottish reel. All the proceeds of the teaching goes to Alport UK too.



Some of the young people reeling in aid of alport uk, December 2022.

- **Sandra Jones** for raising more funds by doing the Kiltwalk – this year in person rather than virtually



Sandra Jones finishing the Kilt Walk

- **Margaret and Sam Maidment** for their fabulous 'tea in a barn' fundraising event.



Margaret and Sam Maidment's 'tea in a barn'

- **Charlotte and Will Swain** who completed a incredible 10k run for alport uk



Charlotte and Will Swain and family

- **Those who donated funds raised from funerals** of loved ones
- **All** those people who purchased digital Christmas cards to raise funds through Don't Send A Card
- **Everyone** who uses Amazon Smile and Easyfundraising for their shopping to raise small but important funds which keep the lights on at Alport UK.

**Thank you to those who generously provided alport uk with a grant:**

- **Amelia Chadwick Trust**
- **D'Oyly Carte Charitable Trust**
- **Dyer's Company and other livery companies**
- **Jeans for Genes**
- **Popham Kidney Support**
- **Kidney Care UK**
- **Kidney Foundation of Canada**
- **Kidney Research UK**
- **Kidney Wales**
- **Liverpool Charity and Volunteer Services**

- **Commercial companies – Calliditas, Eloxx, Sanofi, Travers** who sponsored either patient days in Newcastle or Cardiff or our international workshop which formed part of The 2022 International workshop on Alport Syndrome

**And a number of people who wish to remain anonymous** but to whom we are very grateful for their support and encouragement.

**We wish to thank our Scientific Advisory Committee** for continuing to spend so much time this year advising and supporting support the community as the pandemic continued its hold whilst they were all also very busy on clinical wards helping with renal issues. They answered all queries within 24 hours, ensuring the community remained as calm as possible at such a worrying time for renal patients. We are so very grateful to the scientific community for their help to answer all questions and emails as and when they arose from patients or other scientists. Very many thanks to our UK Scientific Advisory Group:

- **Emeritus Professor Frances Flinter**
- **Professor Danny Gale**
- **Professor Rachel Lennon**
- **Dr Omar Mahroo**
- **Professor Neil Turner**
- **Professor Colin Baigent.**

**Alport online workshops** – Patients, patient families and clinicians continued to volunteer for alport uk. A small working group of volunteers was formed which included: **Susie Gear, Louise Hopkinson, Professor Rachel Lennon, Professor Jeffrey Miner, and Heidi Zealey and Katie Brown.** Thanks to **Patrick Walker** and **Aura Zealey-Smith** for their



Aura Zealey Smith moderating a workshop online

excellent moderation and broadcasting skills quizzing the scientists to make each production so much more engaging for the online audiences - see Alport Workshops on YouTube channel: <https://tinyurl.com/y9cuhgby>. Katie is to be particularly congratulated as she participated in workshops right up to her kidney transplant in the summer of 2022. Thanks also to **Dan Long, Archie Walker** and **Alice Cooper** for managing the productions behind the scenes, doing the rehearsals with scientific teams all over the world and training people up to deliver some outstanding workshops.

Thank you to **Patrick Walker** for his excellent video-editing work that makes each Podcast so professional when loaded onto YouTube. We

are so grateful for the ongoing inspiration from this group who help run the very professional **Alport online workshops** featuring the latest



Patrick Walker moderating an online workshop

Alport research, using Zoom, which were provided for the international Alport community (patients and scientists) by alport uk and with set up costs kindly funded by Kidney Research UK. Volunteers who helped with the workshops, acting as moderators or contributors telling their stories also included **Katie Brown, Sam Clarke, Dan Long, Aby Lucy, Patrick Walker, Andre Weinstock, Heidi Zealey, Aura Zealey-Smith**

We wish to thank those involved in growing **Alport Avengers**, an invaluable WhatsApp group specifically aimed at 18–35-year-olds, joining and sharing their experiences to help others. This included **Katie Brown, Sam Clarke, Jamie Walker, Patrick Walker** and **Aura Zealey-Smith**.

We are also very grateful to our colleagues who run the other national patient organisations and collaborate with alport uk, such as **Andre Weinstock** (Alport Syndrome Foundation, USA), **Renee de Wildt** (The Netherlands), **Maria José Cacharron** (Spain) and **Daniela Lai and Rossella Ferrari** (Italy), **Jessie Zhang and Mr Cai** (China), **Christof Finkler** (Germany), **Dave Blatt** (Australia).

Huge thanks to the inspiration of many volunteers around the world – each Alport experts in both their scientific area and geography - that made up the **Workshop Organising Committee for The 2022**

**International workshop on Alport Syndrome in Calgary, Canada:**

**Dr Marina Aksenova**, Veltischev Research and Clinical Institute for Pediatrics of the Pirogov Russian National Research Medical University, Moscow, Russia

**Assistant Professor Moumita Barua**, Toronto General Hospital, Toronto, Canada

**Dr Agnė Čerkauskaitė**, Division of diagnosis and treatment of Rare Kidney and Metabolic Diseases, Nephrology Center, Vilnius University Hospital Santaros Klinikos, Vilnius, Lithuania

**Professor Constantinos Deltas**, University of Cyprus, Molecular Medicine Research Center, Nicosia, Cyprus

**Professor Jie Ding**, Department of Pediatrics, Peking University First Hospital, Beijing, China

**Professor Frances Flinter**, Emeritus Professor of Clinical Genetics, Guy's and St Thomas' NHS Foundation Trust, London, UK

**Professor Daniel Gale**, Department of Renal Medicine,

University College London, UK

**Professor Danica Galešić-Ljubanović**, Department of Pathology  
University of Zagreb School of Medicine, Head of Department of  
Nephropathology and Electron Microscopy, Dubrava University Hospital,  
Zagreb, Croatia

**Professor Oliver Gross**, Department of Nephrology and  
Rheumatology, Georg-August-Universität Göttingen, Germany

**Professor Julia Höfele**, Institute of Human Genetics, Munich, Germany

**Professor Hirofumi Kai**, Graduate School of Pharmaceutical  
Sciences, Kumamoto University, Japan

**Professor Clifford Kashtan**, Department of Pediatrics, University  
of Minnesota, USA

**Professor Bertrand Knebelmann**, Necker Hospital, Paris, France

**Associate Professor Ron Korstanje**, The Jackson Laboratory,  
Bar Harbor, USA

**Professor Rachel Lennon**, Wellcome Trust Centre for Cell-Matrix  
Research, University of Manchester, UK

**Associate Professor Beata Lipska**, Department of Biology and  
Medical Genetics, Medical University of Gdańsk

**Dr Laura Massella**, Division of Nephrology, Dpt. of  
Pediatric Subspecialties, Bambino Gesù Children's Hospital - IRCCS,  
Rome, Italy

**Professor Julian Midgley**, Department of Paediatrics, Alberta  
Children's Hospital, Canada

**Professor Jeffrey Miner**, Washington University in St. Louis, USA

**Associate Professor Laura Perin**, Saban Research Institute, University  
of Southern California, USA

**Professor Alessandra Renieri**, Professor of Medical  
Genetics, Director of Medical Genetics Unit, Azienda Ospedaliera  
Universitaria Senese viale Bracci 2, Siena, Italy

**Associate Professor Michelle Rheault**, Department of  
Pediatrics, University of Minnesota, USA

**Professor Judith Savage**, University of Melbourne, Australia

**Professor Roser Torra**, Fundació Puigvert, Barcelona, Spain

**Professor Neil Turner**, Professor of Nephrology, University of Edinburgh  
and Consultant Nephrologist, Royal Infirmary of Edinburgh, UK

#### **Patient representatives:**

**Dave Blatt**, Alport Foundation of Australia

**Andre Weinstock**, USA

**Maria José Cacharron**, Spain

**Christof Finkler**, Alport Selbsthilfe, Germany

**Susie Gear**, alport uk

**Daniela Lai**, A.S.A.L., Associazione Sindrome di Alport, Italy

**Julia Schifter**, Alport Foundation Israel

**Renee de Wildt**, NierpatiëntenVereniging Nederland (NVN), The  
Netherlands

**Jessie Zhang and Mr Cai**, Chinese patient group, China

Our special thanks to **all members of the Lennon Lab of Manchester University** who are based at the Wellcome Centre for Cell Matrix and led by the inspirational **Professor Rachel Lennon**, also responsible for running the **Stoneygate and Kidney Research UK Alport Research Hub**. The team all volunteered and worked very closely with alport uk on a number of different events and projects over the year including the Alport Online Workshops and are doing some amazing basic science research and collaborations with the Alport community around the world. The Lennon lab research work is internationally recognised as leading edge and helping us better understand what happens in the kidneys with Alport Syndrome. They also are always on hand to support alport uk with

explaining scientific terms, helping design workshop agendas and generally engaging with the patient community. It is unusual for



Professor Rachel Lennon being filmed by patient Sam Clarke

patients to be so engaged in research and we have the Lennon lab and Rachel Lennon to thank for this exciting collaboration that is leading to new ways of working.

When we organise **Alport information Days**, such as the ones in Newcastle (October 2022) and Cardiff (April 2023), we rely on local people living with Alport Syndrome and local kidney doctors to volunteer and help us find suitable venues, engage the local patient community etc. To update people on the latest Alport research, we also rely on the Stoneysgate and Kidney Research Alport Research Hub employees to give up a Saturday and to travel across the country to come and present their latest research. For these two information days we are very grateful to the following volunteers:

- **Newcastle Alport information day** (October 2022) with thanks to: **Amanda Little, John Sayer, Neil Turner**
- **Cardiff Alport information day** (April 2023) with thanks to: **Mark Thomas, Pippa Llywelyn Thomas, Sian Griffin and Mychel Morais.**

The international workshops on Alport Syndrome also require a local team in that country to organise the local aspects of the workshop. For helping alport uk with **The 2022 International workshop on Alport Syndrome**, grateful thanks go to **Julian Midgley, Tanya Graves-Smith** and **the Pedersen family** and the organisers of the International Society of Pediatric Nephrology (IPNA) who kindly allowed the workshop to be a pre-meeting to their 19<sup>th</sup> congress.

There are also a number of people we would like to recognise for their contributions to our projects. Although we pay them for the project work they do, each has given way more time and ideas than they charge us for. Their continued support we very much appreciate:

- **Jane Keightley** – for her marketing advice and on-going support to build the brand of Alport UK to raise its profile along with communicating and engaging people in our aims and objectives and core activities. We also very much appreciate Jane's writing and editorial advice that sets the written tone for all our communications.
- **Robina Newman** – for her continued work on our brand and design

and generally helping us to create a bright and distinctive identity that sets the visual tone for our activities including some lovely branded

merchandise which helps our patients be proud of their Alports and of our community.



Alport UK merchandise which is now sold through an online shop

- **Chris Francis and Paul Heaps** – who kindly took on the challenge of taking photos whilst we worked in Cardiff and Newcastle to share what we do, celebrate our special team, and photograph all who participated.
- **Sam Clarke** – for his excellent videos that are making our work come alive and enabling alport uk to share the important work we do. This year Sam filmed:
  - **Some more short documentaries of people living with Alport Syndrome** – see links to videos in later section.
  - **People’s reactions to the international workshops we run for the Alport Syndrome Alliance** – to grow the global network advancing treatments and knowledge. For example, Sam came to Calgary, Canada to film the The 2022 International workshop on Alport Syndrome. These films help us get funding for future workshops.
- **Alice Cooper** – continued in the role of Engagement Manager for alport uk until the end of 2022 and worked with the alport uk volunteers including Susie Gear to:
  - maintain the Alport Online workshop process, engaging the Alport community in the workshops
  - reach out to a wider group of people across the world to engage them in the international workshops using mailings and social media
  - update and deliver an invaluable website for the Alport Syndrome Alliance to automate the registration to register all those interested in participating in The 2022 International workshop on Alport Syndrome in Calgary, Canada
  - organise the first in-person Alport information day (after Covid) in Newcastle in October 2022, soon after the Calgary workshop
  - design branded merchandise and designed an online shop to sell to much needed funds for alport uk.

Alice contributes many more hours than the part-time work we pay her for, particularly in the lead up to key events such as The 2022 International workshop on Alport Syndrome. We are incredibly grateful for Alice’s wonderful dedication and ability to get things done which accelerates what alport uk delivers.



Alice Cooper supporting one of the online workshops



Thank you to Alice Cooper from those at the Newcastle information day, October 2022

- **Hannah Russell** initially became a volunteer for alport uk soon after her daughter Florence was diagnosed with Alport Syndrome. Hannah's role as Engagement Director was formalised and became a paid part-time role in 2023. Hannah consistently gives alport uk many more hours than she is employed to do. With her understanding of the journey that newly-diagnosed families go on, means Hannah sensitively supports those who can find the initial diagnosis challenging. Hannah does this selflessly and with great compassion helping them adjust to their situation and connect with others living with Alport Syndrome.
- **Jayne Perrin** joined alport uk in June 2023 initially as Administrator. With Jayne's background as a company secretary and with the templates, filing and systems kindly set up by Alice Cooper as part of her handover, Jayne is quickly mastering the processes to run events and manage alport uk operations. Jayne's first big event to run is The 2024 International workshop on Alport Syndrome in Cyprus in March next year. Jayne clearly thrives off the everyday challenges alport uk sets her, is expert at working remotely and it is great having her as part of the team. Jayne already keeps us smiling and reminds us we achieve a lot as three part-time women running the charity with so much help from the incredible networks of amazing volunteers.

**Thank you to all who contribute!**



Chief Executive, Susie Gear and Engagement Director, Hannah Russell

### Summary of the main achievements of the charity during the year

The achievements of alport uk this year build from last year and are summarised under the headings of our key objectives and areas of activity below. **Overall, our main outcome is to create a more positive and brighter future for individuals and families living with Alport Syndrome.** Being a rare and therefore small community, we aim to deliver sustainable strategic change for Alport Syndrome, using virtual networks and limited resources to effectively support patients and develop treatments for Alport Syndrome. Positivity and engagement are the main ingredients for all the support we offer – we aim to inspire and encourage people living with Alport Syndrome to be optimistic and explore their own individual route to a brighter future.

Measuring our performance and listening to patient feedback on what works and adjusting what we do is vital:

Patient: *“Thank you for another truly excellent meeting Susie & all. This is such an important activity & we appreciate your tremendous efforts and skills in pulling us all together.”*

### The philosophy that underpins our performance

The Six Pillars of Wellbeing – long established as a framework to think about mental health and wellbeing - is a useful structure to encourage positive outcomes for individuals and families living with Alport Syndrome. The Six Pillars that inspire our activities:

- **Stress management** – keeping the community calm and informed with the latest information, so they can become more independent, strong and resilient over time
- **Nutrition** – inspiring the community to eat healthily to protect their kidneys for as long as possible and when on restricted diet, explore new foods they can eat
- **Community** – connect to reduce the feeling of isolation caused by having a rare disease that few others either know or understand
- **Sleep** – ensure the community members can have a routine with good sleep to enable them to deal with the rollercoaster journey that some individuals and families face as part of living with a rare disease and coping with critical events along the way, such as hearing declining, kidney failure and eye issues.
- **Exercise** – we know cardiovascular exercise is good for the kidneys. It is also vital to rebalance the chemical impact brought on by the feeling of anxiety that overwhelms some people living with the fact that their or their children's kidneys may fail and hearing might decline at some unknown time in the future
- **Meaningful activity** – encourage individuals, families, and researchers to connect around a shared objective of helping our community in some way, whether it be volunteering for our community, advocating, fundraising, collaborating on research or useful information or sharing stories to help others living with Alport Syndrome.

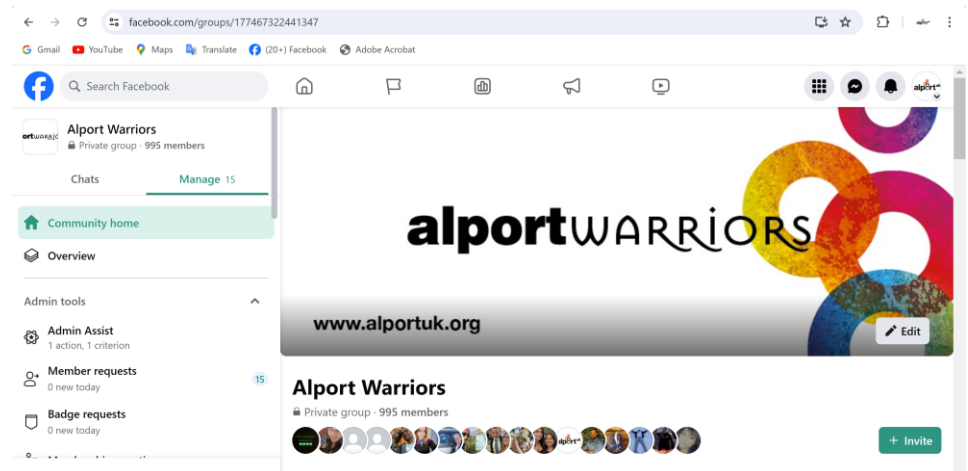
### As a tiny charity we are very clear what we can do

Supporting a rare disease is a challenge as there are few people who have Alports, or who want to research it or to fund it. So as a charity we aim to think wisely about how we use our strengths, capabilities, and resources and how to collaborate to complement these. Our volunteers have strong capabilities in delivering commercial innovation and collaboration across virtual networks of international stakeholders around

the world. Some examples of the principles that guide what we do in our five key areas of work:

### 1. Support network

With a small, isolated patient community with such differing needs, we like to deliver **personal support in a timely way that delivers practical advice** and solves practical issues. alport uk's role is to empathise, understand the needs/issues, advocate for patients (and researchers) and support delivery of solutions through a virtual organisation with minimal overheads. The power of the internet and social media provide us with very economical tools such as our closed Facebook community page, **Alport Warriors** and our public **Alport UK Facebook page**. With our limited resources, this often means facilitating patient/researcher access to resources. For example, alport uk facilitates patients getting the right diagnosis via genetic testing, understanding treatment options or facilitating the grant application process for holiday breaks via Kidney Care UK's grant system. alport uk also writes letters of support for researchers to facilitate grant applications for Alport research.



Alport Warriors – private Facebook page



Alport UK – public Facebook page

### 2. Provision of information

With a diverse community and a very complex condition to explain, we try out different ways to provide information in a **variety of formats that suit different stakeholders**. With many of the community facing critical medical decisions as young adults, increasingly we use a combination of **in-person Information Days** with **short videos, social media and engaging activities to enable the patient community to engage in formats and content they find valuable**. For example, we encourage

young adults to become our 'media team' at events, to engage in content, choose what is important and create videos and social media content themselves. Sam Clarke made additional videos about Living with Alport Syndrome to illustrate the positive attitude patients have despite facing health challenges – see one of the videos here that was filmed about a patient's experience of a clinical trial: <https://youtu.be/67w3zY-c0Zk>. We also publish **scientific information in the appropriate international journals so that it builds consensus across our community and is peer reviewed and globally available** for researchers, clinicians and patients.

### 3. Support research

With limited funds and fundraising capability, we choose to focus our efforts to **inspire and facilitate collaborative behaviours such as information and resource sharing to facilitate and accelerate innovative ways of working and the development of new treatments and knowledge**. For example, alport uk continues to facilitate **the international research community coming together as the Alport Syndrome Alliance – a global network to advance treatments and knowledge for Alport Syndrome. alport uk use in-person and online workshops to share and exchange ideas**. This strategy aims to create a vibrant international research community that attracts more researchers and pharmaceutical or biotech companies interested in developing new treatments. These activities complement the strengths and activities of our colleagues in organisations such as:

- Kidney Research UK – who raise money to fund specific UK Alport and kidney research projects eg elements of Rachel Lennon's lab based at Manchester University.
- Alport Syndrome Foundation in the USA – who have more recently focused on very specific areas of Alport research that they prioritise eg relationship of annurisms to Alport Syndrome, hearing and other topics at an early stage of development.

### 4. Continued support of a UK research registry

With significant investment made by Kidney Care UK and Kidney Research UK into The **National Registry of Rare Kidney Diseases (RaDaR)** – the UK Kidney Association's (UKKA) initiative designed to pull together information from patients with certain rare kidney diseases - alport uk support this vital project by **encouraging patients, clinicians and kidney units to upload long-term clinical data into this database to enable natural history studies in the future to progress Alport Syndrome research**. This will give a much better understanding of how Alport Syndrome affects people. It will also speed up research. The value for:

- Alport patients:
  - Access to their clinical data online which records blood and urine results, medications and clinic letters.
  - Ability to be contacted about future potential research studies or patient information events
  - Contribute to the increase in knowledge about their condition
- Clinicians:
  - Share knowledge with other colleagues
  - Use RaDaR as part of a research study or clinical trial.

### 5. Fundraising

With a small number of people in the UK (compared with other countries with much larger populations) impacted by Alport Syndrome, awareness of the condition is limited and traditional fundraising by the public typically

focuses on the key health areas of cancer, heart conditions etc. **We heartily encourage individuals and families living with Alport Syndrome to fundraise when inspired to do so, by providing support, encouragement and new branded merchandise** (eg t-shirts, badges, wrist bands, shaking tins etc) to enable them to achieve whatever challenge motivates them. This means that **we raise significant funds for each major project (eg an international workshop or a new website) or a programme of activities (information days) by applying for grants from larger charities or from pharmaceutical companies.** We specifically support large fundraising events each year eg a dinner with an auction, a major activity eg swimming the channel or cycling round Europe etc.

### Highlights: achievements and performance this year

#### Engaging our community in the diverse locations with greatest need

To be taken seriously as a rare disease community, by the pharmaceutical and biotech companies who develop treatments, we need an engaged patient community who understands the need for treatments and how vital engaging in clinical trials is for the development of treatments for generations to come. We have a number of different ways in which people living with Alport Syndrome engage across the UK and across the world. We specifically focus on and engage the larger communities in the UK and abroad, informed by statistics such as the population tables below which show a) the locations of largest groups of Alport patients across the UK and b) the countries that have the largest group of Alport patients. numbers of Alport patients if you assume that 80% of patients (typically with x-linked inheritance pattern) account for a prevalence of 1 in 10,000 in any population. The reality is that recent research by Gibson et al (2022) suggests the prevalence is closer to 1 in 2,300 in any population which obviously increases the market size for treatments as indicated by the tables below:

#### a) Table showing locations of largest groups of Alport patients across the UK, based on prevalence in a city

Population - UK most populated cities 2024

| Location             | Approx Current Population 2024 | 1 in 10,000 in 2014<br>0.0001 | 1 in 2,300 in 2024 |
|----------------------|--------------------------------|-------------------------------|--------------------|
| United Kingdom TOTAL | 67,851,030                     | 6785                          | 29500              |
| London               | 7,556,900                      | 7,556                         | 3,285              |
| Birmingham           | 984,333                        | 984                           | 427                |
| Liverpool            | 864,122                        | 864                           | 375                |
| Nottingham           | 729,977                        | 729                           | 317                |
| Sheffield            | 685,368                        | 685                           | 297                |
| Bristol              | 617,280                        | 617                           | 268                |
| Glasgow              | 591,620                        | 592                           | 257                |
| Leicester            | 508,916                        | 508                           | 221                |
| Edinburgh            | 464,990                        | 464                           | 202                |
| Leeds                | 455,123                        | 455                           | 197                |
| Cardiff              | 491,755                        | 491                           | 213                |
| Manchester           | 395,515                        | 395                           | 171                |
| Stoke-on-Trent       | 372,775                        | 372                           | 162                |
| Coventry             | 359,262                        | 259                           | 156                |
| Sunderland           | 335,415                        | 335                           | 145                |

Data reference <https://worldpopulationreview.com/countries/united-kingdom-population>

These figures guide our UK engagement. A practical example of this, is that we prioritise running information days in UK cities where there are

the greatest potential number of Alport patients for example systematically **prioritising locations to date: London, Birmingham, Liverpool, Glasgow, Edinburgh, Cardiff, Manchester.**

**b)Table showing countries with the largest groups of Alport patients across the world, based on prevalence in a country population**

| Population - Global 2024 |                                |             |      |                     |                    |
|--------------------------|--------------------------------|-------------|------|---------------------|--------------------|
| Location                 | Approx Current Population 2024 | Growth Rate | Rank | 1 in 10,000 in 2014 | 1 in 2,300 in 2024 |
| Global                   | 8,005,176,000                  | 0.91%       |      | 800,158             | 3,480,511          |
| India                    | 1,435,286,555                  | 0.92%       | 1    | 143,528             | 623,602            |
| China                    | 1,425,490,616                  | -0.03%      | 2    | 142,552             | 619,778            |
| United States            | 340,920,914                    | 0.53%       | 3    | 34,075              | 148,226            |
| Indonesia                | 278,691,792                    | 0.82%       | 4    | 27,848              | 121,070            |
| Pakistan                 | 242,866,242                    | 1.96%       | 5    | 24,243              | 105,594            |
| Nigeria                  | 226,479,269                    | 2.39%       | 6    | 22,599              | 98,469             |
| Brazil                   | 217,047,958                    | 0.56%       | 7    | 21,704              | 94,368             |
| Bangladesh               | 173,841,212                    | 1.01%       | 8    | 17,384              | 75,583             |
| Russia                   | 144,192,493                    | 0.34%       | 9    | 14,419              | 62,692             |
| Ethiopia                 | 128,131,124                    | 2.52%       | 10   | 12,812              | 55,709             |
| Mexico                   | 128,931,127                    | 0.73%       | 11   | 12,893              | 55,709             |
| Japan                    | 122,960,996                    | -0.54%      | 12   | 12,296              | 53,461             |
| Philippines              | 118,230,898                    | 1.51%       | 13   | 11,823              | 51,335             |

Data reference <https://worldpopulationreview.com/countries/united-kingdom-population>

These country populations focus our international engagement activities. alport uk invested time and engagement efforts to engage patients from China, Indonesia, Nigeria, Brazil, Russia, Japan. alport uk do this through clinical contacts in the countries, or social media and in-person international workshops in countries with larger populations of Alport patients. **To date we have patients and clinicians engaging in person or online from 66 countries.** Thanks to alport uk's initial investment in 2014 to support patients engaging in China, the Chinese patients have now set up there own **Chinese Alport Syndrome Parents Association** which today is now one of the largest patient organisations in the Alport global community connecting so many diverse people across Asia and significantly reducing their feeling of isolation. alport uk continue to support and collaborate with this vital community of people living with Alport Syndrome.

### Support network proactively increased

Before the charity existed in 2013, it was typical that a family diagnosed with Alport Syndrome would never meet or talk to anyone outside their own family impacted by the condition. There was no support network and no mechanism for connecting individuals and families. People felt isolated. Through regular annual **national Alport Information Days**, our **web site** and closed Facebook page - **Alport Warriors** - and other social media pages (Instagram, X formerly Twitter), support networks developed and each year the community feels stronger, more connected and able to deal with issues as they arise and particularly as we work through challenges together. People don't feel alone anymore. This infrastructure proved invaluable in supporting patients through the unknown stages of the pandemic and as we emerged beyond.

The closed Facebook community – **Alport Warriors** – is one of the ways alport uk proactively encourages peer support – people living with Alport Syndrome helping others in a similar situation. The carefully moderated group continues to grow and now numbers over 995 members from all over the world, trusting and appreciating the excellent advice we get from our colleagues in the UK's NHS. In 2019, there were 350 members. Each

year we are contacted by more and more people from around the world as they are diagnosed with Alport Syndrome. We provided advice specifically relating to COVID and the impact on kidney patients. As we work as a 'virtual' organisation anyway, alport uk was able to easily respond, during Covid, to the increase in requests and with more of the community online – patients and researchers – more people were able to help each other. This engagement from the wider community was valuable for all and so alport uk thrived in a really positive way, despite the pandemic. It was an opportunity for more to engage and more got value from this engagement.

One practical way of supporting patients is with the **Don't Wait Fund** – a fund that people living with Alport Syndrome can apply to for a grant of up to £250 to start a new activity: Over this year, we funded 8 people living with Alport Syndrome:

- **A young woman in her 30s** who bought **gym kit** so that while on dialysis and awaiting transplant, she could continue to exercise at the gym.
- **A young man, aged 19** who, despite his kidney function declining, learnt to be a ski instructor and bought a **ski jacket**.
- **An Aunt** to buy a **bike and bike helmet** for her nephew when he was newly diagnosed with Alport Syndrome.
- **A young woman in her 20s** who got a grant to pay for a **gym subscription**.
- **A woman** got a grant for her husband to get a **gym subscription**.
- **A mother of two** got three different grants for herself (half her annual **gym subscription**) and her two boys to buy kit for their different activities: **climbing kit** and **drama lessons**.

#### Key support network achievements this year

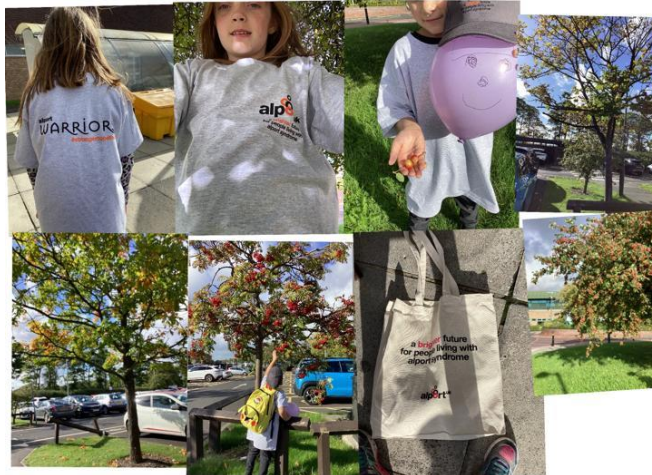
**Delivered two Alport information days in Newcastle** (October 2022) **and Cardiff** (April 2023):

| Participant numbers           | Newcastle, October 2022 | Cardiff, April 2023 |
|-------------------------------|-------------------------|---------------------|
| Adults                        | 13                      | 29                  |
| Young adults                  | 8                       | 16                  |
| Older children and teens, 12+ | 0                       | 1                   |
| Younger children, 0-11        | 6                       | 13                  |
| Total                         | 27                      | 59                  |

These in-person Alport Information Days, advertised via our social media and email, combine a mix of information (from experts), social networking and getting to know the city we are in. The information days are organised around the country to attract diverse groups impacted by Alport Syndrome and target specifically the larger cities with large populations. The days particularly attract newly diagnosed individuals and families and connect them with others on similar journeys, whether as individuals, parents, young adults or children. We combine the activities with social activities particularly aimed at the young adults. The information day agendas are designed specifically to create a safe space for people to ask any questions they may have of the experts, to connect with others and engage in understanding Alport better. The days are 'immersive', designed to support and attract a diverse group of people. Professional childcare is a key element of the day, so both parents and

children get their questions answered and they have the opportunity to connect and meet with others impacted by Alport Syndrome.

#### Feedback on Newcastle Alport Information Day – October 2022



**Going through Alport syndrome is not fun but when I came to New Castle to meet other people like me. I had a lot of changes happening to me, I was scared but they told me that I am a brave warrior, I feel better now.**

Feedback on the Newcastle information day by Lolah, aged 10



People at the Newcastle information day watching Sam Clarke's filmed stories of *Living with Alport Syndrome*. These stories are a key feature at the workshop. The young adults, many going through dialysis or transplants, are on hand to answer questions posed by newly diagnosed individuals or families.



Alport experts Professor John Sayer, Susie Gear and Professor Neil Turner are on hand to answer questions, Newcastle 2022

When asked to comment on the value of the weekend in Newcastle to family and friends, the people living with Alport Syndrome commented:

*"The workshop was extremely valuable to us as a family, increasing our understanding, especially of genetics and treatment options. It was such an encouragement to meet others with Alport Syndrome, and really exciting to be a part of John Sayer's research."*

*"Found out important information about alports. Makes me feel like there's hope for the future"*

Information day organiser: *"It is heartwarming to see the transition of people's body language over the day. As they arrive, they are hesitant, don't want to engage and parents worry about their children and husbands/wives/partners/friends hold onto each other very tight. By the end of the day, the kids all made new friends, created Lego models and the adults visibly relax as they watch their children have fun. The young adults and adults also then relax enough to engage and start asking questions, raise topics they'd like to hear more about and the whole day becomes more interactive and they share stories that benefit everyone and help them also feel less alone on their journey. The young adults are particularly helpful leading on this. They are such an inspiration to us."*

#### **Feedback on Cardiff Alport Information day – April 2022**

When asked to comment on the value of the weekend in Cardiff to family and friends, the people living with Alport Syndrome commented:

*"Priceless! We have been provided something we have been seeking for so many years."*

*"It was really informative and supportive. I feel empowered having attended."*

*"Great weekend to be able to connect with people that understand and connect on a whole different level."*

*"This weekend has taught me more about -Alports than my renal team ever did. I found the information to be invaluable and something I can now apply to my life going forward. Even though I'm probably further than*



Mychel Morais, a laboratory scientist, talking to patients about the progress in the Alport Research Hub based in Manchester



A passing ice cream van was spotted and a very thoughtful patient paid for ice creams for all – members of the Alport Avengers group enjoying theirs

*most people in terms of the kidney dialysis and transplantation journey, I felt extremely new when learning about Alports. The patients different experiences with it and the possibility of potentially avoiding dialysis and transplantation in future alport patients is amazing."*

*"Spending time with other people who understand is priceless, it provides hope and reassurance, especially important for those newly diagnosed/ with young children.*

*Having the opportunity to speak to medical professionals in such a relaxed environment is fantastic and really enables you to ask questions and then liaise with your own medical team about the latest research etc."*

*"Great to meet fellow patients and be part of the Alport Family."*

*"It was so valuable to meet others, share stories, feel less alone, and for our children to make friends with others in similar situations."*



Confidence-building workshops engaged the young people in an afternoon of fun activities



Grateful thanks to Pippa and Mark, the local team, who found the great venue looking out over Cardiff bay!

**alport uk's private Facebook page - Alport Warriors** - provides support to a group that increased to over 995 members. Membership is supported by Wilma Calderwood whose steady hand ensures the group remains in a well-protected, safe space. Discussions are initiated by both regular and new contributors and cover such subjects as kidney donation, hearing, sight, drug trials, transplant successes, successes at the annual Transplant games, fundraising opportunities, celebrating birthdays, links from other Alport Facebook sites, fundraising activities, and a range of questions about Alport Syndrome, its' symptoms and side effects. Connection with others who are in a similar situation is clearly valued by some people in the Alport community. Connection is not valued by all, so we aim to provide support for individuals or families in other ways to suit their needs.

A large percentage of patients with Alport Syndrome face Chronic Kidney Disease (CKD) in their late teens or early 20s and will require dialysis or a transplant. The exact details of prognosis for the genetic mutations of these young adults are not yet known, so the young adults face an emotional 'waiting game' for their kidney function to start declining. Some describe it as a 'timebomb'! The young adults find it most helpful to connect with young people of their own age – peers who provide information from their own personal experience - so they can learn from and mentor each other when facing these particularly challenging times such as declining kidney failure and transplants. This is one of the roles of the **Alport Avengers group** – a group of 18–35-year-olds that emerged and was set up on WhatsApp. If a young adult has a question or a parent of a young adult raises a question, alport uk offer membership of this vital group:

**Parent of one young Alport patient facing transplant** who we connected up with another young person who recently had a transplant: *"Thank you. We have seen a big change in our son since he started talking about his worries."*

**Young Czech patient needing a transplant who is a member of Alport Avengers:** *I know it does seem daunting although I've found it helpful to hear what others are experiencing as I know what to expect."*

We arranged the second and third social events in Newcastle and Cardiff for the Alport Avengers to meet in person which they found incredibly valuable, particularly after the past couple of years' Covid limitations. They spent time variously talking, sightseeing and getting to know each other and, importantly, sharing experiences of Alport Syndrome.



Margherita Venturini, an Italian medical student and Alport patient studying in Cardiff, joined the Alport Information Day in Cardiff (April 2023) shared some of her experiences of living with Alport

The feedback we had from the Alport Avengers at Newcastle included:

**Young adult man:** *"Understanding the science and what's really going on has been incredibly valuable... whether I fully understand the science or not though, just meeting others has made me feel a lot less isolated living with the condition. Knowledge about the science and mechanisms of Alport's has also helped me to realise that there is no-one to blame for this condition... it allows me to release the inward and often self-afflicted*



Young adult group participating in a confidence building workshop in at the Cardiff Alport Information Day

*negativity towards myself by knowing that mutations are a natural occurrence in humans... acceptance brings gratitude."*

**Young adult woman:** *"Honestly priceless, I can't explain how connected this makes me feel to others and the hope it gives me is just beyond words. Genuinely thank you."*

We continued the dissemination of information and support for both patients and carers, including:

- **Answering enquiries emailed to alport uk** at [info@alportuk.org](mailto:info@alportuk.org) and phone calls sent to our landline number of 01793 847264 and putting people in touch with experts to answer their questions, writing letters to support children's needs at school or putting people in touch with other families to share stories and experiences. Feedback from a woman who was struggling to get support at school for her son: *"The report was so so helpful! Everyone asked to read it. And I think everyone in the room suddenly gathered a greater understanding. Thank you to you and the whole team who contributed."*
- **Sending out information electronically** – there was a high number of enquiries about information for women and girls living with Alport Syndrome, about hearing and about whether taking Flozins which seem to show signs of prolong the life of kidneys, affording patients valuable time prior to transplant.

### Provision of information

With the help of our scientific advisors, alport uk continue to offer information and expert advice on our closed Facebook page – **Alport Warriors** - to the community to answer queries as they arise. This approach - informing people to enable them to take control and build resilience - is vital as our community has so many differing needs, many different age groups, at differing stages of kidney failure, undergoing different types of kidney replacement therapy and many patients and family members from other countries seeking advice. We are very proud of the alport uk team, how they anticipate queries, increase the advice and information to enable people to stay as calm as possible during the pandemic, including sourcing food banks and writing letters to employers

to explain the needs of their employees with Alport Syndrome. We are incredibly proud of the patients, their positive and pragmatic approaches to looking after themselves and helping each other across the community at what continued to be a very concerning time long after the pandemic finished.

As mentioned above in 'Support' above, the **Alport Avengers** group (18-35 year-olds) on Whatsapp continues to grow and the young adults share the information they've learned from their individual journeys. The group is monitored to make sure the information is accurate and relevant.

**Young woman:** "I like the fact that it doesn't feel too formal. It's a group of friends, where you can ask questions, compare symptoms, discuss struggles, but also have a laugh! Without the group I think people could potentially feel more isolated and not have that space they can easily access! Sometimes posting on a social forum feels intimidating, so this is a nice balance :)"

**Young man:** "For me mainly, I love that we all feel comfortable sharing how we feel in real time, knowing that we're going to get a quick response from someone who fully understands the challenges we might be facing. It provides a level of reassurance and understanding that I (and I know many others!) never got while growing up."

With this young adult group, as the most critical group facing declining kidney function just at the time they are trying to leave home, build careers etc, their feedback increasingly indicates that short videos are the most useful way of sharing information. We now use short videos to explain Alport Syndrome and to share patient stories. Our most shared videos include four filmed and produced for alport uk by filmmaker, Sam Clarke who is also a young person living with Alport Syndrome:

- **My Only Antidote:** Sam Clarke, cycled round Europe raising funds for people living with Alport Syndrome and filming his experiences: <https://youtu.be/4vRuYBn6St4>. We use this video for newly diagnosed patients as it explains the real challenges of living with Alport Syndrome. Sam also ably inspires patients with the fun activities that he does such as sky diving, cycling and generally having fun. These are such an important messages for young patients.
- Sam also helps alportuk by filming a **series of 2-3-minute documentaries about Living with Alport Syndrome**. These short films document the highs and lows of living with Alport Syndrome. The films are invaluable communication materials that engage the wider community in what it is really like to live with Alport Syndrome. We are very grateful to the following people that Sam filmed about their journeys and living with Alport Syndrome:  
**Katie Brown** - <https://youtu.be/DJTKNLWQfmo>  
**Lesley Forrest** - <https://youtu.be/RoDWE-8Ck60>  
**Jospeh McLean** - <https://youtu.be/4bz5-tK6m6w>.
- **Patients inspire Alport Syndrome research**, a collaboration between alport uk and University of Manchester: <https://www.youtube.com/watch?v=77p7nzKz6nc>
- **Highlights from The 2019 International workshop on Alport Syndrome**, Siena, October 2019: <https://youtu.be/QH8mDTmKaVU>
- **Highlights of Podocyte 2021**, a film made by young patients who have podocyte-related kidney conditions, Manchester, July 2021: <https://youtu.be/3-ZDm2CR8Ow>
- **Highlights from The 2022 International workshop on Alport Syndrome**, Calgary, Canada, September 2023.

We are very grateful to patient Sam Clarke for making these upbeat and

very professional videos. Sam is exemplary in that he also is willing to collaborate with other Alport patients on the content and editing. Sam himself gets a lot of value from meeting members of the Alport community and he talks openly about how it helps his own mental health and living with being told about a 'timebomb' of when his own kidneys would fail. The work on these videos means we have a very engaged young adult group who feature on the videos telling their stories and sharing their opinions, plus doing some of the interviews to create the content. The success of content and style of these videos is because they are designed and filmed by people living with Alport Syndrome *for* people living with Alport Syndrome. As a result, the videos are often watched by clinicians and researchers and admired for their inspiration. In addition to being excellent providers of information, the videos also inspire many others who watch them. The videos demystify what it is like to live with Alport Syndrome and why patient/research scientist collaboration on Alport research is so important. In addition to being good information providers, the videos are excellent emotive marketing tools to potential funders and give a lot of positive hope for the community and people who want to find out more about it.

A number of years ago, a very successful **series of two-minute animated videos were written, illustrated and produced by a group of our young people with Alport Syndrome for their peers**, some in collaboration with University of Manchester. The writing of the videos and working with the clinicians to make them scientifically accurate was a valuable process for the young people to engage in understanding Alport better as sometimes they can be in denial about what is important to keep them healthy or sources of support. We continue to use these videos, pasting the links onto Facebook when questions are raised by patients, carers and their families about Alport. Topics included:

- Why Alport research is important <https://youtu.be/TU0m6qGvTFY>
- Alport Community <https://www.youtube.com/watch?v=5gJEtmhcClU>
- Alport Syndrome: Know your numbers <https://www.youtube.com/watch?v=jtkmJdwG0nE>
- Kidney transplants and Alport Syndrome <https://www.youtube.com/watch?v=Gd4yB9PVnM0&t=52s>
- Update on clinical trials and potential treatments for Alport Syndrome (written in English and translated into Italian, German and Chinese by the young patients with Alport Syndrome) at The 2019 International workshop in Siena, Italy <https://youtu.be/JRsJtUu8Lh8>

When someone is diagnosed with Alport Syndrome, some of the regional genetics units e.g. at Guy's Hospital and some of the paediatric kidney units e.g. at Manchester University Hospital, have a small leaflet giving some summary details about the condition and our alport uk leaflets. Beyond this, there is an array of information one can find on the web, but it is hard to decipher what is medically correct or up to date. On our website is:

- **A summary leaflet for Alport UK** to encourage people to get in touch with us – this is now handed out at the genetics units when people are newly diagnosed with Alport Syndrome. It was also sent out, along with laminated posters with our contact details on, to all the main adult and children's kidney units around the country to advertise where to find out information about Alport Syndrome
- **A dictionary of scientific terms** to help patients learn more about the biology of Alport Syndrome, so when their clinicians explain things, they understand a bit more about what they are talking about as it is so hard to pick much up in a short clinic appointment.
- **Definitions of related rare renal diseases** – Nephrotic Syndrome,

IgA Nephropathy, Membranous Nephropathy and Focal Segmental Glomerular Sclerosis (FSGS) that sometimes overlap with Alport Syndrome or people can be diagnosed with more than one disease or if people are misdiagnosed.

- **Videos available through our website** ([www.alportuk.org](http://www.alportuk.org)), on our YouTube @alportuk channel, and a special section on Alport Syndrome on [www.healthtalk.org](http://www.healthtalk.org) (<http://www.healthtalk.org/peoples-experiences/long-term-conditions/alport-syndrome/topics>) of our key experts talking about specific aspects of Alport Syndrome. Topics are varied about all aspects of living with Alport Syndrome and include: Genetics, An introduction to Alport Syndrome, Hearing and hearing aids, caring for people with Alport Syndrome, medication, women with Alport Syndrome etc.
- **Our website remains an invaluable resource.** We are currently fundraising to improve our information on the internet. We intend to update [www.alportuk.org](http://www.alportuk.org) to make the information clearer and more accessible and to answer the questions we have received over the last few years or so through our closed Facebook page, Alport Warriors. The plan is to collaborate with the other national patient organisations and provide an international website for the most up-to-date information, research papers and clinical guidelines. We need to establish what information is critical to hold and update at the international level (eg simple explanations of Alport Syndrome, clinical guidelines etc) and what is specific to a national community, such as how to navigate the NHS in the UK to access treatment. This project will mean we will update [www.alportuk.org](http://www.alportuk.org) so as not to duplicate resources.
- **Information about new clinical trials** that patients can sign up to is shared through our website 'Latest news' section, through our closed Facebook page (Alport Warriors) and through directly emailing our database of patients. alport uk specifically do not recommend any trials, but signpost people to the most up to date information and encourage them to discuss it with their own clinicians who can discuss the relevance of the trial with them, knowing their personal situation.

### Supporting or driving research?

With limited funding available for rare kidney disease research, alport uk's strategy is use our small amount of funding to facilitate a virtual Alport research collaborative giving support, encouragement to scientists and to drive towards deadlines – what we call the '**oil to lubricate the Alport research ecosystem**' to accelerate research. Instead of funding a specific project we invest considerable time and our limited funds to get the research community together at international workshops to enable them to work together to set the research programme and create a vibrant and innovative research community that attracts more researchers and pharmaceutical companies interested in developing new treatments. The emerging innovative and vibrant global network – the Alport Syndrome Alliance - is advancing treatments and knowledge. **Over six international workshops, the clinicians and laboratory scientists featured 370 new research projects. Many went on to publish their findings in international journals.**

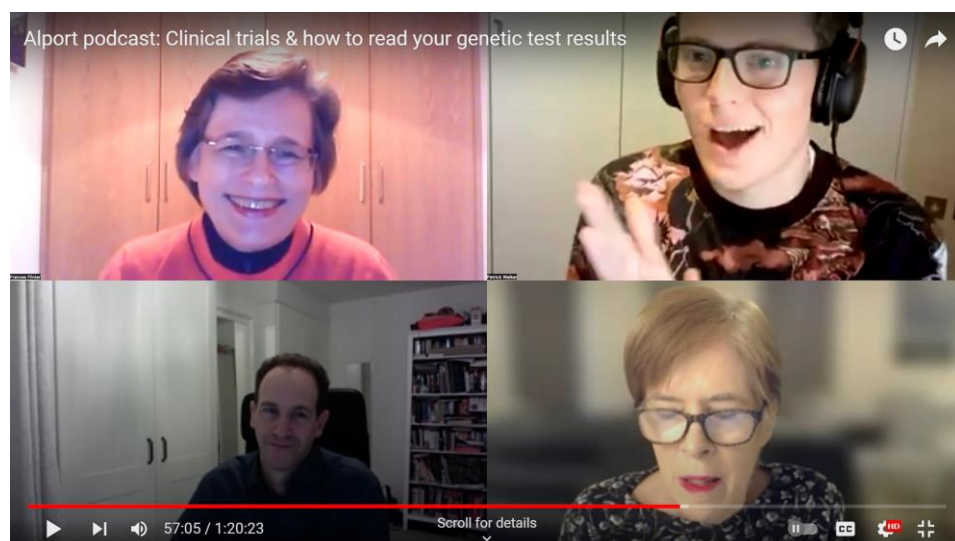
Alport UK is closely involved in an exciting new research development – the **Stoneygate Trust and Kidney Research UK Alport Research Hub**. The hub is directed by **Professor Rachel Lennon** from the University of Manchester, in collaboration with **Professor Daniel Gale** from University

College London and **Professor Neil Turner** from the University of Edinburgh, all three of whom are Trustees of alport uk. The first hub meeting kicked off in January 2022 and was launched in June 2022, and aims to deliver a world leading research programme. Using patient data along with a new platform of technologies to test new treatments such as gene therapy, researchers aim to deliver major results within five years; this acceleration in research is extremely exciting for Alport patients, researchers and clinicians. Here is a short film that explains the Hub: <https://youtube.com/shorts/4SKzPemRYCU>.

As part of the need to provide people living with Alport Syndrome, with the most up to date information, we often provide links to the **series of over 36 international Alport online workshops**, which were run and moderated by our young adult Alport patients. The workshops are all listed on alport uk's YouTube channel @alportworkshops: <https://tinyurl.com/y9cuhgby>.

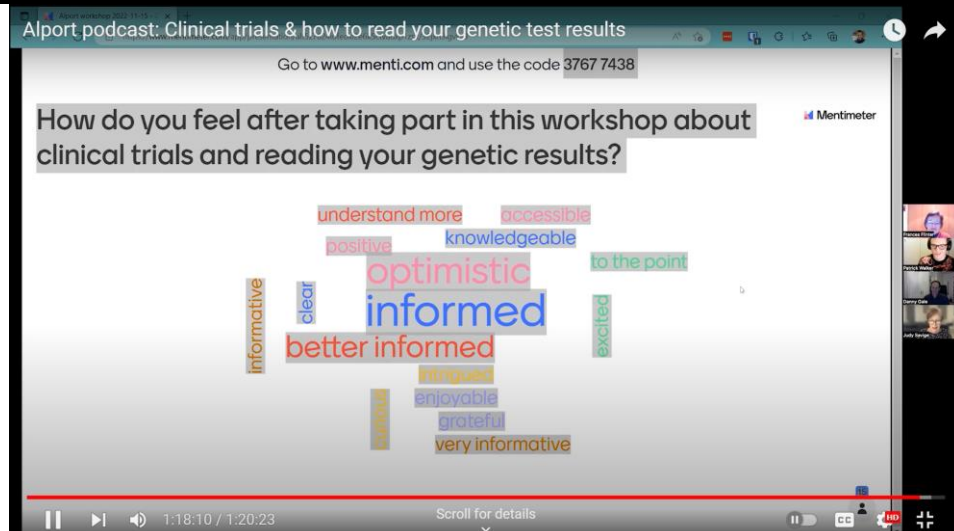
**Subjects covered include:**

**Transplantation experience, hearing, eyes, genetics and family planning**, and spotlights on labs around the world researching Alport Syndrome. The most recent workshop was about **Clinical Trials and how to read your genetic test** and featured **Professors Danny Gale** (UK), **Frances Flinter** (UK) and **Judy Savage** (Australia). With a new clinical trial upcoming that was for a drug that potentially could treat a specific type of genetic variant, it was important to educate the community to help people living with Alport Syndrome interpret their genetic test and understand whether they are eligible for a trial with specific genetic requirements or not.



From top left clockwise: Professor Frances Flinter, Patrick Walker, Professor Judy Savage, Professor Danny Gale running the Alport online workshop about Clinical trials.

The workshops feature scientists from all over the world. **From a patient who attended the Hearing workshop:** *'So good to hear this subject properly discussed, thanks all'*. We enjoyed the patient's sense of humour in the feedback! Jokes aside, this was the first time our community focused on hearing in detail – both the physiology and understanding research looking at the performance of the ear particularly. The plan is to do more on hearing and eyes as these are topics requested by patients again and again – the fear of losing hearing and eyesight ie going deaf and blind understandably concerns people (and unnecessarily as they can have hearing aids or treatments to transform the symptoms) when they are first diagnosed with Alport Syndrome. alport uk always encourage recently diagnosed people to find out more about the Alport implications and aim to help them realise that the



Feedback from participants using a Wordcloud at the end of the Clinical trials Alport online workshop.

symptoms are very varied on a spectrum of mild to severe so there are different symptoms for different people, potentially dependent on their genetic variant of the Alport gene and any genetic modifying genes involved. Largely the hearing loss associated with Alport Syndrome is partial hearing loss that can be helped with hearing aids for the majority of patients. The eye abnormalities are also on a spectrum and require an eye test at Moorfields to understand the severity; symptoms are also potentially dependent on the genetic variant of Alports. We also know the eye symptoms can also be alleviated with simple treatments or extend to lens replacement therapy – like a cataract operation – that transform what appears to be increasing ‘blindness’ for patients. This information is vital to share with patients – that they can do something about the eye complications. So, we provide this information through the online workshops, and then post links to the workshops on the closed Facebook page and via social media to save people suffering unnecessarily.

The first part of the year focused on the organisation and delivery **The 2022 International workshop on Alport Syndrome** in Calgary, Canada. The hybrid workshop took place as a one day, pre-congress workshop to the 19<sup>th</sup> congress of the International Society of Pediatric Nephrology (IPNA). This was the first in-person event after Covid and it suited the needs of the potential mixed audience of patients, clinicians, research scientists and pharmaceutical companies. The workshops are put on to grow the Alport Syndrome Alliance – a powerful and growing collaborative network advancing treatments and knowledge for Alport syndrome. The network includes people living with Alport syndrome, clinicians, researchers and pharmaceutical companies. As a founding member of the Alport Syndrome Alliance, alport uk chair the international Workshop Organising Committee meetings to develop the agenda, organise the logistics and raise the funding for the workshops. **The Calgary workshop was a hybrid meeting, with 171 participants from 28 countries: Australia, Belgium, Brazil, Canada, China, Croatia, Cyprus, France, Germany, Greece, India, Ireland, Italy, Indonesia, Israel, Lithuania, New Zealand, Nigeria, Poland, Russia, Spain, Singapore, Sweden, The Netherlands, Turkey, UK, USA. This included 90 participants in person and 81 participants online and also included 90 patients from 18 countries and 7 young adults. All the patients participated free of charge. Disappointingly, there was not time in the agenda to feature presentations about individual research projects.**

Participants feedback when asked to summarise their perspectives on the workshop and the value to them or their work, for example:

Clinician (Nigeria): “Awesome platform for engagement and international collaboration.”

Laboratory Scientist (USA): “Gave me new ideas to pursue in the laboratory.”

Pathologist (Croatia): “Very good! Please continue this beautiful collaboration of different specialities and patients.”

Clinician (Italy): “It helped me to update my knowledge on when to order a genetic test and the actual clinical trials ongoing.”

Patient family (USA): “My experience at the Alport International Workshop in Calgary was remarkable. Not only did I get to meet and greet with the most knowledgeable Alport clinicians in the world, I also got to hear the latest science, trials, and pharmaceutical interests in addressing Alport. Lastly, the experience of meeting other Alport patients was an emotional and deeply bonding experience. I am so glad I came and am looking forward to continuing to be a part of this community.”

“I am a clinician, (genetics). I found this added somewhat to my knowledge of treatment options for families and what might be coming in the research pipeline. It is helpful to know of this organization to direct families to.”

“I am a newly diagnosed patient and patient parent [from Europe]. The updates on treatment guidelines were directly useful as I communicate with my physicians and advocate for my care. Presentations on research, such as gene therapy for hearing loss gave me so much hope for my son's future.”

Clinician (South Korea): “Eye-opening experience as a pediatrician. Thank you so much.”

After their presentations – either at an online workshop or at The 2022 International workshop on Alport Syndrome, a number of the researchers fed back stories to alport uk about how the workshops ‘furthered their science’. Presenting researchers confirmed that members of the Zoom or in-person audiences at their workshop reached out to them via email to:

- set up new collaborations
- initiate new collaborative research projects and
- provide vital new input to current projects.

The online workshop format was a catalyst for new research, thanks to the pandemic and the inspiration of the team who devised the format:

**Professor Rachel Lennon, Professor Jeffrey Miner, and two members of the Lennon lab - Louise Hopkinson and Richard Naylor.**

alport uk is incredibly grateful particularly to Louise and Richard, who worked from home whilst unable to get into the lab, and helped us identify new research to feature, created material to post on social media, participated in the discussions and helped ‘translate’ some the difficult terms into a dictionary of layman’s terms to make the science more accessible for patients with no science background.

Feedback from patients:

*“It was so enlightening to find out these people (the researchers) are doing their very best on our behalf. I had no idea of the methods used for this kind of research. They seemed to be a happy team too!”*

*“It was reassuring that such research is carrying on.”*

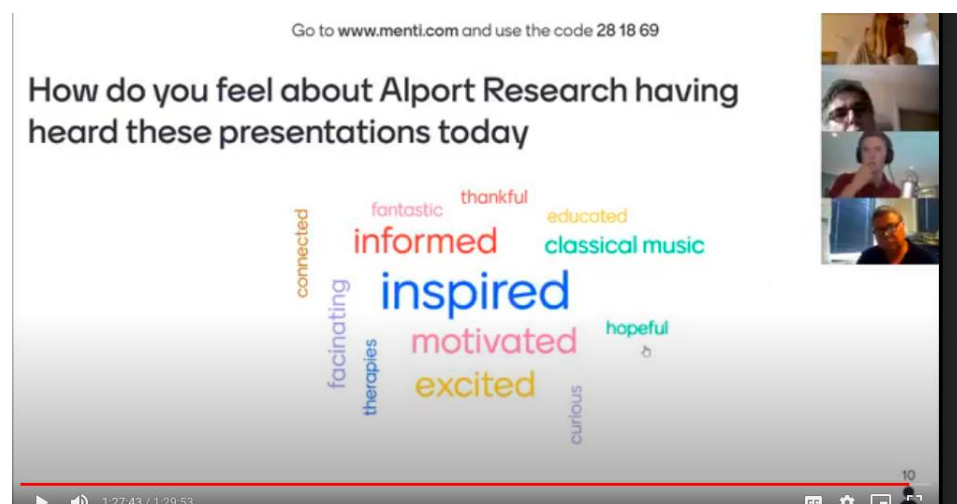
*“Fantastic idea and I'm sure the rest of the Alport community would be*

*very interested in seeing this. I did not have a clue so much was going on and to hear all the info has made me feel very hopeful. Many thanks again"*

**From a patient advocacy person:** *"...congratulations for the Alport workshops. It is a fantastic way to keep connected and continue learning about Alport Syndrome."*

After each workshop, we invite people to submit one word to express how they feel after a workshop. For example:

#### Feedback from a Hearing workshop:



**Patient:** *'I found this so interesting as I have hearing loss myself - thank you all.'*

#### Feedback from the Spotlight on Jie Ding's lab, based in Beijing, workshop:

How are you feeling after watching these presentations?



#### Feedback from Chat and emails:

*'Really helpful to see an example of a variant being demonstrated to be benign. Otherwise, it is so easy to make an incorrect diagnosis.'*

**Building on the Alport research indicators from 2019**

In the 1990s, groups of leading clinicians, academics and scientists regularly met to discuss topics related to Alport Syndrome. They published a number of key papers about Alport Syndrome, but the regular meetings stopped. In 2012, alport uk commissioned a web audit of people publishing material on Alport Syndrome through to the current day and prepared a report on the status of research into Alport Syndrome. This report was used to identify the missing areas of activity and needs for research including:

- A shared international strategy and plan for Alport Syndrome research
- New research ideas and projects to develop new treatments and therapies and more research generally
- Ways to reengage the leading experts in Alport Syndrome
- Co-ordination of national patient registries
- The need to engage the pharmaceutical industry in developing new treatments
- How alport uk could complement the current contributions of other national patient organisations, for example the Alport Syndrome Foundation who currently run an excellent programme of seed funding for Alport research, commissioning projects each year
- How Alport Syndrome is a model renal disease and that new treatments developed for Alport Syndrome could help other patients living with kidney disease.

In 2019, to check on the performance of our investment to get researchers together through these workshops, alport uk circulated a simple survey with the Workshop Organising Committee members and their research teams (ie not the full Alport research community, just some of the key members) to understand the impact of the international workshops, emphasis on collaboration and how much research is now being done. Overall, the numbers indicate a very healthy research community to whom we are incredibly grateful for all they do to help with the awareness and understanding of Alport Syndrome by delivering:

- 242 new research projects featured at four international workshops
- 131 publications with the majority in international journals
- 18 book chapters
- 38 major grants to fund the ongoing research.
- over 90% of the projects and publications were collaborative efforts.

These survey results confirmed to alport uk that our efforts to drive collaboration and accelerate research are delivering the results we need. Indeed at the time of writing, **there are now over 400 new projects featured at international workshops since 2014.** ie the Alport research progress is accelerating and alport uk's strategy to use workshops to drive Alport research is the right approach to both drive research and engage new communities to join the global network.

To continue the collaborative international workshops in Oxford (2014) Göttingen, Germany (2015), Glasgow, Scotland (2017), Siena, Italy (2019), online (2021) and Calgary Canada (2022 – one-day hybrid format), alport uk started work on a seventh workshop in the series: **The 2024 International Workshop for Alport Syndrome to be held in Cyprus.** The aim is to make this seventh workshop in the series an in-person 3-day workshop (as they had not really been all together since 2019) to refresh the Alport Syndrome Alliance's global network with their shared aim to advance treatments and knowledge and make sure it was as accessible to patients, clinicians, early career researchers and pharma alike. The planning started in earnest over the summer to get the

workshop programme ready for a week-long workshop planned for March 2024. alport uk restarted the conference calls with the international workshop organising committee to share progress, keep the researchers engaged in delivering the agenda in a number of key areas such as genetics, pathology (as there is an increasing interest in this area), clinical guidelines, registries, basic science and particularly new therapies.

### **Support of a UK research registry**

In parallel to alport uk being set up, the then called UK Renal Association (now called UK Kidney Association - UKKA) established a working group on Alport Syndrome, funded jointly by Kidney Research UK and Kidney Care UK (previously British Kidney Patient Association) to support the development of a national renal registry of patients, called RaDaR. RaDaR. Some of the trustees from alport uk contribute to the working group on an ongoing basis to devise ways of promoting RADAR to patients and clinicians across the UK to increase the number of patients and patient records online as this will provide invaluable data for research to understand the natural history of Alport Syndrome. At the time of writing, RaDaR has over 1,000 patients registered (compared with the 800 registered in the previous year) as having Alport Syndrome and with some clinical data going back 30 years. alport uk specifically contribute to the support of this UK research registry of patients and an international alliance of patient registries by:

- Promoting the importance of RaDaR to patients at Alport information days, along with information about the value of RaDaR to research.
- Making the research registry a central part of the national contribution to international efforts to collaborate on research coming out of the 2014, 2015, 2017, 2019, 2021 and 2022 International Workshops on Alport Syndrome and proposing to for there to be significant topics on it at the 2024 workshop.
- Supporting the enrichment of data as part of the programme of the Alport Research Hub, including chasing up the transfer of historical genetic data that transferred from Guy's Hospital to the Bristol genetic testing labs when they took on the testing service.
- Continuing the development of the UK's contribution to an international alliance of Alport Syndrome research. An 'alliance' is necessary as long-term there are not enough patients in the UK for Clinical trials and so pharmaceutical companies will want to do trials in a number of different countries to try new therapies. alport uk enlisted the help of designer Robina Newman to develop the branding for the Alport Syndrome Alliance and apply it to a new website built by Alice Cooper to simplify the registration process for participants for The 2021 and 2022 International workshops on Alport Syndrome. The plans for the 2024 international workshop planned for March 2024 (in the next financial year) are to double the number of participants, compared with previous years, applying to join the international workshop and with the encouragement of other national patient organisations, especially across Europe to build the Alport Syndrome Alliance to help the Alport community act as one global network focused on advancing treatments and knowledge, with one voice.

If anyone reading this annual report is interested in more information or to get involved or support us with activities or fund raising, please email Susie Gear (Chief Executive) or Hannah Russell (Engagement Director) at [info@alportuk.org](mailto:info@alportuk.org) or call us on 01793 847264.

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

Reserves from fundraising are kept in separate Barclays bank savings accounts, labelled for their specific use and to make sure restricted and unrestricted funds are used appropriately. For example, for:

- **Information days** (Alport UK Meetings)
- **UK Development of information, website and marketing material** (Alport UK)
- **Facilitating the International Workshops on Alport Syndrome** (Alport UK Research)
- **Supporting patients take up a new sport or activity** (Don't Wait Fund)

### Details of any funds materially in deficit

No funds in deficit

### Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

alport uk's principal sources of funds this year were, despite the pandemic, again more diverse than in the previous year:

- Personal donations – limited this year
- Personal fund-raising activities such as sports activities such as the KiltWalk in Scotland.
- Just Giving and Virgin Money Giving pages of sponsorship for various activities that our community get involved in to raise funds for alport uk – this year Sam Clarke's amazing efforts increased the money raised to over £20,000 for a new fund we will call the 'Don't Wait Fund' to support patients taking up a new sport or hobby.
- Social media fundraising pages eg Facebook giving for birthdays
- PayPal and Amazon payments/donations to Alport UK
- Sales of Christmas cards and a wider variety of merchandise such as hoodies, t-shirts, water bottles etc
- Standing orders from a couple of very supportive patient families
- Customised shaking tins located in retail venues
- Donations from larger charities or foundations for specific activities and particular thanks to **Kidney Care UK, Kidney Research UK, the Amelia Chadwick Trust, Kidney Wales, Popham Kidney Support, Kidney Foundation of Canada.**
- Donations from **The Worshipful Company of Dyers**. With thanks to Alice and Sebastian Cooper.

Grants given by a number of pharmaceutical companies: alport uk are very grateful to the support from **Calliditas, Eloxx, Sanofi** and **Traverse**.

As funds were all allocated to specific activities that support our key objectives this year, there was no opportunity for investment during this accounting period.

## Section F

## Other optional information

None

# Alport UK

## Report and Financial Statement For the year ended 31<sup>st</sup> July 2023

Charity number: 1154774

Shilton Accounting Services  
1<sup>st</sup> Floor, 1 The Clock House  
Brize Norton Road  
Carterton  
OX18 3HN

**Alport UK**  
**Charity number: 1154774**  
**Legal and administrative information**

|                                 |                                                                                                                                                           |
|---------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|
| Charity name:                   | Alport UK                                                                                                                                                 |
| Charity registration number:    | 1154774                                                                                                                                                   |
| Type of organisation:           | Charitable Unincorporated Organisation                                                                                                                    |
| Registered office and business: | 9 Bagpath<br>Tetbury<br>Gloucestershire<br>GL8 8YG                                                                                                        |
| Trustees:                       | Colin Baigent<br>Jules Skelding<br>Susie Gear<br>Frances Flinter<br>Rachel Lennon                                                                         |
| Accountants:                    | Shilton Accounting Services<br>Certified Practising Accountants<br>1 <sup>st</sup> Floor, 1 The Clock House<br>Brize Norton Road<br>Carterton<br>OX18 3HN |

**Alport UK**  
**Charity number: 1154774**  
**Independent Examiner's report to the Trustees of Alport UK**

I report on the accounts of the Charity for the year ended 31<sup>st</sup> July 2023 which are set out below.

**Respective responsibilities of trustees and examiner.**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under section 43(2) of the Charities Act 1993 (the 1993 Act) and that an independent examination is needed.

It is my responsibility to:

- a) Examine the accounts (under section 43(7)(b) of the Act.
- b) To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 43(7)(b) of the Act.
- c) To state whether particular matters have come to my attention.

**Basis of independent examiner's report.**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence which would be required in an audit and consequently I do not express an audit opinion on the accounts.

**Independent examiner's statement.**

In connection with my examination, **no** matter has come to my attention

1. Which gives me reasonable cause to believe that in any material respect, the requirements of a) to keep proper accounting records in accordance with section 41 of the 1993 Act and b) to prepare accounts which accord with the accounting records and to comply with the requirements of the Act, have not been met.
2. To which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

David Cuthbertson – ICPA Cert Acc (Open)  
Shilton Accounting Services  
Honeystone Cottage  
Ladburn Lane  
Shilton  
OX18 4AJ

**Alport UK**  
**Charity number: 1154774**  
**Director's report for the year ended 31<sup>st</sup> July 2023**

The trustees present their report and financial statement for the year ended 31<sup>st</sup> July 2023.

**Objects** – The relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- a) The establishment and facilitation of a support network for Alport Syndrome patients, carriers, their families and carers;
- b) The provision of information on Alport Syndrome;
- c) The support of research into Alport Syndrome both in the UK and internationally;
- d) The support of a research registry in the UK and an international alliance of national registers.

**Governing document** – the charity is governed by a constitution based upon a Charity Commission document that was adopted on 27<sup>th</sup> November 2013. A copy of the full governing document can be obtained from the charity.

**Trustees** - The overall responsibility of the organisation rests with the Board of Trustees. The selection of Trustees is designed to supplement the existing skills and expertise of the board and is governed by an informal skills assessment. The appointment of trustees is made in accordance with the constitution.

**Risk assessment** – Disclosure and Barring checks are carried out for all appropriate trustees, staff and volunteers. The Trustees have examined the major strategies, business and operational risks which the charity faces and confirm that systems have been established to enable regular reports to be produced so that the necessary steps can be taken to minimise these risks.

**Public benefit statement** – Alport UK is a patient-led organisation dedicated to facilitating a support and information network for all those affected by Alport Syndrome. Our vision is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life. This creates public benefits in health and community cohesion.

**Reserves policy** – The Trustees are actively trying to build reserves, with a view to being able to fund further research and to strengthen its support structure.

This report was approved by the Trustees on 31 July 2024 and signed on its behalf by



**Susie Gear**

**Alport UK**  
Charity number 115774

**Statement of Financial Activities (including Income & expenditure Account)**  
**For the year ended 31<sup>st</sup> July 2023**

|                          | Restricted      | Unrestricted    | Total          | 2022          |
|--------------------------|-----------------|-----------------|----------------|---------------|
| <b>Income</b>            |                 |                 |                |               |
| Donations/Sponsors       | 24,075          | 62,985          | 87,060         | 56,187        |
| Delegate fees            | 2,741           | 270             | 3,011          | 11,330        |
| Fundraising/merchandise  |                 | 2,119           | 2,119          | 1,981         |
| <b>Total Income</b>      | <b>26,816</b>   | <b>65,374</b>   | <b>92,190</b>  | <b>69,498</b> |
| <b>Expenditure</b>       |                 |                 |                |               |
| Employee costs           | 30,204          | 37              | 30,241         | 29,720        |
| Bank & service charges   |                 | 70              | 70             | 321           |
| Direct Events costs      | 6,874           | 2,349           | 9,223          | 5,400         |
| Branded goods            |                 |                 |                | 1,800         |
| Administration           |                 | 2,700           | 2,700          | 850           |
| Travel & subsistence     | 14,569          | 22,897          | 37,466         | 13,658        |
| Internet/website         |                 | 4,493           | 4,493          | 1,481         |
| Marketing                | 1,511           | 2,292           | 3,803          | 7,645         |
| Insurance                |                 | 710             | 710            | 700           |
| Subscriptions            |                 | 1,807           | 1,807          | 2,067         |
| Bursaries/grants         | 1,022           | 1,035           | 2,057          | 279           |
| Others                   |                 |                 |                | 5,021         |
| Accountants fees         |                 | 1,288           | 1,288          | 1,420         |
| <b>Total Expenditure</b> | <b>54,180</b>   | <b>39,678</b>   | <b>93,858</b>  | <b>70,362</b> |
| <b>Net movement</b>      | <b>(27,364)</b> | <b>25,696</b>   | <b>(1,668)</b> | <b>(864)</b>  |
| <b>Transfers</b>         | <b>30,873</b>   | <b>(30,873)</b> | <b>0</b>       |               |
| <b>Opening Balance</b>   | <b>22,815</b>   | <b>26,552</b>   | <b>49,367</b>  | <b>50,231</b> |
| <b>Closing Balance</b>   | <b>26,324</b>   | <b>21,375</b>   | <b>47,699</b>  | <b>49,367</b> |

There are no recognised gains or losses other than in the Statement of Financial Activity.

**Alport UK**  
Charity number 115774

**Balance Sheet as at 31<sup>st</sup> July 2023**

|                                            | Notes    | 2023          | 2022          |
|--------------------------------------------|----------|---------------|---------------|
|                                            |          | £             | £             |
| <b>Fixed assets</b>                        |          | <b>3,075</b>  | <b>-</b>      |
|                                            |          |               |               |
| <b>Current assets</b>                      |          |               |               |
| <i>Cash at bank</i>                        | <b>4</b> | <b>47,048</b> | <b>51,751</b> |
|                                            |          |               |               |
| <b>Total Current assets</b>                |          | <b>47,048</b> | <b>51,751</b> |
|                                            |          |               |               |
| <b>Current liabilities</b>                 |          |               |               |
| <i>Creditors falling due within 1 year</i> | <b>5</b> | 2,424         | 2,384         |
|                                            |          |               |               |
| <b>Net current assets</b>                  |          | <b>44,624</b> | <b>49,367</b> |
|                                            |          |               |               |
| <b>Assets less liabilities</b>             |          | <b>47,699</b> | <b>49,367</b> |
|                                            |          |               |               |
| <b>Represented by</b>                      |          |               |               |
| <i>Restricted funds</i>                    |          | 26,324        | 22,815        |
| <i>Unrestricted funds</i>                  |          | 21,375        | 26,552        |
|                                            |          |               |               |
| <b>Total funds</b>                         | <b>6</b> | <b>47,699</b> | <b>49,367</b> |
|                                            |          |               |               |

**Signed on behalf of the charity's trustees**



**Date: 31 July 2024**

**Notes to the financial statements**

**For the year ending 31<sup>st</sup> July 2023.**

**1. Accounting policies**

**a. Basis of accounting**

The financial statements have been prepared under the historic cost convention with items recognised at cost or transaction value unless otherwise state in the relevant notes to these accounts. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and reporting by Charities preparing their accounts in accordance with Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS102) issued on 16<sup>th</sup> July 2014 and the Charities Act 2011. The trust constitutes a public benefit entity as defined by FRS102.

**b. Going concern**

The trustees consider that there are no material uncertainties about the trust's ability to continue as a going concern.

**c. Fund accounting**

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

**d. Income resources**

All incoming resources are included in the statement of financial activities when the charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of financial activities when receivable.

Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes entitled to the grant.

Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by volunteers has not been included in these accounts.

Investment income is included when receivable.

Income resources from charitable trading activity are accounted for when earned.

**Notes to the financial statements**  
**For the year ending 31<sup>st</sup> July 2023.**

**e. Resources expended**

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

Costs of generating funds comprise of the costs associated with attracting voluntary income and costs of trading for fund raising purposes.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include accountancy and legal fees.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resources. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

**2. Staff costs**

The charity employed an average of two members of staff in the financial year.

**3. Trustee remuneration & related party transactions.**

The trustees all give freely of their time and expertise without any remuneration or other benefit in kind. Expenses incurred on behalf of the charity are reimbursed at cost.

## Alport UK

Charity number: 1154774

### Notes to the financial statements For the year ending 31<sup>st</sup> July 2023.

#### 4. Cash at bank.

|                                      |               |
|--------------------------------------|---------------|
| Barclays General Account 93696405    | 15,256        |
| Barclays Research Account 93725642   | 8,371         |
| Barclays Don't wait Account 33742210 | 17,953        |
| Caxton FX                            | 5,458         |
| Paypal                               | 10            |
| <b>Total</b>                         | <b>47,048</b> |

#### 5. Creditors: Amounts falling due within one year

Accounting fee accrual £

#### 6. Movement in funds

|              | Opening<br>balance | Incoming<br>resources | Outgoing<br>resources | Balance<br>31 <sup>st</sup> July 2023 |
|--------------|--------------------|-----------------------|-----------------------|---------------------------------------|
| Restricted   | £22,815            | 57,689                | 54,180                | 26,324                                |
| Unrestricted | £26,552            | 65,374                | 70,551                | 21,375                                |
| <b>Total</b> | <b>£49,367</b>     | <b>123,063</b>        | <b>124,731</b>        | <b>47,699</b>                         |

**ALPORT UK**

England & Wales - Charity number 1154774

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# Accounts

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# ANNUAL REPORT AND ACCOUNTS



**a brighter future** for people living with alport syndrome

For the year ended 31 July 2021

| Trustees' Annual Report for the period |  |                   |   |      |    |  |                 |   |
|----------------------------------------|--|-------------------|---|------|----|--|-----------------|---|
| From                                   |  | Period start date |   |      | To |  | Period end date |   |
|                                        |  | 1                 | 8 | 2020 |    |  | 31              | 7 |

## Section A Reference and administration details

|                                           |                         |  |  |
|-------------------------------------------|-------------------------|--|--|
| <b>Charity name</b>                       | alport uk               |  |  |
| <b>Other names charity is known by</b>    | n/a                     |  |  |
| <b>Registered charity number (if any)</b> | 1154774                 |  |  |
| <b>Charity's principal address</b>        | PO Box 329              |  |  |
|                                           | Cirencester             |  |  |
|                                           |                         |  |  |
|                                           | <b>Postcode</b> GL7 9JA |  |  |

### Names of the charity trustees who manage the charity

|   | Trustee name    | Office (if any) | Dates acted if not for whole year | Name of person (or body) entitled to appoint trustee (if any) |
|---|-----------------|-----------------|-----------------------------------|---------------------------------------------------------------|
| 1 | Colin Baigent   |                 | Whole year                        |                                                               |
| 2 | Julia Skelding  |                 | Whole year                        |                                                               |
| 3 | Susie Gear      | Chief Executive | Whole year                        |                                                               |
| 4 | Frances Flinter |                 | Whole year                        |                                                               |
| 5 | Rachel Lennon   |                 | Whole year                        |                                                               |
| 6 | Neil Turner     |                 | Whole year                        |                                                               |
| 7 | Danny Gale      |                 | Whole year                        |                                                               |
| 8 | Tim McLean      |                 | Whole year                        |                                                               |
| 9 | Amanda McLean   |                 | Whole year                        |                                                               |

### Names of the trustees for the charity, if any, (for example, any custodian trustees)

| Name | Dates acted if not for whole year |
|------|-----------------------------------|
| n/a  |                                   |
|      |                                   |
|      |                                   |

### Names and addresses of advisers (Optional information)

See table of Advisors over the page

| Type of adviser                                                                 | Name                      | Address                                                                                                                                                                          |
|---------------------------------------------------------------------------------|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Medical – paediatric nephrologist                                               | Professor Rachel Lennon   | Royal Manchester Children's Hospital, Oxford Road, Manchester M13 9WL                                                                                                            |
| Medical – adult nephrologist                                                    | Professor Neil Turner     | University of Edinburgh Renal and Autoimmunity Group, MRC Centre for Inflammation, Queen's Medical Research Institute, Little France, Edinburgh, EH16 4TJ                        |
| Medical – adult nephrologist                                                    | Professor Daniel Gale     | Department of Renal Medicine, University College London                                                                                                                          |
| Geneticist                                                                      | Professor Frances Flinter | Emeritus Professor of Clinical Genetics, Guy's & St Thomas' NHS Foundation Trust<br>Genetics Department, 7th floor Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT |
| Eye specialist                                                                  | Dr Omar Mahroo            | St Thomas' Hospital Campus, 3rd Floor South Wing Block D, Westminster Bridge Road, London SE1 7EH                                                                                |
| PR, Communication and Marketing                                                 | Jane Keightley            | JK Branding and Communications Limited                                                                                                                                           |
| Accountant                                                                      | David Cuthbertson         | Shilton Accounting Services Ltd                                                                                                                                                  |
| Name of chief executive or names of senior staff members (Optional information) |                           |                                                                                                                                                                                  |
| Susie Gear, Chief Executive                                                     |                           |                                                                                                                                                                                  |
|                                                                                 |                           |                                                                                                                                                                                  |

## Section B Structure, governance and management

### Description of the charity's trusts

|                                                                     |                                                                                                               |
|---------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| Type of governing document<br>(eg. trust deed, constitution)        | Constitution                                                                                                  |
| How the charity is constituted<br>(eg. trust, association, company) | Charitable Incorporated Organisation                                                                          |
| Trustee selection methods<br>(eg. appointed by, elected by)         | Appointed for a term of 3 years by a resolution passed at a properly convened meeting of the Charity Trustees |

### Additional governance issues (Optional information)

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>You <b>may choose</b> to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> <li>• policies and procedures adopted for the induction and training of trustees;</li> <li>• the charity's organisational structure and any wider network with which the charity works;</li> <li>• relationship with any related parties;</li> <li>• trustees' consideration of major risks and the system and procedures to manage</li> </ul> | <p>Policies and procedures for the induction and training of trustees</p> <ul style="list-style-type: none"> <li>• Provided with a guide for how the charity operates – this now includes a set of policies on topics such as expenses, relationship with pharmaceutical companies, sponsorship etc.</li> <li>• Disclosure and Barring checks</li> <li>• Given a briefing on the charity and engaged in activities to enable them to participate fully in the decisions of the charity.</li> </ul> <p>Organisational structure of the charity and wider network</p> <ul style="list-style-type: none"> <li>• We are a small charity and so have a very flat organisational structure.</li> <li>• Day-to-day activities are run by one of the trustees – Susie Gear with a number of volunteers. All day-to-day decisions are jointly taken with at least one of the other Trustees eg Julia Skelding, Professor Frances Flinter or Professor Rachel Lennon. If we need to check any of the decisions, we involve the other trustees - who are less involved in the day-to-day activities and so provide excellent challenge and objectivity.</li> <li>• Our closed Facebook page, Alport Warriors, is moderated day-to-day</li> </ul> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

them.

by one of our volunteers – Wilma Calderwood – with back up from Jules Skelding, Alice Cooper and Susie Gear and with any specific medical questions answered by our medical advisory team – see list above.

- Our public facing social media eg Facebook and Instagram pages are run by Susie Gear, Alice Cooper and some of the younger Alport Warriors.
- Alport UK's Scientific Advisory Committee provide expert medical input and advice as required: Professor Colin Baigent (Strategic direction of research and Clinical trials), Professor Frances Flinter (Clinical and particularly Genetics and diagnoses), Professor Danny Gale (Rare Renal Database RaDaR and Clinical trials), Professor Rachel Lennon (Paediatric Nephrology, Podocyte research and clinical guidelines) and Professor Neil Turner (Adult Nephrology and RaDaR).
- Alport UK's international Workshop Organising Committee is made up of a wide range of 39 experts – researchers, clinicians, academics and Alport patients – with representation from Australia, Canada, China, Croatia, Cyprus, France, Germany, Israel, Italy, Japan, Lithuania, Poland, Russia, Spain, UK, USA.

Trustees' consideration of the major risks & procedures to manage them:

- **Support** – as we support patients and family members living with Alport Syndrome, there can be specific questions or situations that require medical advice or input. We have a scientific advisory committee which is available, whenever required, to provide expert medical input and advice to patients and their families. All committee members are practising/retired clinicians in the NHS and are recognised internationally for their experience and expertise. We also have a wider network of international experts from whom we can get additional opinions, as required. As we support a number of young adults and vulnerable adults, we have a Safeguarding Officer, who we consult if there are any safeguarding concerns. Mental health is an ongoing challenge for patients living with a life-long condition where the health declines, let alone with the context of the pandemic, so we encourage patients to seek professional help from the NHS and help them access the necessary services often through the renal units.
- **Information** – all the information and recommendations published on our website, [alportuk.org](http://alportuk.org), is reviewed by members of our scientific advisory committee.
- **Research** – all projects we embark on are reviewed by members of our scientific advisory committee and we get input from a wider network of international experts, as required. This includes assessing clinical trials and although, as a charity, we never recommend participation in a trial, we will provide as much information as possible to support patients' decisions on participating in a trial, publishing views in international publications, as necessary.
- **Collaboration** – is a core way of working for our charity. We collaborate with other national patient organisations and an international scientific community interested in research into Alport Syndrome. We run monthly conference calls and a series of international workshops for all involved to keep in touch with progress. Funds for these international research activities are kept in a separate bank account so that the expenditure is transparent to maintain the open collaborative working environment. To ensure all appropriate risks are managed related to this collaboration, we have set up an international Workshop Organising Committee to ensure there is a balance of work and information from or relating to different countries or continents.
- **Fundraising, finances and projects** – As a small charity, we fundraise for specific projects and these funds are kept in separate

bank accounts ‘ring-fenced’ for each project. The majority of our fundraising is through applications to larger charities that support small charities, such as ours, with funds allocated for specific activities, such as the information days or international workshops undertaken by alport uk. Increasingly, we also seek funding for work from pharmaceutical companies. We aim to raise collaborative funding for any project, so we are not reliant on one company for project funding which also means Alport UK is not associated with one company for one particular project.

## Section C Objectives and activities

### Summary of the objects of the charity set out in its governing document

The objects of the CIO are the relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- The establishment and facilitation of **a support network** for Alport Syndrome patients, carriers, their families and carers;
- The **provision of information** on Alport Syndrome;
- The **support of research** into Alport Syndrome both in the UK and internationally;
- The **support of a research registry in the UK** and an international alliance of national registries

### Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

#### Public benefit – statutory declaration by Trustees

The Trustees have paid due regard to the Charity Commission’s guidance on public benefit in deciding what activities the charity should undertake. alport uk recognises and welcomes the need to carry out its charitable activities to the benefit of those affected by Alport Syndrome, and retains this aim at the centre of its strategic planning.

**alport uk is a patient-led organisation** dedicated to facilitating a support and information network for all those affected by Alport Syndrome.

**Alport Syndrome** is an inherited condition that can cause kidney failure, deafness and eye abnormalities. Those that inherit it will probably require a kidney transplant when they are young adults. It can impact a large number of people in a family. It is the second most common form of inherited kidney disease. Meet Sam to understand the impact it has on a family: <https://sam-clarke.com/fighting-failure-challenge/>.

**Our Vision** is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life.

**Our Mission** is to work in partnership with individuals, families and the scientific community to:

- Facilitate a **support** network for patients and families
- Be a conduit for high quality, accessible **information**
- **Raise the profile** of Alport Syndrome in the scientific community
- Contribute to the international **research** agenda
- **Collaborate** on the development of a UK patient registry and alliance of international patient registries.

#### alport UK fund four key areas of activity

1. **Support** – Providing support for UK patients and families through a support network, website and information days.
2. **Information** – Working with clinicians, individuals and families to

educate them on more effective diagnosis and treatment, for example national guidelines for diagnosis, treatment and the best care for children, teenagers and adults.

3. **Research** – Working with other national patient organisations (eg USA, across Europe and Asia) and clinicians to design, develop and maintain an international research strategy and plan for Alport Syndrome, supported by an alliance of national patient organisations and national patient registries.
4. **Collaboration** – Bringing together the scientific community to work across the different clinical disciplines that specialise in kidneys, ears, eyes, mental health, other rare disease areas with similar issues etc. and working with the national patient organisations or other rare renal disease groups to share best practice with developed and developing countries.

The activities of alport uk are grounded in the local communities across the UK as we aim to connect up regional groups of individuals and families that are affected by Alport Syndrome. As the possible 2-3,000 individuals impacted in the UK is a small group if looked at on their own, this requires the charity to work internationally with other national patient organisations and clinicians to co-ordinate activities and research across a far bigger group of patients, particularly those with 10,000 or 100,000 patients in countries such as China and USA.

#### **Additional details of objectives and activities (Optional information)**

You **may choose** to include further statements, where relevant, about:

- policy on grant making;
- policy programme related investment;
- contribution made by volunteers.

## Contribution by volunteers

**alport uk mostly relied on voluntary help to run the activities over this period as for the previous nine years. Our community often reflect and remark on the journey we've been on and the remarkable progress alport uk makes and their ability to support patients and deliver professional international events that appeal to all stakeholders.**

**We are incredibly grateful to the volunteers for this remarkable progress, especially for the many contributions from the following key and very motivated people:**

- **Wilma Calderwood** for her day-to-day moderation on our closed Facebook page, Alport Warriors, which saw the community double in size during the pandemic.
- **Sam Clarke** whose 4,776-mile cycle ride in 2019 allows us to use the funds raised for the 'Don't Wait Fund' to support patients with Alport Syndrome take up a new activity or hobby. A number of patients have taken up the opportunity including:
  - **Alfie Bailey**. His mother Jeanette said 'he has lost weight and never looked back' since he took up horse-riding with funds donated for body armour and a riding hat by the Don't Wait Fund.
  - **Rachael Norris** who had a swimming subscription
  - **Joseph McLean** who bought cycling kit so he could do off-road cycling as well as on-road.
- **Katie Brown** and **Heidi Zealey** for helping us run the 20+ Alport online workshops during the various lockdowns.
- **Alice Turner** for her tireless energy, enthusiasm and fundraising work, ideas and help with running alport uk and supporting what fundraising activities could be done during the pandemic and for keeping us all positive during a very worrying year. Alice also has a forensic knack of putting our annual accounts together and tracking down all receipts and invoices to make the accountant's role much easier as he prepares the annual accounts.
- **All those who raised money for us this year** – every penny makes a difference, and this year people were very limited with what they could do to raise funds and increase our income. Particular thanks go to:
  - **Terry Sopp** for his fundraising dressing up as Father Christmas
  - **Sandra Jones** for raising funds through a virtual Kiltwalk
  - **Lauren Brand** for her continued efforts to raise funds for Alport with the plant sales and other activities
  - **Those many who donated funds raised from funerals** of loved ones eg Walker family
  - **Barclays employee fundraising**
  - **All** those people who purchased digital Christmas cards to raise funds through Don't Send A Card
  - **Everyone** who uses Amazon Smile and Easyfundraising for their shopping to raise small but important funds which keep the lights on at Alport UK.
- **And those who generously provided alport uk with a grant:**
  - **Kidney Research UK** for online Meeting support for a rare renal disease group
  - **Dyer's Company and other livery companies, London**
  - **Pears Foundation/Department of Culture Media and Sport** who so generously partnered during the pandemic to support tiny

charities, such as alport uk with funds to keep us operational at a time when our community needed us most, but our lovely fundraisers were unable to raise any money – see the feedback below about the benefits this gave our community.

- **And a number of people who wish to remain anonymous** but to whom we are very grateful for their support and encouragement.

**We wish to thank our Scientific Advisory Committee** for continuing to spend so much time this year advising and supporting support the community as the pandemic continued its hold whilst they were all also very busy on clinical wards helping with renal issues. They answered all queries within 24 hours, ensuring the community remained as calm as possible at such a worrying time for renal patients. We are so very grateful to the scientific community for their help to answer all questions and emails as and when they arose from patients or other scientists. Very many thanks to our UK Scientific Advisory Group:

- **Professor Frances Flinter**
- **Professor Danny Gale**
- **Professor Rachel Lennon**
- **Dr Omar Mahroo**
- **Professor Neil Turner**
- **Professor Colin Baigent.**

**Alport online workshops** – during the pandemic, people continued to volunteer for alport uk whilst stuck at home unable to work or go into the lab. A small working group of volunteers was formed which included: **Harriet Carter** (who volunteered for us whilst on furlough), **Susie Gear**, **Louise Hopkinson**, **Professor Rachel Lennon**, **Professor Jeffrey Miner**, and **Richard Naylor** plus **Heidi Zealey** and **Katie Brown** who took over from Harriet when she returned to work. Thanks to **Patrick Walker** and **Aura Zealey-Smith** for their excellent moderation and broadcasting skills quizzing the scientists to make each production so much more engaging for the online audiences - see Alport Workshops on YouTube channel: <https://tinyurl.com/y9cuhgby>





Patrick deserves an extra special mention as he was moderating workshops a couple of weeks after he received a kidney transplant in the middle of Covid!

Thanks also to **Dan Long** and **Archie Walker** for managing the productions behind the scenes, doing the rehearsals with scientific teams all over the world and training people up to deliver some outstanding workshops. Thank you to **Patrick Walker** for his excellent video-editing work that made each Podcast so professional when loaded onto YouTube. We are so grateful for the ongoing inspiration from this group who helped run a very professional series of 20+ **Alport online workshops** featuring the latest Alport research, using Zoom, which were provided for the international Alport community (patients and scientists) by Alport UK and with set up costs kindly funded by Kidney Research UK. Volunteers who helped with the workshops, acting as moderators or contributors telling their stories also included **Katie Brown, Sam Clarke, Steve Fry, Mark Hewitt, Adam Jardine, Karen Kane, Dan Long, Aby Lucy, Patrick Walker, Andre Weinstock, Heidi Zealey, Aura Zealey-Smith,**

We wish to thank those involved in forming **Alport Avengers**, an invaluable WhatsApp group specifically aimed at 18–35-year-olds, joining and sharing their experiences to help others. This included **Katie Brown, Sam Clarke, Jamie Walker, Patrick Walker** and **Aura Zealey-Smith**. Particular thanks go to **Joseph McLean, Jamie Walker** and **Aura Zealey-Smith** for modelling the newly branded alport uk 'merch' - on the next page - designed to sell to raise important funds for alport uk.



We are also very grateful to our colleagues who run the other national patient organisations and collaborate with alport uk, such as **Andre Weinstock** (Alport Syndrome Foundation, USA), **Jacqueline van Kempen** (The Netherlands), **Maria José Cacharron** (Spain) and **Daniela Lai** (Italy), **Jessie Zhang and Mr Cai** (China), **Christof Finkler** and **Ute Rosenthal** (Germany), **Dave Blatt** (Australia).

Huge thanks to the inspiration of many volunteers around the world – each Alport experts in both their scientific area and geography - that made up the **Workshop Organising Committee for The 2021 online International workshop on Alport Syndrome** after we had to cancel the in person workshop planned for Beijing in China:

**Dr Marina Aksenova**, Veltischev Research and Clinical Institute for Pediatrics of the Pirogov Russian National Research Medical University, Moscow, Russia

**Professor Colin Baigent**, MRC Scientist, Hon Consultant in Public Health, Oxford, UK

**Assistant Professor Moumita Barua**, Toronto General Hospital, Toronto, Canada

**Dr Agnė Čerkauskaitė**, Division of diagnosis and treatment of Rare Kidney and Metabolic Diseases, Nephrology Center, Vilnius University Hospital Santaros Klinikos, Vilnius, Lithuania

**Professor Constantinos Deltas**, University of Cyprus, Molecular Medicine Research Center, Nicosia, Cyprus

**Professor Jie Ding**, Department of Pediatrics, Peking University First Hospital, Beijing, China

**Professor Frances Flinter**, Emeritus Professor of Clinical Genetics, Guy's and St Thomas' NHS Foundation Trust, London, UK

**Professor Daniel Gale**, Department of Renal Medicine, University College London, UK

**Professor Danica Galešić-Ljubanović**, Department of Pathology University of Zagreb School of Medicine, Head of Department of Nephropathology and Electron Microscopy, Dubrava University Hospital, Zagreb, Croatia

**Professor Oliver Gross**, Department of Nephrology and Rheumatology, Georg-August-Universität Göttingen, Germany

**Professor Julia Höfele**, Institute of Human Genetics, Munich, Germany

**Professor Hirofumi Kai**, Graduate School of Pharmaceutical Sciences, Kumamoto University, Japan

**Professor Clifford Kashtan**, Department of Pediatrics, University of Minnesota, USA

**Professor Bertrand Knebelmann**, Necker Hospital, Paris, France

**Associate Professor Ron Korstanje**, The Jackson Laboratory, Bar Harbor, USA

**Professor Rachel Lennon**, Senior Research Fellow and Consultant Paediatric Nephrologist, Manchester, UK

**Dr Laura Massella**, Division of Nephrology, Dpt. of Pediatric Subspecialties, Bambino Gesù Children's Hospital - IRCCS, Rome, Italy

**Professor Julian Midgley**, Department of Paediatrics, Alberta Children's Hospital, Canada

**Professor Jeffrey Miner**, Washington University in St. Louis, USA

**Associate Professor Laura Perin**, Saban Research Institute, University of Southern California, USA

**Professor Judith Savige**, University of Melbourne, Australia

**Professor Alessandra Renieri**, Professor of Medical Genetics, Director of Medical Genetics Unit, Azienda Ospedaliera Universitaria Senese viale Bracci 2, Siena, Italy

**Associate Professor Michelle Rheault**, Department of Pediatrics, University of Minnesota, USA

**Professor Roser Torra**, Fundació Puigvert, Barcelona, Spain  
**Professor Neil Turner**, Professor of Nephrology, University of Edinburgh and Consultant Nephrologist, Royal Infirmary of Edinburgh, UK

**Patient representatives:**

**Dave Blatt**, Alport Foundation of Australia

**Maria José Cacharron**, Spain

**Christof Finkler** and **Ute Rosenthal**, Alport Selbsthilfe, Germany

**Susie Gear**, alport uk

**Daniela Lai**, A.S.A.L., Associazione Sindrome di Alport, Italy

**Julia Schifter**, Alport Foundation Israel

**Jacqueline van Kempen** and **Evy van Kempen**,  
NierpatiëntenVerenigingNederland (NVN), The Netherlands

**Andre Weinstock**, Alport Syndrome Foundation, USA

**Jessie Zhang** and **Mr Cai**, Chinese patient group, China

Our special thanks to **all members of the Lennon Lab of Manchester University** who are based at the Wellcome Centre for Cell Matrix and led by the inspirational **Professor Rachel Lennon**. The team have all volunteered and worked very closely with alport uk on a number of different events and projects over the year including the Alport Online Workshops, Podocyte 2021 and are doing some amazing basic science research and collaborations with the Alport community around the world. The Lennon lab research work is internationally recognised as leading edge and helping us better understand what happens in the kidneys with Alport Syndrome. They also are always on hand to support alport uk with explaining scientific terms, helping design workshop agendas and generally engaging with the patient community. It is so unusual for patients to be so engaged in research and we have the Lennon lab and Rachel Lennon to thank for this exciting collaboration that is leading to new ways of working.



**We also very much value the funding and support of a number of important organisations and charities:**

- **Kidney Care** (was British Kidney Patient Association) for their expert advice and support, particularly through the pandemic.
- **Kidney Research UK** - with specific thanks to **Sandra Currie** and colleagues for so quickly approving a grant to pay for Alport UK's Zoom webinar subscription when the pandemic hit. We were so grateful to them for recognising we needed urgent help and for their continued support at a time when their own funds became very limited and they had to review their own operations.
- **Alport Syndrome Foundation (USA)** – with specific thanks to Andre

Weinstock, Kevin Schnurr and Janine Diebel for their continued collaboration on the online workshops and Joy Toal particularly for connecting and sharing her experience to support patients on the closed Facebook page, Alport Warriors, during the pandemic.

- **A couple of charities who wish to remain anonymous** for both their financial support and advice which is very much appreciated.

There are also a number of people we would like to recognise for their contributions to our projects. Although we pay them for the project work they do, each has given way more time and ideas than they charge us for. Their continued support we very much appreciate:

- **Jane Keightley** – for her marketing advice and on-going support to build the brand of Alport UK to raise its profile along with communicating and engaging people in our aims and objectives and core activities. We also very much appreciate Jane's writing and editorial advice that sets the written tone for all our communications.
- **Robina Newman** – for her thoughtful brand and design work on various materials (in the photo below) and generally helping us to create a bright and distinctive identity that sets the visual tone for our activities including some lovely branded merchandise which helps our patients be proud of their Alports and of our community.





- **Harriet Carter** – who so ably then ran the process to deliver the series of 20+ Alport Online workshops once her furlough ended.
- **Paul Heaps** – who kindly took on the challenge of taking photos whilst we worked in Manchester to share what we do and celebrate our special team, plus photographed our merchandise.
- **Sam Clarke** – for his excellent videos that are making our work come alive and enabling alport uk to share the important work we do. The films are invaluable communication materials that engage the Alport community in everything we are doing. For example, Sam filmed at Manchester University to share the collaboration and exciting research happening at the hybrid Podocyte meeting hosted by Manchester: <https://youtu.be/3-ZDm2CR8Ow>.



Thanks also to **Patrick Walker** for volunteering to help Sam with the online interviews that contributed to the Podocyte 2021 film.



- **Alice Cooper** – who took on the role of Engagement Manager for alport uk – our first paid person - and worked with the alport uk volunteers including Susie Gear to:
  - run the Alport Online workshop process when Harriet left, engaging the Alport community in the workshops
  - reach out to a wider group of people across the world to engage them in the international workshops using mailings and social media
  - design and deliver a hybrid international patient day – online and in person in Manchester - for the glomerular disease patient groups at Podocyte 2021 – featuring talks on exercise and nutrition and the work of basic scientists plus collaborating with and co-ordinating the input from other charities eg Nephrotic Syndrome Trust, Membranous Nephropathy organisation, IgA Nephropathy organisation etc
  - design an invaluable website for the Alport Syndrome Alliance to register all those interested in participating in The 2021 International workshop on Alport Syndrome
  - design branded merchandise and designed an online shop to sell to much needed funds for alport uk.

Alice contributes many more hours than the part-time work we pay her for, particularly in the lead up to key events such as Podocyte 2021. We are incredibly grateful for Alice's wonderful dedication and ability to get things done which accelerates what alport uk delivers.



### Summary of the main achievements of the charity during the year

The achievements of alport uk this year build from last year and are summarised under the headings of our key objectives and areas of activity below. **Overall, our main outcome is to create a more positive and brighter future for individuals and families living with Alport Syndrome.** Being a rare and therefore small community, we aim to deliver sustainable strategic change for Alport Syndrome, using virtual networks and limited resources to effectively support patients and develop treatments for Alport Syndrome. Positivity and engagement are the main ingredients for all the support we offer – we aim to inspire and encourage people living with Alport Syndrome to be optimistic and explore their way to a brighter future.

Measuring our performance and listening to patient feedback on what works and adjusting what we do is vital: **Parents with a young daughter recently diagnosed with Alport Syndrome:** *“...always hugely impressed with you and the team for effort, organisation, enthusiasm, info, results etc – well done it is so appreciated by us all out in the Alport community!”*

### The philosophy that underpins our performance

The Six Pillars of Wellbeing – long established as framework to think about mental health and wellbeing - is a useful structure to encourage positive outcomes for individuals and families living with Alport Syndrome. The Six Pillars that inspire our activities:

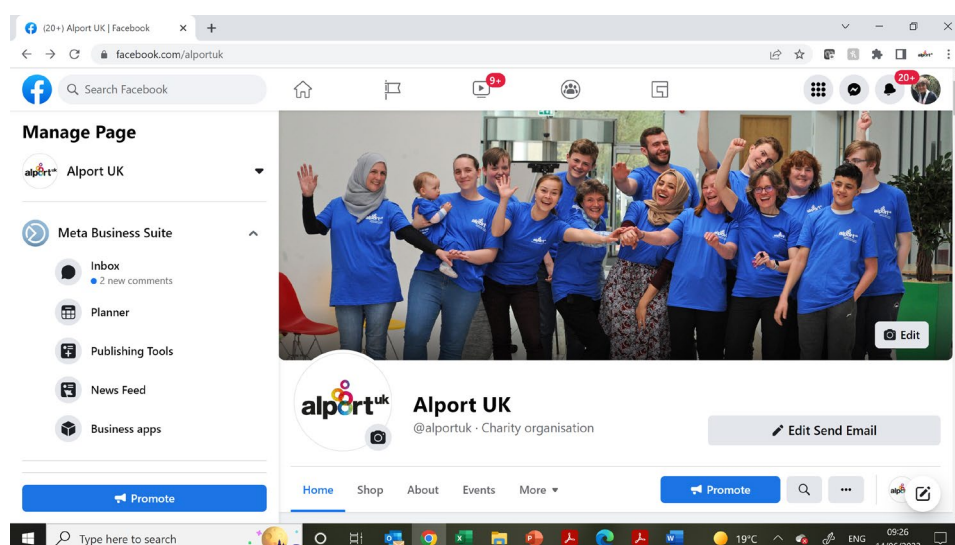
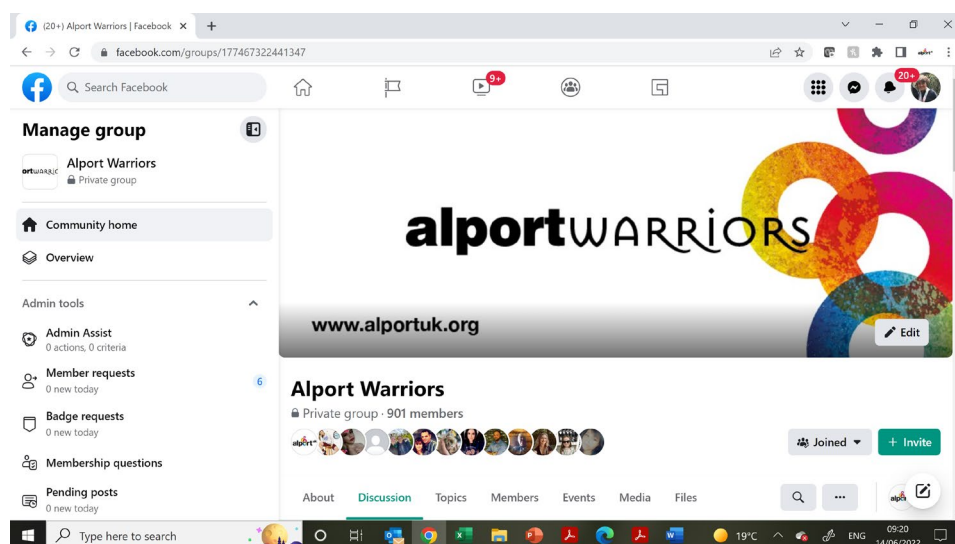
- **Stress management** – keeping the community calm and informed with the latest information, so they can become more independent, strong and resilient over time
- **Nutrition** – inspiring the community to eat healthily to protect their kidneys for as long as possible and when on restricted diet, explore new foods they can eat
- **Community** – connect to reduce the feeling of isolation caused by having a rare disease that few others either know or understand
- **Sleep** – ensure the community members can have a routine with good sleep to enable them to deal with the rollercoaster journey that some individuals and families face as part of living with a rare disease and coping with critical events along the way, such as hearing declining, kidney failure and eye issues.
- **Exercise** – we know cardiovascular exercise is good for the kidneys. It is also vital to rebalance the chemical impact brought on by the feeling of anxiety that overwhelms some patients living with the fact that their kidneys may fail at some unknown time in the future
- **Meaningful activity** – encourage individuals, families, and researchers to connect around a shared objective of helping our community in some way, whether it be volunteering for our community, advocating, fundraising, collaborating on research or useful information or sharing stories to help others living with Alport Syndrome.

### As a tiny charity we are very clear what we can do

Supporting a rare disease that science now tells us impacts 1 in 2,000 in a population (rather than the previously proven 1 in 10,000) is a challenge as there are few people who have Alports, who want to research it or fund it. So as a charity we think wisely about how we use our strengths, capabilities and resources and how to collaborate to complement these. Our volunteers have strong capabilities in delivering

commercial innovation and collaboration across virtual networks of international stakeholders around the world. Some examples of the principles that guide what we do in our five key areas of work:

1. **Support network:** with a small, isolated patient community with such differing needs, we like to deliver **personal support in a timely way that delivers practical advice** and solves practical issues. alport uk's role is to empathise, understand the needs/issues, advocate for patients (and researchers) and support delivery of solutions through a virtual organisation with minimal overheads. The power of the internet and social media provide us with very economical tools such as our closed Facebook community page, **Alport Warriors** and our public **Alport UK Facebook page**. With our limited resources, this often means facilitating patient/researcher access to resources. For example, alport uk facilitates patients getting the right diagnosis via genetic testing, understanding treatment options or facilitating the grant application process for holiday breaks via Kidney Care's grant system. alport uk also writes letters of support for researchers to facilitate grant applications for Alport research.



2. **Provision of information:** with a diverse community and a very complex condition to explain, we try out different ways to provide information in a **variety of formats that suit different stakeholders**. With many of the community facing critical medical decisions as young adults, increasingly we use **short videos, social media and**

**engaging activities to enable the patient community to engage in formats and content they find valuable.** For example, we encourage young adults to become our 'media team' at events, to engage in content, choose what is important and create videos and social media content themselves. See the video patients created about clinical trials and new treatments:

<https://youtu.be/JRsJtUu8Lh8>. This was translated into 3 other languages by the patients working together on the script. We also publish **scientific information in the appropriate international journals so that it seeks consensus across our community and is peer reviewed and globally available** for researchers, clinicians and patients.

3. **Support research:** with limited funds and fundraising capability, we choose to focus our efforts to **inspire and facilitate collaborative behaviours such as information and resource sharing to facilitate and accelerate innovative ways of working and the development of new treatments and knowledge.** For example, during the pandemic, we **facilitated the international research community coming together to share and exchange ideas through a series of online international workshops.** This strategy aims to create a vibrant international research community that attracts more researchers and pharmaceutical or biotech companies interested in developing new treatments. These activities complement the activities of our colleagues in organisations such as:
  - Kidney Research UK – who raise money to fund specific UK Alport and kidney research projects eg elements of Rachel Lennon's lab based at Manchester University.
  - Alport Syndrome Foundation in the USA – who raise money to provide vital 'seed funding' for Alport research at an early stage of development.
4. **Continued support of a UK research registry:** with significant investment made by Kidney Care UK and Kidney Research UK into The **National Registry of Rare Kidney Diseases (RaDaR)** – the UK Renal Association's initiative designed to pull together information from patients with certain rare kidney diseases - alport uk support this vital project by **encouraging patients, clinicians and renal units to upload long-term clinical data into this database to enable Natural History Studies in the future to progress Alport Syndrome research.** This will give a much better understanding of how Alport Syndrome affects people. It will also speed up research. The value for:
  - Alport patients:
    - Access to their clinical data online via Patient View, an online system which records blood and urine results, medications and clinic letters.
    - Ability to be contacted about future potential research studies or patient information events
    - Contribute to the increase in knowledge about their condition
  - Clinicians:
    - Share knowledge with other colleagues
    - Use RaDaR as part of a research study or clinical trial.
5. **Fundraising:** with so few people in the UK impacted by Alport Syndrome, awareness of the condition is limited and traditional fundraising by the public typically focuses on the key health areas of

cancer, heart conditions etc. **We heartily encourage individuals and families living with Alport Syndrome to fundraise when inspired to do so, by providing support, encouragement and new branded merchandise** (eg t-shirts, badges, wrist bands, shaking tins etc) to enable them to achieve whatever challenge motivates them. This means that **we raise significant funds for each major project or a programme of activities by applying for grants from larger charities or from pharmaceutical companies**. We support large fundraising events each year eg a dinner with an auction, a major activity eg swimming the channel or cycling round Europe etc.

### **Highlights: achievements and performance this year**

#### **The pandemic: an opportunity to connect and engage**

Vulnerable kidney transplant or dialysis patients and many Alport patients continued to shield at home and the closed Facebook community – Alport Warriors – continued to grow and now numbers over 900 members from all over the world, trusting and appreciating the excellent advice we get from our colleagues in the NHS. In 2019, there were 350 members. Each year we are contacted by more and more people as they are diagnosed with Alport Syndrome. We provided advice specifically relating to COVID and the impact on renal patients. As we work as a ‘virtual’ organisation anyway, alport uk was able to easily respond to this increase in requests and with more of the community online – patients and researchers – more people were able to help each other. This engagement from the wider community was valuable for all and so alport uk thrived in a really positive way, despite the pandemic. It was an opportunity for more to engage and more got value from this engagement.

#### **Support network proactively increased during the pandemic**

We remained proactive in our Covid advice for people living with Alport Syndrome, and kept the community as calm as possible as the pandemic changed, lockdowns evolved in different countries and vital vaccine work emerged providing the necessary way to live with Covid longer term with hope for the community.

Before the charity existed in 2013, with Alport Syndrome then thought to affect 1 in 10,000 people, it was typical that a family diagnosed with Alport Syndrome would never have met or talked to anyone outside their own family impacted by the condition. There was no support network and no mechanism for connecting individuals and families. People felt isolated. Through regular National Alport Information Days, our web site and closed Facebook page, support networks developed and each year the community feels stronger, more connected and able to deal with issues as they arise and particularly as we work through challenges together. People don't feel alone anymore. This infrastructure proved invaluable in supporting patients through the early unknown stages of the pandemic.

**Young woman in her 20s with a young daughter, both impacted by Alport Syndrome and mother needing a transplant urgently,** commenting about young adult workshop: *“It was really good to not feel so alone.”*

**Young male patient from Georgia with no support locally,** but joins the online workshops to understand more about Alport Syndrome: *“Thank you so much. Really appreciate what you guys are doing.”*

Some of the key support network achievements over the year:

- At the time of writing our Facebook Alport Warriors increased to over 900. The community doubled during lockdown as people sought information online. Discussions were initiated by both regular and new contributors and covering such subjects as kidney donation, hearing, sight, drug trials, transplant successes, successes at the annual Transplant games, fundraising opportunities, celebrating birthdays, links from other Alport Facebook sites, fundraising activities, and a range of questions about Alport Syndrome, its symptoms and side effects. There was one very touching story of a teenager who attended our first information day in London with his parents. The teenager met one of our inspirational and celebrated patients who has now had three transplants. After the teenager had their transplant, the two of them met up again at the Transplant games and shared a picture on Facebook. Connection with others who are in a similar situation is clearly valued by some people in the Alport community. Connection is not valued by all, so we aim to provide support for individuals or families in other ways to suit their needs. **Following the support we gave the parent of a young Alport patient facing kidney failure and living in unsuitable accommodation** for their condition: *"Hi, I just wanted to let you know that the council have agreed to fully refurbish (patient name)'s wet room after it went to a panel meeting last week... Thank you ever so much for your continued help and support."*
- We continued the dissemination of information and support for both patients and carers, including:
  - Sending out information electronically – there was a high number of enquiries about information for women and girls living with Alport Syndrome.
  - Answering enquiries emailed to us at [info@alportuk.org](mailto:info@alportuk.org) and phone calls sent to our landline number of 01793 847264 and putting people in touch with experts to answer their questions or with other families to share stories and experiences.
  - Eg **A Dad contacted us as daughter wanting to start IVF and concerned about whether her side of the family has inherited Alport Syndrome like her cousin and wanting advice on best way to get a diagnosis in the COVID environment:** *"Thanks Alport UK – and to the Professor for the prompt & concise response. Your advice is crystal clear.... Thanks again for your help."*
- When patients contact us for advice on specific topics, we put them in touch with the relevant clinicians, experts. Initially, much of this was done via email, but now we connect people through Alport Warriors, our phone line and email. Alport Warriors is our closed Facebook page where people share experiences of living with Alport Syndrome. **Parent of one young Alport patient facing transplant who we connected up with another young person who recently had a transplant:** *"Thank you. We have seen a big change in our son since he started talking about his worries and the extra support seems to be what he needs now."*
- We took the lead role in the organisation of the patient day portion of Podocyte 2021, the 13th annual Podocyte conference hosted by Professor Rachel Lennon of Manchester University. We coordinated the work for four kidney conditions including Alport UK, Membranous Nephropathy, Nephrotic Syndrome and IgA Nephropathy. We coordinated a day which involved 298 delegates, of which 85 were

patients. Patient experiences and stories were incorporated into the agenda along with how to get support. We also held a 'Reflections' session to get feedback from Pharma representatives who were keen to participate in the patient day.

**Patient feedback included:**

*'Beautifully organised with excellent hosts and the platform you used worked really well. I'd particularly like to thank the academics and medics involved for not 'dumbing down' their presentations, but being clear and straightforward in what they discussed.'*

**Provision of information**

With the help of our scientific advisors, we offered advice on our closed Facebook page – Alport Warriors - to the community to answer pandemic queries as they arose. We duplicated the same information on the Alport Syndrome Foundation's USA Facebook page as they have a number of UK patients as members, working together to benefit the international community. This approach - informing people to enable them to take control and build resilience - was vital as our community has so many differing needs, many different age groups, at differing stages of renal failure, undergoing different types of renal replacement therapy and many patients and family members from other countries seeking advice. We are very proud of the alport uk team, how they anticipated queries, increased the advice and information to enable people to stay as calm as possible, including sourcing food banks and writing letters to employers to explain the needs of their employees with Alport Syndrome. We are incredibly proud of the patients, their positive and pragmatic approaches to looking after themselves and helping each other across the community at what continued to be a very concerning time.

Potentially 80% of patients with Alport Syndrome face Chronic Kidney Disease (CKD) in their late teens or early 20s and will require dialysis or a transplant. The exact details of prognosis for the genetic mutations of these young adults are not yet known, so the young adults face an emotional 'waiting game' for their kidney function to start declining. Some describe it as a 'timebomb'! The young adults find it most helpful to connect with young people of their own age, so they can learn from and mentor each other when facing these particularly challenging times such as declining kidney failure and transplants. This was one of the roles of the **Alport Avengers group** – a group of 18–35-year-olds that emerged and was set up on WhatsApp. If a young adult had a question or a parent of a young adult raised a question, we would offer membership of this vital group: **Parent of one young Alport patient facing transplant who we connected up with another young person who recently had a transplant:** *"Thank you. We have seen a big change in our son since he started talking about his worries."* **Young Czech patient needing a transplant who is a member of Alport Avengers:** *I know it does seem daunting although I've found it helpful to hear what others are experiencing as I know what to expect."*

With this young adult group, as the most critical group facing declining kidney function just at the time they are trying to leave home, build careers etc, their feedback increasingly indicates that short videos are the most useful way of sharing information. We now use short videos to explain Alport Syndrome and to share patient stories. Our most shared videos include four filmed and produced for alport uk by filmmaker, Sam Clarke who is also a young person living with Alport Syndrome:

- **Fighting failure:** Sam Clarke, prepared for his challenge to cycle round Europe <https://youtu.be/1A1adCj-cvo>. We use this video for

newly diagnosed patients as it explains the challenges of living with Alport Syndrome but Sam ably inspires patients with the fun activities that he does such as sky diving, cycling and generally having fun. This is such an important message for young patients.

- **Patients inspire Alport Syndrome research**, a collaboration between alport uk and University of Manchester: <https://www.youtube.com/watch?v=77p7nzKz6nc>
- **Highlights from The 2019 International workshop on Alport Syndrome**, Siena, October 2019: <https://youtu.be/QH8mDTmKaVU>
- **Highlights of Podocyte 2021**, a film made by young patients who have podocyte-related kidney conditions, Manchester, July 2021: <https://youtu.be/3-ZDm2CR8Ow>

We are very grateful to patient Sam Clarke for making these upbeat and very professional videos. Sam is exemplary in that he also is willing to collaborate with other Alport patients on the content and editing. Sam himself gets a lot of value from meeting members of the Alport community and he talks openly about how it helps his own mental health and living with the ‘timebomb’ of when his own kidneys will fail. The work on these videos means we have a very engaged young adult group who feature on the videos telling their stories and giving their opinions, plus doing some of the interviews to create the content. The success of content and style of these videos is because they are designed and filmed by people living with Alport Syndrome for people living with Alport Syndrome. As a result, the videos are often watched and admired for their inspiration. In addition to being excellent providers of information, the videos also inspire many others who watch them. The videos demystify what it is like to live with Alport Syndrome and why patient/research scientist collaboration on Alport research is so important. In addition to being good information providers, the videos are excellent emotive marketing tools to potential funders and give a lot of positive hope for the community and people who want to find out more about it.

In 2018, a very successful **series of two-minute animated videos were written, illustrated and produced by a group of our young people with Alport Syndrome for their peers**. The writing of the videos and working with the clinicians to make them scientifically accurate was a valuable process for the young people to engage in understanding Alport better as sometimes they can be in denial about what is important to keep them healthy or sources of support. We continue to use these videos, pasting the links onto Facebook when questions are raised by patients, carers and their families about Alport. Topics included:

- Why Alport research is important <https://youtu.be/TU0m6qGvTFY>
- Alport Community <https://www.youtube.com/watch?v=5qJEtmhcCIU>
- Alport Syndrome: Know your numbers <https://www.youtube.com/watch?v=jtkmJdwG0nE>
- Kidney transplants and Alport Syndrome <https://www.youtube.com/watch?v=Gd4yB9PVnM0&t=52s>
- Update on clinical trials and potential treatments for Alport Syndrome (written in English and translated into Italian, German and Chinese by the young patients with Alport Syndrome) at The 2019 International workshop in Siena, Italy <https://youtu.be/JRsJtUu8Lh8>

When someone is diagnosed with Alport Syndrome, some of the regional genetics units e.g. at Guy’s Hospital and some of the paediatric renal units e.g. at Manchester University Hospital, have a small leaflet giving some summary details about the condition and our alport uk leaflets. Beyond this, there is an array of information one can find on the web, but it is hard to decipher what is medically correct or up to date. On our website is:

- **A summary leaflet for Alport UK** to encourage people to get in touch with us – this is now handed out at the genetics units when people are newly diagnosed with Alport Syndrome. It was also sent out, along with laminated posters with our contact details on, to all the main adult and paediatric renal units around the country to advertise where to find out information about Alport Syndrome
- **A dictionary of scientific terms** to help patients learn more about the biology of Alport Syndrome, so when their clinicians explain things, they understand a bit more about what they are talking about as it is so hard to pick much up in a short clinic appointment.
- **Definitions of related rare renal diseases** – Nephrotic Syndrome, IgA Nephropathy, Membranous Nephropathy and Focal Segmental Glomerular Sclerosis (FSGS) that sometimes overlap with Alport Syndrome or people can be diagnosed with more than one disease or if people are misdiagnosed.
- **Videos available through our website** ([www.alportuk.org](http://www.alportuk.org)) and a special section on Alport Syndrome on [www.healthtalk.org](http://www.healthtalk.org) (<http://www.healthtalk.org/peoples-experiences/long-term-conditions/alport-syndrome/topics>) of our key experts talking about specific aspects of Alport Syndrome. Topics are varied about all aspects of living with Alport Syndrome and include: Genetics, An introduction to Alport Syndrome, Hearing and hearing aids, caring for people with Alport Syndrome, medication, women with Alport Syndrome etc.
- **Our website remains an invaluable resource.** We are currently fundraising to improve our information on the internet. We intend to update [www.alportuk.org](http://www.alportuk.org) to make the information clearer and more accessible and to answer the questions we have received over the last few years or so through our closed Facebook page, Alport Warriors. The plan is to collaborate with the other national patient organisations and provide an international website for the most up-to-date information, research papers and clinical guidelines. We need to establish what information is critical to hold and update at the international level (eg simple explanations of Alport Syndrome, clinical guidelines etc) and what is specific to a national community, such as how to navigate the NHS in the UK to access treatment. This project will mean we will update [www.alportuk.org](http://www.alportuk.org) so as not to duplicate resources. **A mother contacted us via the website about vaccination for a 19-year-old daughter with Alport Syndrome and on strong medication:** *“Thank you for putting my mind at rest. I got your contact details from the Alport UK website. My daughter said it's not really her thing joining groups. Shame, as I think it's really good that support is out there. Thank you for your support.”*
- **Information about new clinical trials** that patients can sign up to is shared through our website 'Latest news' section, through our closed Facebook page (Alport Warriors) and through directly emailing our database of patients.

### Supporting or driving research?

With limited funding for research, alport uk's strategy is use our small amount of funding to facilitate a virtual Alport research collaborative giving support and encouragement for the research community enabling them to work together to set the research programme and create a vibrant research community that attracts more researchers and pharmaceutical companies interested in developing new treatments.

The major programme for the first half of the year was to continue to deliver our **series of international Alport online workshops**, run and moderated by our young adult Alport patients:

- With the pandemic continuing, the ensuing limitations on mobility, and with many patients shielding at home and the alport researchers unable to get into the lab, people had time on their hands and we continued our series of Alport online workshops with two a month. **Subjects covered included: eye abnormalities, kidney organoids, new treatments and clinical trials, modifier genes, planning a family, the use of Flozins, Transplantation stories, Canadian research, Chinese research, hearing and genetics.**
- The workshops were run monthly thereafter with a few extras fitted in on topics people were particularly keen to hear about eg **eye and hearing complications in Alport syndrome**. The workshops featured scientists from all over the world. **From a patient who attended the Hearing workshop: 'So good to hear this subject properly discussed, thanks all'**. We enjoyed the patient's sense of humour in the feedback! Joking aside, this was the first time our community focused on hearing in detail – both the physiology and understanding research looking at the performance of the ear particularly. The plan is to do more on hearing and eyes as these are topics requested by patients again and again – the fear of losing hearing and eyesight ie going deaf and blind understandably terrifies people when they are first diagnosed with Alport Syndrome. alport uk always encourage recently diagnosed people to find out more about the Alport implications and aim to help them realise that the symptoms are very varied on a spectrum of severe to mild so there are different symptoms for different people, potentially dependent on their genetic variant of the Alport gene and any genetic modifying genes involved. Largely the hearing loss associated with Alport Syndrome is partial hearing loss that can be helped with hearing aids for the majority of patients. The eye abnormalities are also on a spectrum and require an eye test at Moorfields to understand the severity; symptoms are also potentially dependent on the genetic variant of Alports. We also know the eye symptoms can also be alleviated with simple treatments or extend to lens replacement therapy – like a cataract operation – that transform what appears to be increasing 'blindness' for patients. This information is vital to share with patients – that they can do something about the eye complications. So, we provide this information through the online workshops, and then post links to the workshops on the closed Facebook page and via social media to save people suffering unnecessarily.
- The second part of the year saw the international Workshop Organising Committee reformed and increased in size with additional Alport experts added and some from new countries who had not previously engaged eg Canada, Croatia, Lithuania, Poland, Russia. This new committee started work on the fifth international workshop planned for online with Covid limiting travel and creating an uncertain environment for the community: work started to plan **The 2021 Online International workshop on Alport Syndrome** with a new online discussion forum started on Slack to share the workshop programme being developed to make sure it suited the needs of the potential mixed audience of patients, clinicians, research scientists and pharmaceutical companies.

In alport uk's previous annual report, the aim was declared to increase the diversity of participation and contributions to the Alport Online Workshops, which was achieved as you can see below, particularly in the

moderators. This meant alport uk engaged many more Alport experts and patients from around the world, despite there being less workshops as the lockdowns lifted in different countries people spent less time online. The number of Alport Online workshops delivered over 2020/21 compared with the previous year:

| Numbers of                                                                                              | Current year 2020/21                                  | Compared with previous year 2019/20                  |
|---------------------------------------------------------------------------------------------------------|-------------------------------------------------------|------------------------------------------------------|
| Participants in the workshops                                                                           | 412 participants from 12 different countries          | 279 participants from 33 different countries         |
| Online workshops                                                                                        | 12 online workshops                                   | 14 online workshops                                  |
| Speakers presenting                                                                                     | 36                                                    | 38                                                   |
| Latest research projects presented                                                                      | 20 projects from 8 different countries                | 42 projects from 8 different countries               |
| Moderators asking questions                                                                             | 41 moderators contributed from 8 different countries  | 15 moderators contributed from 3 different countries |
| Views of the videos on YouTube, <a href="https://tinyurl.com/y9cuhgby">https://tinyurl.com/y9cuhgby</a> | 1,501 views with 5,132 views across the whole channel | 1,786 views                                          |

The researcher and clinician participants represented a range of different disciplines: basic science, lab technicians, adult and paediatric nephrology, clinical and laboratory genetics, pathology, ophthalmologists, transplant surgeons, dialysis specialists, academics.

Some of the online workshops featured specific labs and were an opportunity for early career researchers to present their work to the international Alport community and get feedback and questions. In the spirit of 'collaboration' – such an important principle of alport uk's strategic direction – the pandemic actually enabled us to accelerate our progress, share more research to a wider audience and at a reduced cost compared with the four 'in person' workshops delivered previously. The lock-in format of these four 'in person' workshops meant the community had already spent plenty of time getting to know each other over the last 7 years and this investment in enabling the community to 'get to know each other' and collaborate paid off as we worked online. Busy clinicians, battling to deliver frontline care to patients in hospitals all over the world, still made time to join us online and connect.

After their presentations, a number of the researchers fed back stories to alport uk about how the workshops 'furthered their science'. Presenting researchers confirmed that members of the Zoom audience on their workshop reached out to them via email to:

- set up new collaborations
- initiate new collaborative research projects and
- provide vital new input to current projects.

The online workshop format was a catalyst for new research, thanks to the pandemic and the inspiration of the team who devised the format:

**Professor Rachel Lennon, Professor Jeffrey Miner, and two members of the Lennon lab - Louise Hopkinson and Richard Naylor.**

alport uk is incredibly grateful particularly to Louise and Richard, who worked from home whilst unable to get into the lab, and helped us identify new research to feature, created material to post on social media, participated in the discussions and helped 'translate' some the difficult terms into a dictionary of layman's terms to make the science more accessible for patients with no science background.

Feedback from patients:

*"It was so enlightening to find out these people (the researchers) are doing their very best on our behalf. I had no idea of the methods used for this kind of research. They seemed to be a happy team too!"*

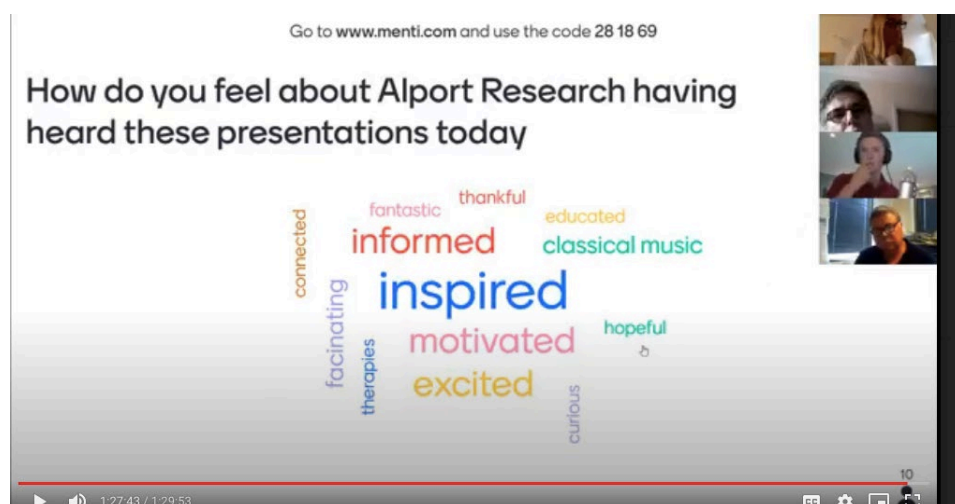
*"It was reassuring that such research is carrying on."*

*"Fantastic idea and I'm sure the rest of the Alport community would be very interested in seeing this. I did not have a clue so much was going on and to hear all the info has made me feel very hopeful. Many thanks again"*

**From a patient advocacy person:** "...congratulations for the Alport workshops. It is a fantastic way to keep connected and continue learning about Alport Syndrome."

After each workshop, we invite people to submit one word to express how they feel after a workshop. For example:

**Feedback from the Hearing workshop:**



**Patient:** 'I found this so interesting as I have hearing loss myself - thank you all.'

**Feedback from the Spotlight on Jie Ding's lab, based in Beijing, workshop:**

**How are you feeling after watching these presentations?**



**Feedback from Chat and emails:**

*'Really helpful to see an example of a putative variant being demonstrated to be benign. Otherwise, it is so easy to make an incorrect diagnosis.'*

**Alport research indicators in 2019**

In the 1990s, groups of leading clinicians, academics and scientists regularly met to discuss topics related to Alport Syndrome. They published a number of key papers about Alport Syndrome, but the regular meetings stopped. In 2012, alport uk commissioned a web audit of people publishing material on Alport Syndrome through to the current day and prepared a report on the status of research into Alport Syndrome. This report was used to identify the missing areas of activity and needs for research including:

- A shared international strategy and plan for Alport Syndrome research
- New research ideas and projects to develop new treatments and therapies and more research generally
- Ways to reengage the leading experts in Alport Syndrome
- Co-ordination of national patient registries
- The need to engage the pharmaceutical industry in developing new treatments
- How alport uk could complement the current contributions of other national patient organisations, for example the Alport Syndrome Foundation who currently run an excellent programme of seed funding for Alport research, commissioning projects each year
- How Alport Syndrome is a model renal disease and that new treatments developed for Alport Syndrome could help other patients living with renal disease.

In 2019, to check on the performance of our investment to get researchers together through these workshops, alport uk circulated a simple survey with the Workshop Organising Committee members and their research teams (ie not the full Alport research community, just some of the key members) to understand the impact of the international workshops, emphasis on collaboration and how much research is now being done. Overall, the numbers indicate a very healthy research community to whom we are incredibly grateful for all they do to help with the awareness and understanding of Alport Syndrome by delivering:

- 131 publications with the majority in international journals
- 18 book chapters
- 38 major grants to fund the ongoing research.
- over 90% of the projects and publications were collaborative efforts.

These survey results confirmed to alport uk that our efforts to drive collaboration and accelerate research are delivering the results we need.

To continue the collaborative international workshops in Oxford (2014) Göttingen, Germany (2015), Glasgow, Scotland (2017), and Siena, Italy (2019), alport uk started work on a fifth workshop in the series: **The 2021 Online International Workshop for Alport Syndrome**. The aim was to make the online workshop over a week as accessible to as many people around the world as possible whether they be patients, clinicians, early career researchers etc. The planning started in earnest over the summer to get the workshop programme ready for a week-long workshop online in November 2021. alport uk restarted the conference calls with the international workshop organising committee to share progress, keep the

researchers engaged in delivering the agenda in a number of key areas such as genetics, pathology (as there is an increasing interest in this area), clinical guidelines, registries and basic science. Rather than run the Zoom sessions themselves, alport uk researched getting a production company involved to make sure the workshop planning and delivery was as professional as the in-person workshops.

### **Support of a UK research registry**

In parallel to alport uk being set up, the Renal Association established a working group on Alport Syndrome, funded jointly by Kidney Research UK and Kidney Care (previously British Kidney Patient Association) to support the development of a national renal registry of patients, called RaDaR. RaDaR is linked to a system that patients can access, called Renal Patient View. Some of the trustees from alport uk contribute to the working group on an ongoing basis to devise ways of promoting RADAR to patients and clinicians across the UK to increase the number of patients and patient records online as this will provide invaluable data for research to understand the natural history of Alport Syndrome. At the time of writing, RaDaR has over 1,000 patients registered (compared with the 800 registered in the previous year) as having Alport Syndrome and with some clinical data going back 30 years. alport uk specifically contribute to the support of this UK research registry of patients and an international alliance of patient registries by:

- Promoting the importance of RaDaR and Renal Patient View to patients at Alport information days, along with information about the value of RaDaR to research.
- Making the research registry a central part of the national contribution to international efforts to collaborate on research coming out of the 2014, 2015, 2017 and 2019 International Workshops on Alport Syndrome and proposing to make it one of the key topics for 2021.
- Continuing the development of the UK's contribution to an international alliance of Alport Syndrome research. An 'alliance' is necessary as there are not enough patients in the UK for Clinical trials and so pharmaceutical companies will want to do trials in a number of different countries to try new therapies. alport uk enlisted the help of designer Robina Newman to develop the branding for the Alport Syndrome Alliance and apply it to a new website built by Alice Cooper to simplify the registration process for participants for The 2021 Online International workshop on Alport Syndrome. The plans for this workshop planned November 2021 (in the next financial year) are to double the number of participants, compared with previous years, applying to join the international workshop and with the encouragement of other national patient organisations, especially across Europe to build the Alport Syndrome Alliance to help the Alport community act as one global network focused on treatments and knowledge, with one voice.

If anyone reading this annual report is interested in more information or to get involved or support us with activities or fund raising, please email Susie Gear and Alice Cooper at [info@alportuk.org](mailto:info@alportuk.org) or call us on 01793 847264.

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

Reserves from fundraising are kept in separate Barclays bank savings accounts, labelled for their specific use and to make sure restricted and unrestricted funds are used appropriately. For example, for:

- **Information days** (Alport UK Meetings)
- **Development of information, website and marketing material** (Alport UK)
- **Facilitating the International Workshops on Alport Syndrome** (Alport UK Research)
- **Supporting patients take up a new sport or activity** (Don't Wait Fund)

### Details of any funds materially in deficit

No funds in deficit

### Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

alport uk's principal sources of funds this year were, despite the pandemic, again more diverse than in the previous year:

- Personal donations – limited this year
- Limited personal fund-raising activities such as online sports activities such as the virtual KiltWalk in Scotland.
- Just Giving and Virgin Money Giving pages of sponsorship for various activities that our community get involved in to raise funds for alport uk – this year Sam Clarke's amazing efforts increased the money raised to over £20,000 for a new fund we will call the 'Don't Wait Fund' to support patients taking up a new sport or hobby.
- Social media fundraising pages eg Facebook giving for birthdays
- PayPal and Amazon payments/donations to Alport UK
- Sales of Christmas cards and a wider variety of merchandise such as hoodies, t-shirts, water bottles etc
- Standing orders from a couple of very supportive patient families
- Customised shaking tins located in retail venues
- Donations from larger charities or foundations for specific activities and particular thanks to Kidney Care UK, Kidney Research UK
- Donations from Pears DCMS (two separate donations) and The Worshipful Company of Dyers

Grants given by a number of pharmaceutical companies: alport uk are very grateful to the support from Sanofi Genzyme.

One of our Trustees loaned us a sum to partly fund the next stage of the healthtalk.org project and a number of expenses incurred in the early stages of the charity. The loan is interest free and there is no deadline to pay it back, just when funds are available.

As funds were all allocated to specific activities that support our key objectives this year, there was no opportunity for investment during this accounting period.

## Section F

## Other optional information

None

# Alport UK

## Report and Financial Statement For the year ended 31<sup>st</sup> July 2021

Charity number: 1154774

Shilton Accounting Services  
1<sup>st</sup> Floor, 1 The Clock House  
Brize Norton Road  
Carterton  
OX18 3HN

**Alport UK**  
**Charity number: 1154774**  
**Legal and administrative information**

|                                 |                                                                                                                                                           |
|---------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|
| Charity name:                   | Alport UK                                                                                                                                                 |
| Charity registration number:    | 1154774                                                                                                                                                   |
| Type of organisation:           | Charitable Unincorporated Organisation                                                                                                                    |
| Registered office and business: | P O Box 329<br>Cirencester<br>Gloucestershire<br>GL7 9JA                                                                                                  |
| Trustees:                       | Colin Baigent<br>Jules Skelding<br>Susie Gear<br>Frances Flinter<br>Rachel Lennon<br>Danny Gale<br>Neil Turner<br>Amanda and Tim McLean                   |
| Accountants:                    | Shilton Accounting Services<br>Certified Practising Accountants<br>1 <sup>st</sup> Floor, 1 The Clock House<br>Brize Norton Road<br>Carterton<br>OX18 3HN |

**Alport UK**  
**Charity number: 1154774**  
**Independent Examiner's report to the Trustees of Alport UK**

I report on the accounts of the Charity for the year ended 31<sup>st</sup> July 2021 which are set out below.

**Respective responsibilities of trustees and examiner.**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under section 43(2) of the Charities Act 1993 (the 1993 Act) and that an independent examination is needed.

It is my responsibility to:

- a) Examine the accounts (under section 43(7)(b) of the Act.
- b) To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 43(7)(b) of the Act.
- c) To state whether particular matters have come to my attention.

**Basis of independent examiner's report.**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence which would be required in an audit and consequently I do not express an audit opinion on the accounts.

**Independent examiner's statement.**

In connection with my examination, **no** matter has come to my attention

1. Which gives me reasonable cause to believe that in any material respect, the requirements of a) to keep proper accounting records in accordance with section 41 of the 1993 Act and b) to prepare accounts which accord with the accounting records and to comply with the requirements of the Act, have not been met.
2. To which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

David Cuthbertson – ICPA Cert Acc (Open)  
Shilton Accounting Services  
Honeystone Cottage  
Ladburn Lane  
Shilton  
OX18 4AJ  
20<sup>th</sup> April 2022

**Alport UK**  
**Charity number: 1154774**  
**Director's report for the year ended 31<sup>st</sup> July 2021**

The trustees present their report and financial statement for the year ended 31<sup>st</sup> July 2021.

**Objects** – The relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- a) The establishment and facilitation of a support network for Alport Syndrome patients, carriers, their families and carers;
- b) The provision of information on Alport Syndrome;
- c) The support of research into Alport Syndrome both in the UK and internationally;
- d) The support of a research registry in the UK and an international alliance of national registers.

**Governing document** – the charity is governed by a constitution based upon a Charity Commission document that was adopted on 27<sup>th</sup> November 2013. A copy of the full governing document can be obtained from the charity.

**Trustees** - The overall responsibility of the organisation rests with the Board of Trustees. The selection of Trustees is designed to supplement the existing skills and expertise of the board and is governed by an informal skills assessment. The appointment of trustees is made in accordance with the constitution.

**Risk assessment** – Disclosure and Barring checks are carried out for all appropriate trustees, staff and volunteers. The Trustees have examined the major strategies, business and operational risks which the charity faces and confirm that systems have been established to enable regular reports to be produced so that the necessary steps can be taken to minimise these risks.

**Public benefit statement** – Alport UK is a patient-led organisation dedicated to facilitating a support and information network for all those affected by Alport Syndrome. Our vision is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life. This creates public benefits in health and community cohesion.

**Reserves policy** – The Trustees are actively trying to build reserves, with a view to being able to fund further research and to strengthen its support structure.

This report was approved by the Trustees on 13 June 2022 and signed on its behalf by



**Susie Gear**

**Alport UK**  
**Charity number 115774**

**Statement of Financial Activities (including Income & expenditure Account)**  
**For the year ended 31<sup>st</sup> July 2021**

|                          | Restricted     | Unrestricted   | Total for 2021  | 2020           |
|--------------------------|----------------|----------------|-----------------|----------------|
| <b>Income</b>            |                |                |                 |                |
| Donations/Sponsors       | 2,335          | 32,859         | 35,194          | 53,480         |
| Delegate fees            |                |                |                 | 17,060         |
| Fundraising/merchandise  |                | 3,048          | 3,048           | 164            |
| Gift Aid refunds         |                | 620            | 620             | 402            |
| Exchange gains/losses    |                | (1,419)        | (1,419)         | 228            |
| <b>Total Income</b>      | <b>2,335</b>   | <b>35,108</b>  | <b>37,443</b>   | <b>71,335</b>  |
| <b>Expenditure</b>       |                |                |                 |                |
| Employee costs           | 14,328         | 1,202          | 15,530          |                |
| Bank & service charges   | 3              | 119            | 122             | 683            |
| Direct Events costs      |                |                |                 | 45,057         |
| Branded goods            |                | 14,556         | 14,556          |                |
| Administration           | 3,948          | 810            | 4,758           | 12,723         |
| Travel & subsistence     |                | 1,012          | 1,012           | 14,272         |
| Internet/website         |                | 1,235          | 1,235           | 2,026          |
| Marketing                |                | 300            | 300             | 247            |
| Insurance                |                | 672            | 672             | 672            |
| Subscriptions            |                | 2,301          | 2,301           | 282            |
| Bursaries/grants         | 329            |                | 329             | 474            |
| Others                   | 94             | 5,359          | 5,453           | 219            |
| <b>Governance costs</b>  |                |                |                 |                |
| DBS/ Training            |                | 232            | 232             | 391            |
| Accountants' fees        |                | 1,256          | 1,256           | 960            |
| <b>Total Expenditure</b> | <b>18,702</b>  | <b>29,054</b>  | <b>47,756</b>   | <b>78,005</b>  |
| <b>Transfers</b>         | 9,700          | (9,700)        | -               |                |
| <b>Net Movement</b>      | <b>(6,667)</b> | <b>(3,646)</b> | <b>(10,313)</b> | <b>(6,671)</b> |
| <b>Opening Balance</b>   | 9,672          | 50,872         | 60,544          | 67,215         |
| <b>Closing Balance</b>   | <b>3,005</b>   | <b>47,226</b>  | <b>50,231</b>   | <b>60,544</b>  |

There are no recognised gains or losses other than in the Statement of Financial Activity.

**Alport UK**  
Charity number 115774

**Balance Sheet as at 31<sup>st</sup> July 2021**

|                                            | Notes | 2021   | 2020   |
|--------------------------------------------|-------|--------|--------|
|                                            |       | £      | £      |
| <b>Fixed assets</b>                        |       | -      | -      |
|                                            |       |        |        |
| <b>Current assets</b>                      |       |        |        |
| <i>Cash at bank</i>                        | 4     | 51,415 | 62,464 |
|                                            |       |        |        |
| <b>Total Current assets</b>                |       |        |        |
|                                            |       |        |        |
| <b>Current liabilities</b>                 |       |        |        |
| <i>Creditors falling due within 1 year</i> | 5     | 1,184  | 1,920  |
|                                            |       |        |        |
| <b>Net current assets</b>                  |       | 50,231 | 60,544 |
|                                            |       |        |        |
| <b>Assets less liabilities</b>             |       | 50,231 | 60,544 |
|                                            |       |        |        |
| <b>Represented by</b>                      |       |        |        |
| <i>Restricted funds</i>                    |       | 3,005  | 11,043 |
| <i>Unrestricted funds</i>                  |       | 47,226 | 49,501 |
|                                            |       |        |        |
| <b>Total funds</b>                         | 6     | 50,231 | 60,544 |
|                                            |       |        |        |

**Signed on behalf of the charity's trustees**



**Date: 13 June 2022**

**Notes to the financial statements**

**For the year ending 31<sup>st</sup> July 2021.**

**1. Accounting policies**

**a. Basis of accounting**

The financial statements have been prepared under the historic cost convention with items recognised at cost or transaction value unless otherwise state in the relevant notes to these accounts. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and reporting by Charities preparing their accounts in accordance with Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS102) issued on 16<sup>th</sup> July 2014 and the Charities Act 2011. The trust constitutes a public benefit entity as defined by FRS102.

**b. Going concern**

The trustees consider that there are no material uncertainties about the trust's ability to continue as a going concern.

**c. Fund accounting**

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

**d. Income resources**

All incoming resources are included in the statement of financial activities when the charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of financial activities when receivable.

Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes entitled to the grant.

Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by volunteers has not been included in these accounts.

Investment income is included when receivable.

Income resources from charitable trading activity are accounted for when earned.

**Notes to the financial statements**

**For the year ending 31<sup>st</sup> July 2021.**

**e. Resources expended**

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

Costs of generating funds comprise of the costs associated with attracting voluntary income and costs of trading for fund raising purposes.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include accountancy and legal fees.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resources. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

**2. Staff costs**

The charity employed one member of staff in the financial year.

**3. Trustee remuneration & related party transactions.**

The trustees all give freely of their time and expertise without any remuneration or other benefit in kind. Expenses incurred on behalf of the charity are reimbursed at cost.

**Alport UK**  
**Charity number: 1154774**

**Notes to the financial statements**  
**For the year ending 31<sup>st</sup> July 2021.**

**4. Cash at bank.**

|                                      |                |
|--------------------------------------|----------------|
| Barclays General Account 93696405    | £25,833        |
| Barclays Research Account 93725642   | £781           |
| Barclays Meeting Account 83477436    | £0             |
| Barclays Don't wait Account 33742210 | £2,224         |
| Caxton FX                            | £22,577        |
| PayPal                               | £0             |
| <b>Total</b>                         | <b>£51,415</b> |

**5. Creditors: Amounts falling due within one year**

Accounting fee accrual £1184.00

**6. Movement in funds**

|              | Opening<br>balance | Incoming<br>resources | Outgoing<br>resources | Balance<br>31 <sup>st</sup> July 2021 |
|--------------|--------------------|-----------------------|-----------------------|---------------------------------------|
| Restricted   | £9,672             | £12,035               | £18,702               | £3,005                                |
| Unrestricted | £50,872            | £35,108               | £38,754               | £47,226                               |
| <b>Total</b> | <b>£60,544</b>     | <b>£37,443</b>        | <b>£47,756</b>        | <b>£50,231</b>                        |

**ALPORT UK**

England & Wales - Charity number 1154774

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# Accounts

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# ANNUAL REPORT AND ACCOUNTS



**a brighter future** for people living with alport syndrome

For the year ended 31 July 2020



## Trustees' Annual Report for the period

| Period start date |          | Period end date |           |
|-------------------|----------|-----------------|-----------|
| <b>From</b>       | 1 8 2019 | <b>To</b>       | 31 7 2020 |

### Section A Reference and administration details

**Charity name** alport uk

**Other names charity is known by** n/a

**Registered charity number (if any)** 1154774

**Charity's principal address** PO Box 329

Cirencester

**Postcode** GL7 9JA

#### Names of the charity trustees who manage the charity

|   | Trustee name    | Office (if any) | Dates acted if not for whole year | Name of person (or body) entitled to appoint trustee (if any) |
|---|-----------------|-----------------|-----------------------------------|---------------------------------------------------------------|
| 1 | Colin Baigent   |                 | Whole year                        |                                                               |
| 2 | Julia Skelding  |                 | Whole year                        |                                                               |
| 3 | Susie Gear      | Chief Executive | Whole year                        |                                                               |
| 4 | Frances Flinter |                 | Whole year                        |                                                               |
| 5 | Rachel Lennon   |                 | Whole year                        |                                                               |
| 6 | Neil Turner     |                 | Whole year                        |                                                               |
| 7 | Danny Gale      |                 | Whole year                        |                                                               |

#### Names of the trustees for the charity, if any, (for example, any custodian trustees)

| Name | Dates acted if not for whole year |
|------|-----------------------------------|
| n/a  |                                   |
|      |                                   |
|      |                                   |

#### Names and addresses of advisers (Optional information)

See table of Advisors over the page

| Type of adviser                                                                 | Name                      | Address                                                                                                                                                                          |
|---------------------------------------------------------------------------------|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Medical – paediatric nephrologist</b>                                        | Professor Rachel Lennon   | Royal Manchester Children's Hospital, Oxford Road, Manchester M13 9WL                                                                                                            |
| <b>Medical – adult nephrologist</b>                                             | Professor Neil Turner     | University of Edinburgh Renal and Autoimmunity Group, MRC Centre for Inflammation, Queen's Medical Research Institute, Little France, Edinburgh, EH16 4TJ                        |
| <b>Geneticist</b>                                                               | Professor Frances Flinter | Emeritus Professor of Clinical Genetics, Guy's & St Thomas' NHS Foundation Trust<br>Genetics Department, 7th floor Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT |
| <b>Eye specialist</b>                                                           | Dr Omar Mahroo            | St Thomas' Hospital Campus, 3rd Floor South Wing Block D, Westminster Bridge Road, London SE1 7EH                                                                                |
| <b>PR, Communication and Marketing</b>                                          | Jane Keightley            | JK Branding and Communications Limited                                                                                                                                           |
| <b>Accountant</b>                                                               | David Cuthbertson         | Shilton Accounting Services Ltd                                                                                                                                                  |
| Name of chief executive or names of senior staff members (Optional information) |                           |                                                                                                                                                                                  |
| Susie Gear, Chief Executive                                                     |                           |                                                                                                                                                                                  |
|                                                                                 |                           |                                                                                                                                                                                  |

## Section B Structure, governance and management

### Description of the charity's trusts

|                                                                     |                                                                                                               |
|---------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| Type of governing document<br>(eg. trust deed, constitution)        | Constitution                                                                                                  |
| How the charity is constituted<br>(eg. trust, association, company) | Charitable Incorporated Organisation                                                                          |
| Trustee selection methods<br>(eg. appointed by, elected by)         | Appointed for a term of 3 years by a resolution passed at a properly convened meeting of the Charity Trustees |

### Additional governance issues (Optional information)

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>You <b>may choose</b> to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> <li>• policies and procedures adopted for the induction and training of trustees;</li> <li>• the charity's organisational structure and any wider network with which the charity works;</li> <li>• relationship with any related parties;</li> <li>• trustees' consideration of major risks and the system and procedures to manage them.</li> </ul> | <p>Policies and procedures for the induction and training of trustees</p> <ul style="list-style-type: none"> <li>• Provided with a guide for how the charity operates – this now includes a set of policies on topics such as expenses, relationship with pharmaceutical companies, sponsorship etc.</li> <li>• Disclosure and Barring checks</li> <li>• Given a briefing on the charity and engaged in activities to enable them to participate fully in the decisions of the charity.</li> </ul> <p>Organisational structure of the charity and wider network</p> <ul style="list-style-type: none"> <li>• We are a small charity and so have a very flat organisational structure.</li> <li>• Day-to-day activities are run by one of the trustees – Susie Gear with a number of volunteers. All day-to-day decisions are jointly taken with at least one of the other Trustees eg Julia Skelding, Professor Frances Flinter or Professor Rachel Lennon. If we need to check any of the decisions, we involve the other trustees - who are less involved in the day-to-day activities and so provide excellent challenge and objectivity.</li> <li>• Our closed Facebook page, Alport Warriors is moderated day-to-day by one of our volunteers – Wilma Calderwood – with back up from Jules Skelding and Susie Gear and with any specific medical questions answered by our medical advisory team – see list above.</li> </ul> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

- Our public facing social media eg Facebook and Instagram pages are run by Susie Gear and some of the younger Alport Warriors.
- Alport UK's Scientific Advisory Committee provide expert medical input and advice as required: Professor Colin Baigent (Strategic direction of research and Clinical trials), Professor Frances Flinter (Clinical and particularly Genetics and diagnoses), Professor Danny Gale (Rare Renal Database RaDaR and Clinical trials), Professor Rachel Lennon (Paediatric Nephrology, Podocyte research and clinical guidelines) and Professor Neil Turner (Adult Nephrology and RaDaR).
- Alport UK's international Workshop Organising Committee is made up of a wide range of experts – researchers, clinicians, academics and Alport patients – with representation from all over the world.

Trustees' consideration of the major risks & procedures to manage them:

- **Support** – as we support patients and family members living with Alport Syndrome, there can be specific questions or situations that require medical advice or input. We have a scientific advisory committee which is available, whenever required, to provide expert medical input and advice to patients and their families. All committee members are practising/retired clinicians in the NHS and are recognised internationally for their experience and expertise. We also have a wider network of international experts from whom we can get additional opinions, as required. As we support a number of young adults and vulnerable adults, we have a Safeguarding Officer, who we consult if there are any safeguarding concerns.
- **Information** – all the information and recommendations published on our website, [alportuk.org](http://alportuk.org), is reviewed by members of our scientific advisory committee.
- **Research** – all projects we embark on are reviewed by members of our scientific advisory committee and we get input from a wider network of international experts, as required. This includes assessing clinical trials and although, as a charity, we never recommend participation in a trial, we will provide as much information as possible to support patients' decisions on participating in a trial, publishing views in international publications, as necessary.
- **Collaboration** – is a core way of working for our charity. We collaborate with other national patient organisations and an international scientific community interested in research into Alport Syndrome. We run monthly conference calls and a series of international workshops for all involved to keep in touch with progress. Funds for these international research activities are kept in a separate bank account so that the expenditure is transparent to maintain the open collaborative working environment. To ensure all appropriate risks are managed related to this collaboration, we have set up an international Workshop Organising committee to ensure there is a balance of work and information from or relating to different countries or continents.
- **Fundraising, finances and projects** – As a small charity, we fundraise for specific projects and these funds are kept in separate bank accounts 'ring-fenced' for each project. The majority of our fundraising is through applications to larger charities that support small charities, such as ours, with funds allocated for specific activities, such as the information days or international workshops undertaken by alport uk. Increasingly, we also seek funding for work from pharmaceutical companies. We aim to raise collaborative funding for any project, so we are not reliant on one company for project funding which also means Alport UK is not associated with one company for one particular project.

**Summary of the objects of the charity set out in its governing document**

**Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)**

The objects of the CIO are the relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- The establishment and facilitation of **a support network** for Alport Syndrome patients, carriers, their families and carers;
- The **provision of information** on Alport Syndrome;
- The **support of research** into Alport Syndrome both in the UK and internationally;
- The **support of a research registry in the UK** and an international alliance of national registries

**Public benefit – statutory declaration by Trustees**

The Trustees have paid due regard to the Charity Commission's guidance on public benefit in deciding what activities the charity should undertake. alport uk recognises and welcomes the need to carry out its charitable activities to the benefit of those affected by Alport Syndrome, and retains this aim at the centre of its strategic planning.

**alport uk is a patient-led organisation** dedicated to facilitating a support and information network for all those affected by Alport Syndrome.

**Alport Syndrome** is an inherited condition that can cause kidney failure, deafness and eye abnormalities. Those that inherit it will probably require a kidney transplant when they are young adults. It can impact a large number of people in a family. It is the second most common form of inherited kidney disease. Meet Sam to understand the impact it has on a family: <https://sam-clarke.com/fighting-failure-challenge/>.

**Our Vision** is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life.

**Our Mission** is to work in partnership with individuals, families and the scientific community to:

- Facilitate a **support** network for patients and families
- Be a conduit for high quality, accessible **information**
- **Raise the profile** of Alport Syndrome in the scientific community
- Contribute to the international **research** agenda
- **Collaborate** on the development of a UK patient registry and alliance of international patient registries.

**alport UK fund four key areas of activity**

1. **Support** – Providing support for UK patients and families through a support network, website and information days.
2. **Information** – Working with clinicians, individuals and families to educate them on more effective diagnosis and treatment, for example national guidelines for diagnosis, treatment and the best care for children, teenagers and adults.
3. **Research** – Working with other national patient organisations (eg USA, across Europe and Asia) and clinicians to design, develop and maintain an international research strategy and plan for Alport Syndrome, supported by an alliance of national patient organisations and national patient registries
4. **Collaboration** – Bringing together the scientific community to work

across the different clinical disciplines that specialise in kidneys, ears, eyes, mental health, other rare disease areas with similar issues etc. and working with the national patient organisations or other rare renal disease groups to share best practice with developed and developing countries.

The activities of alport uk are grounded in the local communities across the UK as we aim to connect up regional groups of individuals and families that are affected by Alport Syndrome. As the possible 2-3,000 individuals impacted in the UK is a small group if looked at on their own, this requires the charity to work internationally with other national patient organisations and clinicians to co-ordinate activities and research across a far bigger group of patients, particularly those with 10,000 or 100,000 patients in countries such as USA and China.

#### **Additional details of objectives and activities (Optional information)**

You **may choose** to include further statements, where relevant, about:

- policy on grant making;
- policy programme related investment;
- contribution made by volunteers.

## Contribution by volunteers

**Alport UK mostly relied on voluntary help to run the activities over this period as for the previous seven years. Our community often reflect and remark the journey we've been on and the remarkable progress Alport UK makes and their ability to support patients and deliver professional international events that appeal to all stakeholders.**

**We are incredibly grateful to the volunteers for this remarkable progress, especially for the many contributions from the following key and very motivated people:**

- **Wilma Calderwood** for her day-to-day moderation on our closed Facebook page, Alports Warriors, which saw the community double in size during the pandemic.
- **Sam Clarke** for cycling an incredible 4,776.02 miles around Europe, and raising over £20,000 to raise awareness of Alport Syndrome and funds for the 'Don't Wait Fund' to support patients with Alport Syndrome take up a new activity or hobby. Sam managed to cycle from Henley-on-Thames to Albania as the pandemic took hold across Europe. Ingeniously, once back in the UK he then set off from Lands End to John O'Groats to add to the kilometres and continue the challenge. Adventure Man Sam even has his own YouTube channel to share the exciting adventure on his bike and his experiences of living with Alport Syndrome:  
<https://www.youtube.com/channel/UCQJsO-IW8UvINcqHZU5gXAq>.
- **Alice Turner** for her tireless energy, enthusiasm and fundraising work, ideas and help with running Alport UK and supporting what fundraising activities could be done during the pandemic and for keeping us all positive during a very worrying year. Alice also has a forensic knack of putting our annual accounts together and tracking down all receipts and invoices to make the accountant's role much easier as he prepares the annual accounts.
- **Anna Mackay** for working with us remotely, whilst based in Portugal, to develop ideas for the Alport Syndrome Alliance, explore contacts in Sweden and be the main operational support co-ordinating speakers and moderators for The 2019 International workshop on Alport Syndrome in Italy. She kept us smiling and the workshop ran incredibly smoothly.
- **Rebecca Moule** for volunteering for us for a number of months, whilst on furlough. Rebecca set up the process and recruited the team to run the Alport Online Workshops during the pandemic and she came to Siena to run the logistics for the workshop. Working with Anna Mackay and the local team in Siena, the workshop ran without a hitch and everyone loved every aspect of it as Rebecca had thought of every detail and had back up strategies for any issues.
- **Carole Taylor**, the grand-daughter of Cecil Alport who kindly made contact with us and set up a campaign, using social media to raise awareness of Alport Syndrome using Verses for Alport ([versesforalport.com](http://versesforalport.com)) and capturing fun rhymes and light-hearted poems on a number of topics.
- **All those who raised money for us this year** – every penny makes a difference and this year people were very limited with what they could do to raise funds and increase our income. Particular thanks to:
  - **The Matthews family** who asked for donations to Alport UK in memory of Mrs Sonja Sinclair.
  - **Sarah Forrester and the Committee of the 2019 Kick Up Your Heels** gathering in Cirencester.
- **And a number of people who wish to remain anonymous** but to whom we are very grateful for their support and encouragement.

**We wish to thank our Scientific Advisory Committee** for fitting in so much time this year particularly to advise us on how to support the community as the pandemic took hold whilst they were all also very busy on clinical wards helping with renal issues. They answered all queries within 24 hours, ensuring the community remained as calm as possible at such a worrying time for renal patients. This amazing contribution was also having already given us a lot of their time in the previous year helping us prepare for and deliver The 2019 International Workshop on Alport Syndrome (which took place in Siena Italy 22-24 October 2019). We are so very grateful to the scientific community for their help to answer all questions and emails as and when they arose from patients or other scientists. Very many thanks to our UK Scientific Advisory Group:

- **Professor Frances Flinter**
- **Professor Danny Gale**
- **Professor Rachel Lennon**
- **Dr Omar Mahroo**
- **Professor Neil Turner.**

**Alport online workshops** – during the pandemic, we were overwhelmed with additional help from people who chose to volunteer for alport uk whilst stuck at home unable to work or go into the lab. A small working group of volunteers was formed which included: **Rebecca Moule** and **Harriet Carter** (who both volunteered for us whilst on furlough), **Susie Gear**, **Louise Hopkinson**, **Professor Rachel Lennon**, **Professor Jeffrey Miner**, **Sophie Emler** and **Richard Naylor**. We are so grateful for the quick thinking and inspiration from this group who together came up with the idea of running a series of **Alport online workshops**, using Zoom, which were provided for the international Alport community (patients and scientists) by Alport UK and with set up costs kindly funded by Kidney Research UK and special thanks to **Sandra Currie** for quickly realising the value of the opportunity for patients.

**We are so grateful to the amazing team – all volunteers - who helped us run and deliver** The 2019 International workshop on Alport Syndrome in Siena, Italy:

- **Alessandra Renieri, Chiara Fallerini and the team at the Molecular Genetics Unit at Siena University** for hosting the workshop with special thanks to **Professor Alessandra Renieri** the Programme content lead, for making it a very exciting agenda focused on Genetics and gene therapy.
- **A. S. A. L. Onlus (Italian Alport patient organisation)** for jointly hosting the patient meeting in Siena in advance of the workshop and for getting 50 Italian patients there including some young people who contributed to the activities of the Media team.
- **Professor Frances Flinter** for being counsel on the preparation of the scientific agenda and running of the workshop.
- **Rebecca Moule** for stepping in to organise and run the logistics.
- **Anna Mackay** for organising all the slides and speakers.
- **Sam Clarke and Remy Archer** for filming the workshop and Sam Clarke for producing two excellent videos to explain what we do and the outcomes at an international workshop.
- **Patrick Walker, Ceri Harrop and Kory Stout** for organising the Media team with the local Italian patient team and for helping the patients write, illustrate and produce a video about new treatments in Alport Syndrome in English, Italian and Chinese!
- **Aura Zealey, Reema Hassan, Noor Hassan, Hashim Hassan** for working together as the Media team with the local Italian patients at the workshop to promote the outcomes of the workshop.

- **Mary Lou McCarthy** for an incredible photographic record of the workshop, including lovely photos of all the speakers and activities.
- **Eleanor Beer** and **Sandra Howgate** for their graphic recording of the workshop.
- **Sophie Bell** for supporting us with the logistics for the The 2019 International workshop.

We wish to thank the Workshop Organising Committee (see list below) for helping us to design and deliver **The 2019 International Workshop on Alport Syndrome**. We are also grateful to our colleagues who run some of the other national patient organisations, such as **Andre Weinstock** (Alport Syndrome Foundation, USA), **Jacqueline van Kempen** (The Netherlands), **Maria José Cacharron** (Spain) and **Daniela Lai** (Italy), **Jessie Zhang and Mr Cai** (China), **Christof Finkler** and **Ute Rosenthal** (Germany), **Dave Blatt** (Australia).

#### **Workshop Organising Committee**

##### **for The 2019 International workshop on Alport Syndrome:**

**Professor Colin Baigent**, MRC Scientist, Hon Consultant in Public Health, Oxford, UK

**Professor Constantinos Deltas**, University of Cyprus, Molecular Medicine Research Center, Nicosia, Cyprus

**Professor Jie Ding**, Department of Pediatrics, Peking University First Hospital, Beijing, China

**Professor Frances Flinter**, Consultant in Clinical Genetics, Guy's Hospital, London, UK

**Professor Daniel Gale**, UCL Centre for Nephrology, London, UK

**Professor Oliver Gross**, Department of Nephrology and Rheumatology, Georg-August-Universität Göttingen, Germany

**Professor Clifford Kashtan**, Department of Pediatrics, University of Minnesota, USA

**Professor Bertrand Knebelman**, Necker Hospital, Paris, France

**Professor Rachel Lennon**, Wellcome Trust Centre for Cell-Matrix Research, University of Manchester, UK

**Associate Professor Julian Midgley**, Department of Paediatrics, Alberta Children's Hospital, Canada

**Professor Jeffrey Miner**, Washington University in St. Louis, USA

**Dr Laura Perin**, Saban Research Institute, University of Southern California, USA

**Professor Judith Savige**, University of Melbourne, Australia

**Professor Alessandra Renieri**, Professor of Medical Genetics, Director of Medical Genetics Unit, Azienda Ospedaliera Universitaria Senese viale Bracci 2, Siena, Italy

**Associate Professor Michelle Rheault**, Department of Pediatrics, University of Minnesota, USA

**Professor Roser Torra**, Fundació Puigvert, Barcelona, Spain

**Professor Neil Turner**, Professor of Nephrology, University of Edinburgh and Consultant Nephrologist, Royal Infirmary of Edinburgh, UK.

#### **Patient representatives:**

**Dave Blatt**, Alport Foundation of Australia

**Maria José Cacharron**, Spain

**Susie Gear**, alport uk

**Andre Weinstock**, Alport Syndrome Foundation, USA

**Daniela Lai**, A.S.A.L., Associazione Sindrome di Alport, Italy

**Julia Schifter**, Alport Foundation Israel

**Christof Finkler**, Alport Selbsthilfe, Germany

**Jessie Zhang and Mr Cai**, Chinese patient group, China.

**We also very much value the funding and support of a number of important organisations and charities:**

- **Kidney Care** (was British Kidney Patient Association) for advice and support, particularly through the pandemic.
- **Kidney Research UK** - with specific thanks to **Sandra Currie** and colleagues for so quickly approving a grant to pay for Alport UK's Zoom webinar subscription when the pandemic hit. We were so grateful to them for recognising we needed urgent help and for their continued support at a time when their own funds became very limited and they had to review their own operations.
- **Alport Syndrome Foundation (USA)** – with specific thanks to Andre Weinstock and Janine Diebel for their continued collaboration on the international research agenda out at the 2019 international workshop in Siena and Joy Toal particularly for connecting and sharing her experience to support patients on Alport Warriors during the pandemic.
- **A couple of charities who wish to remain anonymous** for both their financial support and advice which is very much appreciated.

There are also a number of people we would like to recognise for their contributions to our projects. Although we pay them for the project work they do, each has given way more time and ideas than they charge us for. Their continued support we very much appreciate:

- **Eleanor Beer** and **Sandra Howgate** – translate the complex scientific information into easy-to-understand graphics.
- **Jane Keightley** – for her marketing advice and on-going support to build the brand of Alport UK to raise its' profile along with communicating and engaging people in our aims and objectives and core activities. We also very much appreciate Jane's writing and editorial advice that sets the written tone for all our communications.
- **Robina Newman** – for her thoughtful brand and design work on various materials and generally helping us to create a bright and distinctive identity that sets the visual tone for our activities.
- **Clare Charrington** – for her organisation and administrative support running alport uk.
- **Sylvie Lloyd** – for her analytical work on researching the potential background and structures for an Alport Syndrome Alliance.
- **Davina Liddell** – for her administrative work in preparing us for the 2019 international workshop and the analysis of the feedback after it.
- **Penny Norrie** – for her work in helping us prepare the materials for the 2019 international workshop.
- **Harriet Carter** – who so ably then ran the process to deliver the series of Alport Online workshops once her furlough ended.

### Summary of the main achievements of the charity during the year

The achievements of alport uk this year build from last year and are summarised under the headings of our key objectives and areas of activity below. Overall, our main outcome is to create a more positive and brighter future for individuals and families living with Alport Syndrome. Being a rare and therefore small community, we aim to deliver sustainable strategic change for Alport Syndrome, using virtual networks and limited resources to effectively support patients and develop treatments for Alport Syndrome. Positivity is the main ingredient for all the support we offer – we aim to inspire and encourage people living with Alport Syndrome to be optimistic and understand there can be a brighter future.

Measuring our performance and listening to patient feedback on what works and adjusting what we do is vital: **Parents with a young daughter recently diagnosed with Alport Syndrome:** *“...always hugely impressed with you and the team for effort, organization, enthusiasm, info, results etc – well done it is so appreciated by us all out in the Alport community!”*

### The philosophy that underpins our performance

The Six Pillars of Wellbeing – long established as framework to think about mental health and wellbeing - is a useful structure to encourage positive outcomes for individuals and families living with Alport Syndrome. The Six Pillars that inspire our activities:

- **Stress management** – keeping the community calm and informed with the latest information, so they can become more independent, strong and resilient over time
- **Nutrition** – inspiring the community to eat healthily to protect their kidneys for as long as possible and when on restricted diet, explore new foods they can eat
- **Community** – connect to reduce the feeling of isolation caused by having a rare disease that few others either know or understand
- **Sleep** – ensure the community members can have a routine with good sleep to enable them to deal with the rollercoaster journey that some individuals and families face as part of living with a rare disease and coping with critical events along the way, such as hearing declining, kidney failure and eye issues.
- **Exercise** – we know cardio vascular exercise is good for the kidneys. It is also vital to rebalance the chemical impact brought on by the feeling of anxiety that overwhelms some patients living with the fact that their kidneys may fail at some unknown time in the future
- **Meaningful activity** – encourage individuals, families and researchers to connect around a shared objective of helping our community in some way, whether it be volunteering for our community, advocating, fundraising, collaborating on research or useful information or sharing stories to help others living with Alport Syndrome.

### As a tiny charity we are very clear what we can do

Supporting a rare disease that impacts 1 in 10,000 in a population is a challenge as there are few people who have it, who want to research it or fund it. So as a charity we think wisely about how we use our strengths, capabilities and resources and how to collaborate to complement these. Our volunteers have strong capabilities in delivering commercial innovation and collaboration across virtual networks of international

stakeholders around the world. Some examples of the principles that guide what we do in five key areas of our work:

1. **Support network:** with a small isolated patient community with such differing needs, we like to deliver **personal support in a timely way that delivers practical advice** and solves practical issues. alport uk's role is to empathise, understand the needs/issues, advocate for patients (and researchers) and support delivery of solutions. With our limited resources, this often means facilitating patient/researcher access to resources. For example, alport uk facilitates patients getting the right diagnosis via genetic testing, understanding treatment options or facilitating the grant application process for holiday breaks via Kidney Care's grant system. alport uk also writes letters of support for researchers to facilitate grant applications for Alport research.
2. **Provision of information:** with a diverse community and a very complex condition to explain, we try out different ways to provide information in a **variety of formats that suit different stakeholders**. With many of the community facing critical medical decisions as young adults, increasingly we use **short videos, social media and engaging activities to enable the patient community to engage in formats and content they find valuable**. For example, we encourage young adults to become our 'media team' at events, to engage in content, choose what is important and create videos and social media content themselves. See the video patients created about clinical trials and new treatments: <https://youtu.be/JRsJtUu8Lh8>. This was translated into 3 other languages by the patients working together on the script. We also publish **scientific information in the appropriate international journals so that it is peer reviewed and globally available** for researchers, clinicians and patients.
3. **Support research:** with limited funds and fundraising capability, we choose to focus our efforts to **inspire and facilitate collaborative behaviours such as information and resource sharing to facilitate and accelerate innovative ways of working and the development of new treatments and knowledge**. For example, we **facilitate the international research community coming together to share and exchange ideas through a series of in person and online international workshops**. This strategy aims to create a vibrant international research community that attracts more researchers and pharmaceutical or biotech companies interested in developing new treatments. These activities complement the activities of our colleagues in organisations such as:
  - Kidney Research UK – who raise money to fund specific UK Alport and kidney research projects eg elements of Rachel Lennon's lab based at Manchester University.
  - Alport Syndrome Foundation in the USA – who raise money to provide vital 'seed funding' for Alport research at an early stage of development.
4. **Support of a UK research registry:** with significant investment made by Kidney Care UK and Kidney Research UK into The **National Registry of Rare Kidney Diseases (RaDaR)** – the UK Renal Association's initiative designed to pull together information from patients with certain rare kidney diseases - alport uk support this vital project by **encouraging patients, clinicians and renal units to upload long-term clinical data into this database to enable**

**Natural History Studies in the future to progress Alport**

**Syndrome research.** This will give a much better understanding of how Alport Syndrome affects people. It will also speed up research. The value for:

- Alport patients:
    - Access to their clinical data online via Patient View, an online system which records blood and urine results, medications and clinic letters.
    - Ability to be contacted about future potential research studies or patient information events
    - Contribute to the increase in knowledge about their condition
  - Clinicians:
    - Share knowledge with other colleagues
    - Use RaDaR as part of a research study or clinical trial.
5. **Fundraising:** with so few people in the UK impacted by Alport Syndrome, awareness of the condition is limited and traditional fundraising by the public typically focuses on the key health areas of cancer, heart conditions etc. **We heartily encourage individuals and families living with Alport Syndrome to fundraise when inspired to do so, by providing support, encouragement and branded merchandise** (eg t-shirts, badges, wrist bands, shaking tins etc) to enable them to achieve whatever challenge motivates them. This means that **we raise significant funds for each major project or a programme of activities by applying for grants from larger charities or from pharmaceutical companies.** We support large fundraising events each year eg a dinner with an auction, a major activity eg swimming the channel or cycling round Europe etc.

**Highlights: achievements and performance this year****The pandemic: an opportunity to connect and engage**

The second half of alport uk's financial year was particularly challenging as the pandemic hit the world in early 2020. Vulnerable kidney transplant or dialysis patients and many Alport patients were advised to shield at home and the closed Facebook community – Alport Warriors - doubled in size from 350 members to over 750 members with members joining from all over the world, trusting and appreciating the excellent advice we get from our colleagues in the NHS. Each year we are contacted by more and more people as they are diagnosed with Alport Syndrome. This year, we had double the number of people contacting us for advice and specifically relating to COVID and the impact on renal patients. As we work as a 'virtual' organisation anyway, alport uk was able to easily respond to this increase in requests and with more of the community online – patients and researchers – more people were able to help each other. This engagement from the wider community was so valuable for all and so alport uk thrived in a really positive way, despite the pandemic. It was an opportunity for more to engage and more got value from this engagement.

**Support network proactively increased during the pandemic**

As many Alport patients were asked to urgently isolate in March 2020 due to COVID, ahead of the UK population understanding what was going on, our support activities dramatically changed. We were very

grateful to our Alport colleagues in China (Professor Jie Ding particularly) and Professor Colin Baigent who warned us of the emerging situation in Wuhan and helped us be ahead of the questions as they arose from the community. This set us up to be proactive in our advice for people living with Alport Syndrome, and was invaluable in keeping the community as calm as possible through a very worrying few months.

Before the charity existed in 2013, with Alport Syndrome affecting 1 in 10,000 people, it was typical that a family diagnosed with Alport Syndrome would never have met or talked to anyone outside their own family impacted by the condition. There was no support network and no mechanism for connecting individuals and families. People felt isolated. Through regular National Alport Information Days, our web site and closed Facebook page, support networks developed and each year the community feels stronger, more connected and able to deal with issues as they arise and particularly as we work through challenges together. People don't feel alone anymore. This infrastructure proved invaluable in supporting patients through the early unknown stages of the pandemic.

**Young woman in her 20s with a young daughter, both impacted by Alport Syndrome and mother needing a transplant urgently,** commenting about young adult workshop: *"It was really good to not feel so alone."*

**Young male patient from Georgia with no support locally,** but joins the online workshops to understand more about Alport Syndrome: *"Thank you so much. Really appreciate what you guys are doing."*

Some of the key support network achievements over the year:

- At the time of writing our Facebook Alport Warriors increased to over 800. The community quickly doubled during lockdown as people sought information online. Some members are regular contributors and the conversations are becoming more specific as people feel more connected as a community that is getting to know each other better and value each other's thoughts and opinions. The topics discussed include COVID, kidney donation, transplant successes, successes at the annual Transplant games, celebrating birthdays, links from other Alport Facebook sites, fundraising things, and a range of questions about Alport Syndrome, its' symptoms and side effects. There was one very touching story of a teenager who attended our first information day in London with his parents. The teenager met one of our inspirational and celebrated patients who has now had three transplants. After the teenager had their transplant, the two of them met up again at the Transplant games and shared a picture on Facebook. Connection with others who are in a similar situation is clearly valued by some people in the Alport community. Connection is not valued by all, so we aim to provide support for individuals or families in other ways to suit their needs.  
**Following the support we gave the parent of a young Alport patient facing kidney failure and living in unsuitable accommodation** for their condition: *"Hi, I just wanted to let you know that the council have agreed to fully refurbish (patient name)'s wet room after it went to a panel meeting last week...Thank you ever so much for your continued help and support."*
- We continued the dissemination of information and support from the first five Alport Information Days held in London (December 2012), Edinburgh (September 2013) and Birmingham (February 2015) and Manchester (November 2015), London (January 2017) and

Manchester (2019) for both patients and carers, including:

- Sending out information electronically – there was a high number of enquiries about information for women and girls living with Alport Syndrome.
- Answering enquiries emailed to us at [info@alportuk.org](mailto:info@alportuk.org) and phone calls sent to our landline number of 01793 847264 and putting people in touch with experts to answer their questions or with other families to share stories and experiences.
- Eg **A Dad contacted us as daughter wanting to start IVF and concerned about whether her side of the family has inherited Alport Syndrome like her cousin and wanting advice on best way to get a diagnosis in the COVID environment:** *“Thanks Alport UK – and to the Professor for the prompt & concise response. Your advice is crystal clear.... Thanks again for your help.”*
- When patients contact us for advice on specific topics, we put them in touch with the relevant clinicians, experts. Initially, much of this was done via email, but now we connect people through Alport Warriors, our phone line and email. Alport Warriors is our closed Facebook page where people share experiences of living with Alport Syndrome. **Parent of one young Alport patient facing transplant who we connected up with another young person who recently had a transplant:** *“Thank you. We have seen a big change in our son since he started talking about his worries and the extra support seems to be what he needs now.”*

#### Provision of information

With the help of our scientific advisors, we got advice early as the pandemic emerged and were able to keep one step ahead of the barrage of questions with daily posts on our closed Facebook page – Alport Warriors - to the community to answer queries as they arose. We posted the same information on the Alport Syndrome Foundation’s USA Facebook page in parallel as they have a number of UK patients as members. The USA Facebook page admins were incredibly supportive and we worked together to make sure that the international community benefited from the practical advice we got from our scientific advisors. This timely information reduced the anxiety in the community at a very challenging time. As everyone’s circumstances were different, we provided specific information to help patients work out their own risk levels and the necessary personal actions they needed to take to protect themselves from the virus. This built-up personal confidence and resilience as people took control of their own situations. This approach informing people to enable them to take control and build resilience was vital as our community has so many differing needs, many different age groups, are in differing stages of renal failure, undergoing different types of renal replacement therapy and many patients and family member were also from other countries seeking what advice they could get. We are very proud of the alport uk team, how they anticipated queries, increased the advice and information to enable people to stay as calm as possible, including sourcing food banks and writing letters to employers to explain the needs of their employees with Alport Syndrome. We are incredibly proud of the patients, their positive and pragmatic approaches to looking after themselves and helping each other across the community at a very concerning time.

Sometimes it was most helpful to connect young people to mentor each other when facing particularly challenging times such as declining kidney

failure and transplants: **Parent of one young Alport patient facing transplant** who we connected up with another young person who recently had a transplant: *"Thank you. We have seen a big change in our son since he started talking about his worries."* **Young Alport patient needing a transplant:** *"I think it's not actually as bad as it sounds to be fair...it really helped for me to understand what exactly actually goes on"*

During the pandemic, with most of our community – individuals and families living with Alport Syndrome and all the Alport researchers – isolating or working in their homes, we created **Alport Online Workshops, a series of online workshops featuring topics impacting patients and the latest Alport research from all over the world:** <https://tinyurl.com/y9cuhgby>. The first workshop was about COVID and the impact on kidney patients. The online audience was over 70 people, but the video was put onto YouTube after and received over 450 views. Subsequent workshop topics, requested by patients wanting more information, included for example: Alport eyes, Alport genetics and work by lab researchers in Manchester and USA. During the pandemic and various national lockdowns, the Alport online workshop team went on to produce a total of 20 online workshops including a 'Drop in' session one evening: **Mother with a teenager daughter with Alport Syndrome:** *"I think it's lovely just to have coffee type chats over zoom for the Alport Community however many join. Wishing you all at Alport U.K. a lovely weekend after all your hard work, as a family affected by Alport, we very much appreciate it!"*

With our young adult group, as the most critical group facing declining kidney function just at the time they are trying to leave home, build careers etc, their feedback increasingly indicates that short videos are the most useful way of sharing information. We now use these short videos to explain Alport Syndrome and share patient stories. Our most shared videos include three filmed and produced for alport uk by filmmaker, Sam Clarke who is also a young person living with Alport Syndrome:

- **Fighting failure:** Sam Clarke, prepared for his challenge to cycle round Europe <https://youtu.be/1A1adCj-cvo>. We use this video for newly diagnosed patients as it explains the challenges of living with Alport Syndrome but Sam ably inspires patients with the fun activities that he does such as sky diving, cycling and generally having fun. This is such an important message for young patients.
- **Patients inspire Alport Syndrome research**, a collaboration between alport uk and University of Manchester: <https://www.youtube.com/watch?v=77p7nzKz6nc>
- **Highlights from The 2019 International workshop on Alport Syndrome**, Siena, October 2019: <https://youtu.be/QH8mDTmKaVU>

A very successful **series of two-minute animated videos were written, illustrated and produced by a group of our young people with Alport Syndrome for their peers**. The writing of the videos and working with the clinicians to make them scientifically accurate was a valuable process for the young people to engage in understanding Alport better as sometimes they can be in denial about what is important to keep them healthy or sources of support. Topics included:

- Why Alport research is important <https://youtu.be/TU0m6gGvTFY>
- Alport Community <https://www.youtube.com/watch?v=5qJEtMhcCIU>
- Alport Syndrome: Know your numbers <https://www.youtube.com/watch?v=jtkmJdwG0nE>
- Kidney transplants and Alport Syndrome <https://www.youtube.com/watch?v=Gd4yB9PVnM0&t=52s>

- Update on clinical trials and potential treatments for Alport Syndrome (written in English and translated into Italian, German and Chinese by the young patients with Alport Syndrome) at The 2019 International workshop in Siena, Italy <https://youtu.be/JRsJtUu8Lh8>

When someone is diagnosed with Alport Syndrome, some of the regional genetics units e.g. at Guy's Hospital and some of the paediatric renal units e.g. at Manchester University Hospital, have a small leaflet giving some summary details about the condition and our alport uk leaflets. Beyond this, there is an array of information one can find on the web, but it is hard to decipher what is medically correct or up to date. On our website is:

- **A summary leaflet for Alport UK** to encourage people to get in touch with us – this is now handed out at the genetics units when people are newly diagnosed with Alport Syndrome. It was also sent out, along with laminated posters with our contact details on, to all the main adult and paediatric renal units around the country to advertise where to find out information about Alport Syndrome
- **A dictionary of scientific terms** to help patients learn more about the biology of Alport Syndrome, so when their clinicians explain things, they understand a bit more about what they are talking about as it is so hard to pick much up in a short clinic appointment.
- **Definitions of related rare renal diseases** – Nephrotic Syndrome, IgA Nephropathy, Membranous Nephropathy and Focal Segmental Glomerular Sclerosis (FSGS) that sometimes overlap with Alport Syndrome or people can be diagnosed with more than one disease or if people are misdiagnosed.
- **Videos available through our website** ([www.alportuk.org](http://www.alportuk.org)) and a special section on Alport Syndrome on [www.healthtalk.org](http://www.healthtalk.org) (<http://www.healthtalk.org/peoples-experiences/long-term-conditions/alport-syndrome/topics>) of our key experts talking about specific aspects of Alport Syndrome. Topics are varied about all aspects of living with Alport Syndrome and include: Genetics, An introduction to Alport Syndrome, Hearing and hearing aids, caring for people with Alport Syndrome, medication, women with Alport Syndrome etc.
- **Our website remains an invaluable resource.** We are currently fundraising to improve our website [www.alportuk.org](http://www.alportuk.org) to update and make the information clearer and more accessible and to answer the questions we have received over the last year or so through our closed Facebook page, Alport Warriors. **Mother contacted us about vaccination for a 19-year-old daughter with Alport Syndrome and on strong medication:** *"Thank you for putting my mind at rest. I got your contact details from the Alport UK website. My daughter said it's not really her thing joining groups. Shame, as I think it's really good that support is out there. Thank you for your support."*
- **Information about new clinical trials** that patients can sign up is shared through our website 'Latest news' section, through our closed Facebook page (Alport Warriors) and through directly emailing our database of patients.

### The support of research

With limited funding for research, alport uk's strategy is use our small amount of funding to facilitate an Alport research collaborative plus support and encouragement for the research community in working together to create a vibrant research community that attracts more researchers and pharmaceutical companies interested in developing new

treatments.

The major programme for the first half of the year was to deliver our fourth 'in person' international workshop – The 2019 International workshop on Alport Syndrome in Siena, co-hosted with the Italian national Alport patient association – A.S.A.L. Onlus – and Professor Alessandra Renieri's wonderful genetics team at Siena University. With participation from patients and scientists all over the world, the Siena workshop focused on genetics and gene therapy and was the largest collaboration to date with the international Alport community delivered entirely by alport uk volunteers in collaboration with the team in Italy – the key achievements are listed below including the collaborative effort on sponsorship to provide the funds to make the workshop possible.

A specialist international 'Alport mutations/variants workshop' was then held in London in February 2020 for all those involved in lab testing and diagnosing Alport Syndrome around the world to collaborate on and publish international guidelines and clinical standards to improve diagnosis. Professor Judy Savige from Australia lead the effort, with over 50 experts participating in person from all over the world just before the UK went into Lockdown, supported by alport uk.

When lockdown happened and with many patients shielding at home and the alport researchers unable to get into the lab, people had time on their hands and we quickly formed a small working group to create a series of Alport online workshops. The first workshop, delivered on 12 May 2020 focused on answering COVID questions and explained the new arrangements for Alport genetic testing as the lab facilities moved from Guy's in London to Bristol. The workshops were run monthly thereafter with a few extras fitted in on topics people were particularly keen to hear about eg eye complications in Alport syndrome. The workshops featured scientists from all over the world. **From a patient advocacy person in another country:** "...congratulations for the Alport workshops. It is a fantastic way to keep connected and continue learning about Alport Syndrome."

Over the year:

279 participants from 33 different countries participated in the first 14 online workshops

38 speakers presented 42 of the latest research projects from 8 different countries.

15 moderators contributed from 3 different countries and we aim to increase the diversity for the next set of workshops

So far, the videos on YouTube, <https://tinyurl.com/y9cuhgby>, received 1,786 views.

The researcher and clinician participants represented a range of different disciplines: basic science, lab technicians, adult and paediatric nephrology, clinical and laboratory genetics, pathology, ophthalmologists, transplant surgeons, dialysis specialists, academics.

Some of the workshops featured specific labs and were an opportunity for early career researchers to present their work to the international Alport community and get feedback and questions. In the spirit of 'collaboration' – such an important principle of alport uk's strategic direction – the pandemic actually enabled us to accelerate our progress, share more research to a wider audience and at a reduced cost compared with the four 'in person' workshops delivered previously. The lock-in format of the 'in person' workshops meant the community had

spent plenty of time getting to know each other over the last 6 years and this investment in enabling the community to 'get to know each other' and collaborate paid off as we worked online. Busy clinicians, battling to deliver frontline care to patients in hospitals all over the world, still made time to join us online and connect.

After their presentations, a number of the researchers fed back stories to alport uk about how the workshops 'furthered their science'. Presenting researchers confirmed that members of the Zoom audience on their workshop reached out to them via email to:

- set up new collaborations
- initiate new collaborative research projects and
- provide vital new input to current projects.

The online workshop format was a catalyst for new research, thanks to the pandemic and the inspiration of the team who devised the format:

**Professor Rachel Lennon, Professor Jeffrey Miner, and two members of the Lennon lab - Louise Hopkinson and Richard Naylor.**

alport uk is incredibly grateful particularly to Louise and Richard, who worked from home whilst unable to get into the lab, and helped us identify new research to feature, created material to post on social media, participated in the discussions and helped 'translate' some the difficult terms into a dictionary of layman's terms to make the science more accessible for patients with no science background.

Feedback from patients:

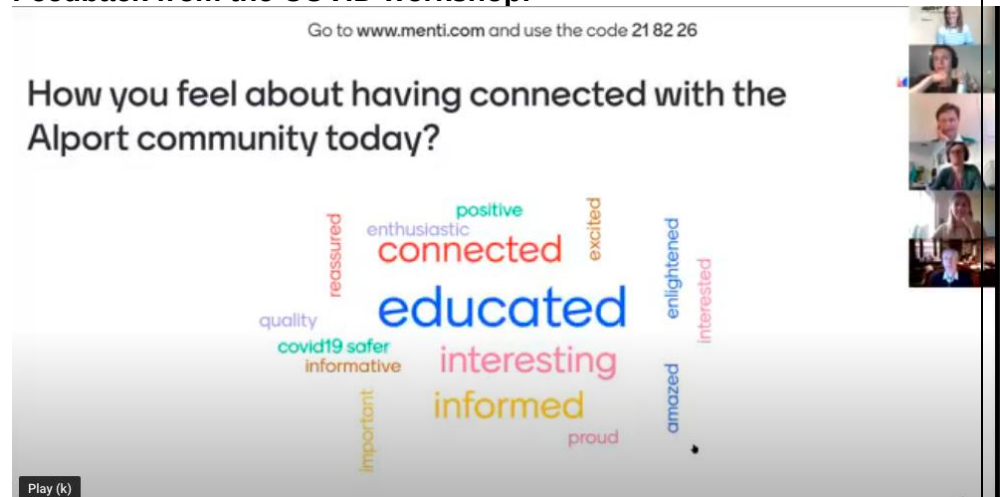
*"It was so enlightening to find out these people (the researchers) are doing their very best on our behalf. I had no idea of the methods used for this kind of research. They seemed to be a happy team too!"*

*"It was reassuring that such research is carrying on."*

*"Fantastic idea and I'm sure the rest of the Alport community would be very interested in seeing this. I did not have a clue so much was going on and to hear all the info has made me feel very hopeful. Many thanks again"*

After each workshop, we invite people to submit one word to express how they feel after a workshop. For example:

**Feedback from the COVID workshop:**



Feedback from the 'Planning a family' workshop:

## Word Cloud



Feedback from the 'Flozins as a potential treatment' workshop:

## Share your thoughts on today's topic!



The science to better understand what causes Alport Syndrome is very complicated. The more we know about the genetics, the more complicated it is with modifier genes impacting the Alport genes creating a vast range of phenotypes. Much of the science was daunting for some patients and the patients provided valuable input to the workshop programme planning for the following year to balance the programme with other topics to feature more patient-friendly science relating to transplantation, dialysis, hearing etc.

### Alport research indicators in 2019

In the 1990s, groups of leading clinicians, academics and scientists regularly met to discuss topics related to Alport Syndrome. They published a number of key papers about Alport Syndrome, but the regular meetings stopped. In 2012, alport uk commissioned a web audit of people publishing material on Alport Syndrome through to the current day and prepared a report on the status of research into Alport Syndrome. This report was used to identify the missing areas of activity and needs for research including:

- A shared international strategy and plan for Alport Syndrome research
- New research ideas and projects to develop new treatments and therapies and more research generally

- Ways to reengage the leading experts in Alport Syndrome
- Co-ordination of national patient registries
- The need to engage the pharmaceutical industry in developing new treatments
- How alport uk could complement the current contributions of other national patient organisations, for example the Alport Syndrome Foundation who currently run an excellent programme of seed funding for Alport research, commissioning projects each year
- How Alport Syndrome is a model renal disease and that new treatments developed for Alport Syndrome could help other patients living with renal disease.

In 2019, to check on the performance of our investment to get researchers together through these workshops, alport uk circulated a simple survey with the Workshop Organising Committee members and their research teams (ie not the full Alport research community, just some of the key members) to understand the impact of the international workshops, emphasis on collaboration and how much research is now being done. Overall the numbers indicate a very healthy research community to whom we are incredibly grateful for all they do to help with the awareness and understanding of Alport Syndrome by delivering:

- 131 publications with the majority in international journals
- 18 book chapters
- 38 major grants to fund the ongoing research.
- over 90% of the projects and publications were collaborative efforts.

These survey results confirmed to alport uk that our efforts to drive collaboration and accelerate research are delivering the results we need.

To continue the collaborative international workshops in Oxford (2014) Göttingen, Germany (2015) and Glasgow, Scotland (2017), alport uk facilitated the delivery of a fourth workshop in the series: **The 2019 International Workshop for Alport Syndrome** in Siena, Italy. Even the preparation work, for the workshop in itself, further consolidated interactions among the various stakeholder groups and addressed the progress being made to move forward with focus on the shared mission to find a long-term multi-target therapy for Alport Syndrome resulting in a lifelong delay of renal failure. In Siena at the 2019 workshop, there were 146 participants including 38 patients and representatives from 12 pharmaceutical companies who came together to continue the progress on a research strategy and collaboration effort. Outputs from the workshop included:

- 46 abstracts highlighting the latest Alport research – a significant growth from the last workshop.
- Drafted a workshop summary ready to publish in a genetics publication.
- A graphic book charting the progress of the science to share with patients and illustrate the work going forward.
- An increased number of countries engaged with new communities emerging in pathology and across eastern Europe eg Croatia, Poland and the Baltic region.
- Further consolidated interactions among the various stakeholder groups and addressed upcoming steps to move forward on the shared mission.
- 12 pharmaceutical or biotech companies participated, a number who are researching Alport Syndrome and some planning or considering clinical trials
- Five pharmaceutical and two hearing aid companies sponsored the workshop.

After this fourth important workshop to reconnect the Alport Syndrome

research community, alport uk intended to restart the conference calls with the international workshop organising committee to share progress, keep the researchers engaged in delivering the agenda agreed at the workshop and start planning the fifth and sixth workshops in Beijing, China and Calgary, Canada respectively. However, when the pandemic hit and with most of our Workshop Organising Committee being kidney doctors, the doctors were needed on the wards to help with the kidney complications that COVID caused. So, the Alport Online Workshops were started instead and plans started for an Online International workshop for 2021.

### **Support of a UK research registry**

In parallel to alport uk being set up, the Renal Association established a working group on Alport Syndrome, funded jointly by Kidney Research UK and Kidney Care (previously British Kidney Patient Association) to support the development of a national renal registry of patients, called RaDaR which is linked to a system that patients can access, called Renal Patient View. Some of the trustees from alport uk contribute to the working group on an ongoing basis to devise ways of promoting RADAR to patients and clinicians across the UK. At the time of writing, RaDaR has over 800 patients registered as having Alport Syndrome. alport uk specifically contribute to the support of this UK research registry of patients and an international alliance of patient registries by:

- Promoting the importance of RaDaR and Renal Patient View to patients at Alport information days, along with information about the value of RaDaR to research
- Making the research registry a central part of the national contribution to international efforts to collaborate on research coming out of the 2014, 2015, 2017 and 2019 International Workshops on Alport Syndrome and proposing to make it one of the key topics for 2021.
- Continuing the development of the UK's contribution to an international alliance of Alport Syndrome research. An 'alliance' is necessary as there are not enough patients in the UK for Clinical trials and so pharmaceutical companies will want to do trials in a number of different countries to try new therapies.

If anyone reading this annual report is interested in more information or to get involved or support us with activities or fund raising, please email Susie Gear and Julia Skelding at [info@alportuk.org](mailto:info@alportuk.org) or call us on 01793 847264.

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

Reserves from fundraising are kept in separate Barclays bank savings accounts, labelled for their specific use. For example, for:

- Information Days (Alport UK Meetings)
- Development of information, website and marketing material (Alport UK)
- Facilitating the International Workshops on Alport Syndrome (Alport UK Research)
- Research commissioned by Alport UK (Alport UK Schools)

### Details of any funds materially in deficit

No funds in deficit

### Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

alport uk's principal sources of funds this year were again more diverse than in the previous year:

- Personal donations
- Limited personal fund-raising activities such as running events, hosting charity evenings, cake sales etc.
- Just Giving and Virgin Money Giving pages of sponsorship for various activities that our community get involved in to raise funds for alport uk – this year Sam Clarke's amazing efforts raised over £20,000 for a new fund we will call the 'Don't Wait Fund' to support patients taking up a new sport or hobby.
- Social media fundraising pages eg Facebook
- PayPal payments/donations to Alport UK
- Sales of Christmas cards, t-shirts and badges
- Standing orders from a couple of very supportive patient families
- Customised shaking tins located in retail venues
- Donations from larger charities or foundations for specific activities and particular thanks to Kidney Care UK and to Kidney Research UK
- Grants given by a number of pharmaceutical companies to fund The 2019 International workshop on Alport Syndrome: alport uk are very grateful to the support from Sanofi Genzyme, Regeneron, Retrophin (now Traveo Therapeutics), Novartis, REATA Pharmaceuticals and two hearing aid companies Audibel and Audiomedical Solutions.
- Income from the registrations for The 2019 International workshop on Alport Syndrome
- One of our Trustees loaned us a sum to partly fund the next stage of the healthtalk.org project and a number of expenses in the early stages of the charity. The loan is interest free and there is no deadline to pay it back, just when funds are available.

As funds were all allocated to specific activities that support our key objectives this year, there was no opportunity for investment during this accounting period.

## Section F

## Other optional information

# Alport UK

## Report and Financial Statement For the year ended 31<sup>st</sup> July 2020

Charity number: 1154774

Shilton Accounting Services  
1<sup>st</sup> Floor, 1 The Clock House  
Brize Norton Road  
Carterton  
OX18 3HN

**Alport UK**  
**Charity number: 1154774**  
**Legal and administrative information**

Charity name: Alport UK  
Charity registration number: 1154774  
Type of organisation: Charitable Unincorporated Organisation

Registered office and business: PO Box 329  
Cirencester  
Gloucestershire  
GL7 9JA

Trustees: Colin Baigent  
Jules Skelding  
Daniel Gale  
Susie Gear  
Frances Flinter  
Rachel Lennon  
Neil Turner

Accountants: Shilton Accounting Services  
Certified Practising Accountants  
1<sup>st</sup> Floor, 1 The Clock House  
Brize Norton Road  
Carterton  
OX18 3HN

**Alport UK**  
**Charity number: 1154774**  
**Independent Examiner's report to the Trustees of Alport UK**

I report on the accounts of the Charity for the year ended 31<sup>st</sup> July 2020 which are set out below.

**Respective responsibilities of trustees and examiner.**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under section 43(2) of the Charities Act 1993 (the 1993 Act) and that an independent examination is needed.

It is my responsibility to:

- a) Examine the accounts (under section 43(7)(b) of the Act.
- b) To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 43(7)(b) of the Act.
- c) To state whether particular matters have come to my attention.

**Basis of independent examiner's report.**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence which would be required in an audit and consequently I do not express an audit opinion on the accounts.

**Independent examiner's statement.**

In connection with my examination, **no** matter has come to my attention

1. Which gives me reasonable cause to believe that in any material respect, the requirements of a) to keep proper accounting records in accordance with section 41 of the 1993 Act and b) to prepare accounts which accord with the accounting records and to comply with the requirements of the Act, have not been met.
2. To which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

David Cuthbertson – ICPA Cert Acc (Open)  
Shilton Accounting Services  
Honeystone Cottage  
Ladburn Lane  
Shilton  
OX18 4AJ  
30/12/2020

**Alport UK**  
**Charity number: 1154774**  
**Director's report for the year ended 31<sup>st</sup> July 2020**

The trustees present their report and financial statement for the year ended 31<sup>st</sup> July 2020.

**Objects** – The relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- a) The establishment and facilitation of a support network for Alport Syndrome patients, carriers, their families and carers;
- b) The provision of information on Alport Syndrome;
- c) The support of research into Alport Syndrome both in the UK and internationally;
- d) The support of a research registry in the UK and an international alliance of national registers.

**Governing document** – the charity is governed by a constitution based upon a Charity Commission document that was adopted on 27<sup>th</sup> November 2013. A copy of the full governing document can be obtained from the charity.

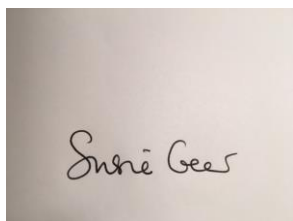
**Trustees** - The overall responsibility of the organisation rests with the Board of Trustees. The selection of Trustees is designed to supplement the existing skills and expertise of the board and is governed by an informal skills assessment. The appointment of trustees is made in accordance with the constitution.

**Risk assessment** – Disclosure and Barring checks are carried out for all appropriate trustees, staff and volunteers. The Trustees have examined the major strategies, business and operational risks which the charity faces and confirm that systems have been established to enable regular reports to be produced so that the necessary steps can be taken to minimise these risks.

**Public benefit statement** – Alport UK is a patient-led organisation dedicated to facilitating a support and information network for all those affected by Alport Syndrome. Our vision is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life. This creates public benefits in health and community cohesion.

**Reserves policy** – The Trustees are actively trying to build reserves, with a view to being able to fund further research and to strengthen its support structure.

This report was approved by the Trustees on 27 February 2021 and signed on its behalf by

A rectangular box containing a handwritten signature in black ink. The signature appears to read 'Susie Gear'.

**Susie Gear**

**Alport UK**  
Charity number 115774

**Statement of Financial Activities (including Income & expenditure Account)**  
**For the year ended 31<sup>st</sup> July 2020**

|                          | <b>Restricted Funds</b> |           |              | <b>Unrestricted</b> |               | <b>Total</b>   | <b>2019</b>   |
|--------------------------|-------------------------|-----------|--------------|---------------------|---------------|----------------|---------------|
|                          | Research                | Meetings  | Don't Wait   | General             | Caxton        |                |               |
| <b>Income</b>            |                         |           |              |                     |               |                |               |
| Donations/ Sponsors      | 14,030                  | -         | -            | 31,339              | 8,111         | 53,480         | 57,009        |
| Delegate fees            | 17,060                  | -         | -            | -                   | -             | 17,060         | -             |
| HMRC Gift Aid            | -                       | -         | -            | 402                 | -             | 402            | 2,804         |
| Sale of books etc        | -                       | -         | -            | 164                 | -             | 164            | 254           |
| Exchange differences     | -                       | -         | -            | -                   | 228           | 228            | -             |
| <b>Total income</b>      | <b>31,091</b>           | <b>-</b>  | <b>-</b>     | <b>31,905</b>       | <b>8,339</b>  | <b>71,335</b>  | <b>60,067</b> |
| <b>Expenditure</b>       |                         |           |              |                     |               |                |               |
| Bank & service charge    | 77                      | -         | -            | 597                 | 9             | 683            | -             |
| Direct cost events       | 14,340                  | -         | -            | 17,199              | 13,518        | 45,057         | 7,886         |
| Administration           | 6,281                   | -         | -            | 6,442               | -             | 12,723         | 4,487         |
| Travel & subsistence     | 10,662                  | -         | -            | 1,960               | 1,650         | 14,272         | 12,192        |
| Internet/website         | -                       | -         | -            | 2,026               | -             | 2,026          | 1,408         |
| Marketing                | -                       | -         | -            | 247                 | -             | 247            | 4             |
| Insurance                | -                       | -         | -            | 672                 | -             | 672            | 672           |
| Subscriptions            | -                       | -         | -            | 282                 | -             | 282            | 501           |
| Bursaries/Grants         | 219                     | -         | 255          | -                   | -             | 474            | -             |
| Others                   | 219                     | -         | -            | -                   | -             | 219            | 216           |
| <b>Governance costs</b>  |                         |           |              |                     |               |                |               |
| DBS checks               | -                       | -         | -            | 391                 | -             | 391            | -             |
| Accountants' fees        | -                       | -         | -            | 960                 | -             | 960            | 960           |
| <b>Total expenditure</b> | <b>31,797</b>           | <b>-</b>  | <b>255</b>   | <b>30,777</b>       | <b>15,176</b> | <b>78,005</b>  | <b>28,327</b> |
| <b>Transfers</b>         | <b>(846)</b>            | <b>-</b>  |              | <b>(29,988)</b>     | <b>30,835</b> | <b>-</b>       | <b>-</b>      |
| <b>Net movement</b>      | <b>(1,553)</b>          | <b>-</b>  | <b>(255)</b> | <b>(28,860)</b>     | <b>23,998</b> | <b>(6,671)</b> | <b>31,740</b> |
| <b>Opening balance</b>   | <b>10,074</b>           | <b>94</b> | <b>2,684</b> | <b>54,364</b>       | <b>-</b>      | <b>67,215</b>  | <b>35,474</b> |
| <b>Closing balance</b>   | <b>8,521</b>            | <b>94</b> | <b>2,429</b> | <b>25,503</b>       | <b>23,998</b> | <b>60,544</b>  | <b>67,215</b> |

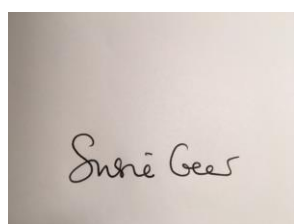
There are no recognised gains or losses other than in the Statement of Financial Activity.

**Alport UK**  
Charity number 115774

**Balance Sheet as at 31<sup>st</sup> July 2020**

|                                            | Notes | 2020   | 2019   |
|--------------------------------------------|-------|--------|--------|
|                                            |       | £      | £      |
| <b>Fixed assets</b>                        |       | -      | -      |
|                                            |       |        |        |
| <b>Current assets</b>                      |       |        |        |
| <i>Cash at bank</i>                        | 4     | 62,464 | 68,175 |
|                                            |       |        |        |
| <b>Total Current assets</b>                | 5     |        |        |
|                                            |       |        |        |
| <b>Current liabilities</b>                 |       |        |        |
| <i>Creditors falling due within 1 year</i> |       | 1,920  | 960    |
|                                            |       |        |        |
| <b>Net current assets</b>                  |       | 60,544 | 67,215 |
|                                            |       |        |        |
| <b>Assets less liabilities</b>             |       | 60,544 | 67,125 |
|                                            |       |        |        |
| <b>Represented by</b>                      |       |        |        |
| <i>Restricted funds</i>                    |       | 11,043 | 12,851 |
| <i>Unrestricted funds</i>                  |       | 49,501 | 54,364 |
|                                            |       |        |        |
| <b>Total funds</b>                         | 6     | 60,544 | 67,215 |
|                                            |       |        |        |

**Signed on behalf of the charity's trustees**



**Date: 27 February 2021**

**Notes to the financial statements**

**For the year ending 31<sup>st</sup> July 2020.**

**1. Accounting policies**

**a. Basis of accounting**

The financial statements have been prepared under the historic cost convention with items recognised at cost or transaction value unless otherwise state in the relevant notes to these accounts. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and reporting by Charities preparing their accounts in accordance with Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS102) issued on 16<sup>th</sup> July 2014 and the Charities Act 2011. The trust constitutes a public benefit entity as defined by FRS102.

**b. Going concern**

The trustees consider that there are no material uncertainties about the trust's ability to continue as a going concern.

**c. Fund accounting**

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

**d. Income resources**

All incoming resources are included in the statement of financial activities when the charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of financial activities when receivable.

Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes entitled to the grant.

Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by volunteers has not been included in these accounts.

Investment income is included when receivable.

Income resources for charitable trading activity are accounted for when earned.

**Notes to the financial statements**

**For the year ending 31<sup>st</sup> July 2020.**

**e. Resources expended**

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

Costs of generating funds comprise of the costs associated with attracting voluntary income and costs of trading for fund raising purposes.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include accountancy and legal fees.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resources. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

**2. Staff costs**

The charity did not employ any staff in the financial year.

**3. Trustee remuneration & related party transactions.**

The trustees all give freely of their time and expertise without any remuneration or other benefit in kind. Expenses incurred on behalf of the charity are reimbursed at cost.

## Alport UK

Charity number: 1154774

### Notes to the financial statements

For the year ending 31<sup>st</sup> July 2020.

#### 4. Cash at bank.

|                                      |                |
|--------------------------------------|----------------|
| Barclays General Account 93696405    | £27,423        |
| Barclays Research Account 93725642   | £7,149         |
| Barclays Meeting Account 83477436    | £94            |
| Barclays Don't wait Account 33742210 | £2,429         |
| Caxton FX                            | £23,998        |
| PayPal                               | £1,371         |
| <b>Total</b>                         | <b>£62,464</b> |

#### 5. Creditors: Amounts falling due within one year

Accounting fee accrual £960.00

#### 6. Movement in funds

|              | Opening<br>balance | Incoming<br>resources | Outgoing<br>resources | Balance<br>31 <sup>st</sup> July 2020 |
|--------------|--------------------|-----------------------|-----------------------|---------------------------------------|
| Restricted   | £12,851            | £31,091               | £32,898               | £11,043                               |
| Unrestricted | £54,364            | £40,244               | £45,107               | £49,501                               |
| <b>Total</b> | <b>£67,215</b>     | <b>£71,335</b>        | <b>£78,005</b>        | <b>£60,544</b>                        |

**ALPORT UK**

England & Wales - Charity number 1154774

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# Accounts

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# ANNUAL REPORT AND ACCOUNTS



**a brighter future** for people living with alport syndrome

For the year ended 31 July 2020



## Trustees' Annual Report for the period

| Period start date |          | Period end date |           |
|-------------------|----------|-----------------|-----------|
| <b>From</b>       | 1 8 2019 | <b>To</b>       | 31 7 2020 |

### Section A Reference and administration details

**Charity name** alport uk

**Other names charity is known by** n/a

**Registered charity number (if any)** 1154774

**Charity's principal address** PO Box 329

Cirencester

**Postcode** GL7 9JA

#### Names of the charity trustees who manage the charity

|   | Trustee name    | Office (if any) | Dates acted if not for whole year | Name of person (or body) entitled to appoint trustee (if any) |
|---|-----------------|-----------------|-----------------------------------|---------------------------------------------------------------|
| 1 | Colin Baigent   |                 | Whole year                        |                                                               |
| 2 | Julia Skelding  |                 | Whole year                        |                                                               |
| 3 | Susie Gear      | Chief Executive | Whole year                        |                                                               |
| 4 | Frances Flinter |                 | Whole year                        |                                                               |
| 5 | Rachel Lennon   |                 | Whole year                        |                                                               |
| 6 | Neil Turner     |                 | Whole year                        |                                                               |
| 7 | Danny Gale      |                 | Whole year                        |                                                               |

#### Names of the trustees for the charity, if any, (for example, any custodian trustees)

| Name | Dates acted if not for whole year |
|------|-----------------------------------|
| n/a  |                                   |
|      |                                   |
|      |                                   |

#### Names and addresses of advisers (Optional information)

See table of Advisors over the page

| Type of adviser                                                                 | Name                      | Address                                                                                                                                                                          |
|---------------------------------------------------------------------------------|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Medical – paediatric nephrologist</b>                                        | Professor Rachel Lennon   | Royal Manchester Children's Hospital, Oxford Road, Manchester M13 9WL                                                                                                            |
| <b>Medical – adult nephrologist</b>                                             | Professor Neil Turner     | University of Edinburgh Renal and Autoimmunity Group, MRC Centre for Inflammation, Queen's Medical Research Institute, Little France, Edinburgh, EH16 4TJ                        |
| <b>Geneticist</b>                                                               | Professor Frances Flinter | Emeritus Professor of Clinical Genetics, Guy's & St Thomas' NHS Foundation Trust<br>Genetics Department, 7th floor Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT |
| <b>Eye specialist</b>                                                           | Dr Omar Mahroo            | St Thomas' Hospital Campus, 3rd Floor South Wing Block D, Westminster Bridge Road, London SE1 7EH                                                                                |
| <b>PR, Communication and Marketing</b>                                          | Jane Keightley            | JK Branding and Communications Limited                                                                                                                                           |
| <b>Accountant</b>                                                               | David Cuthbertson         | Shilton Accounting Services Ltd                                                                                                                                                  |
| Name of chief executive or names of senior staff members (Optional information) |                           |                                                                                                                                                                                  |
| Susie Gear, Chief Executive                                                     |                           |                                                                                                                                                                                  |
|                                                                                 |                           |                                                                                                                                                                                  |

## Section B Structure, governance and management

### Description of the charity's trusts

|                                                                     |                                                                                                               |
|---------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| Type of governing document<br>(eg. trust deed, constitution)        | Constitution                                                                                                  |
| How the charity is constituted<br>(eg. trust, association, company) | Charitable Incorporated Organisation                                                                          |
| Trustee selection methods<br>(eg. appointed by, elected by)         | Appointed for a term of 3 years by a resolution passed at a properly convened meeting of the Charity Trustees |

### Additional governance issues (Optional information)

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>You <b>may choose</b> to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> <li>• policies and procedures adopted for the induction and training of trustees;</li> <li>• the charity's organisational structure and any wider network with which the charity works;</li> <li>• relationship with any related parties;</li> <li>• trustees' consideration of major risks and the system and procedures to manage them.</li> </ul> | <p>Policies and procedures for the induction and training of trustees</p> <ul style="list-style-type: none"> <li>• Provided with a guide for how the charity operates – this now includes a set of policies on topics such as expenses, relationship with pharmaceutical companies, sponsorship etc.</li> <li>• Disclosure and Barring checks</li> <li>• Given a briefing on the charity and engaged in activities to enable them to participate fully in the decisions of the charity.</li> </ul> <p>Organisational structure of the charity and wider network</p> <ul style="list-style-type: none"> <li>• We are a small charity and so have a very flat organisational structure.</li> <li>• Day-to-day activities are run by one of the trustees – Susie Gear with a number of volunteers. All day-to-day decisions are jointly taken with at least one of the other Trustees eg Julia Skelding, Professor Frances Flinter or Professor Rachel Lennon. If we need to check any of the decisions, we involve the other trustees - who are less involved in the day-to-day activities and so provide excellent challenge and objectivity.</li> <li>• Our closed Facebook page, Alport Warriors is moderated day-to-day by one of our volunteers – Wilma Calderwood – with back up from Jules Skelding and Susie Gear and with any specific medical questions answered by our medical advisory team – see list above.</li> </ul> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

- Our public facing social media eg Facebook and Instagram pages are run by Susie Gear and some of the younger Alport Warriors.
- Alport UK's Scientific Advisory Committee provide expert medical input and advice as required: Professor Colin Baigent (Strategic direction of research and Clinical trials), Professor Frances Flinter (Clinical and particularly Genetics and diagnoses), Professor Danny Gale (Rare Renal Database RaDaR and Clinical trials), Professor Rachel Lennon (Paediatric Nephrology, Podocyte research and clinical guidelines) and Professor Neil Turner (Adult Nephrology and RaDaR).
- Alport UK's international Workshop Organising Committee is made up of a wide range of experts – researchers, clinicians, academics and Alport patients – with representation from all over the world.

Trustees' consideration of the major risks & procedures to manage them:

- **Support** – as we support patients and family members living with Alport Syndrome, there can be specific questions or situations that require medical advice or input. We have a scientific advisory committee which is available, whenever required, to provide expert medical input and advice to patients and their families. All committee members are practising/retired clinicians in the NHS and are recognised internationally for their experience and expertise. We also have a wider network of international experts from whom we can get additional opinions, as required. As we support a number of young adults and vulnerable adults, we have a Safeguarding Officer, who we consult if there are any safeguarding concerns.
- **Information** – all the information and recommendations published on our website, [alportuk.org](http://alportuk.org), is reviewed by members of our scientific advisory committee.
- **Research** – all projects we embark on are reviewed by members of our scientific advisory committee and we get input from a wider network of international experts, as required. This includes assessing clinical trials and although, as a charity, we never recommend participation in a trial, we will provide as much information as possible to support patients' decisions on participating in a trial, publishing views in international publications, as necessary.
- **Collaboration** – is a core way of working for our charity. We collaborate with other national patient organisations and an international scientific community interested in research into Alport Syndrome. We run monthly conference calls and a series of international workshops for all involved to keep in touch with progress. Funds for these international research activities are kept in a separate bank account so that the expenditure is transparent to maintain the open collaborative working environment. To ensure all appropriate risks are managed related to this collaboration, we have set up an international Workshop Organising committee to ensure there is a balance of work and information from or relating to different countries or continents.
- **Fundraising, finances and projects** – As a small charity, we fundraise for specific projects and these funds are kept in separate bank accounts 'ring-fenced' for each project. The majority of our fundraising is through applications to larger charities that support small charities, such as ours, with funds allocated for specific activities, such as the information days or international workshops undertaken by alport uk. Increasingly, we also seek funding for work from pharmaceutical companies. We aim to raise collaborative funding for any project, so we are not reliant on one company for project funding which also means Alport UK is not associated with one company for one particular project.

**Summary of the objects of the charity set out in its governing document**

**Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)**

The objects of the CIO are the relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- The establishment and facilitation of **a support network** for Alport Syndrome patients, carriers, their families and carers;
- The **provision of information** on Alport Syndrome;
- The **support of research** into Alport Syndrome both in the UK and internationally;
- The **support of a research registry in the UK** and an international alliance of national registries

**Public benefit – statutory declaration by Trustees**

The Trustees have paid due regard to the Charity Commission's guidance on public benefit in deciding what activities the charity should undertake. alport uk recognises and welcomes the need to carry out its charitable activities to the benefit of those affected by Alport Syndrome, and retains this aim at the centre of its strategic planning.

**alport uk is a patient-led organisation** dedicated to facilitating a support and information network for all those affected by Alport Syndrome.

**Alport Syndrome** is an inherited condition that can cause kidney failure, deafness and eye abnormalities. Those that inherit it will probably require a kidney transplant when they are young adults. It can impact a large number of people in a family. It is the second most common form of inherited kidney disease. Meet Sam to understand the impact it has on a family: <https://sam-clarke.com/fighting-failure-challenge/>.

**Our Vision** is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life.

**Our Mission** is to work in partnership with individuals, families and the scientific community to:

- Facilitate a **support** network for patients and families
- Be a conduit for high quality, accessible **information**
- **Raise the profile** of Alport Syndrome in the scientific community
- Contribute to the international **research** agenda
- **Collaborate** on the development of a UK patient registry and alliance of international patient registries.

**alport UK fund four key areas of activity**

1. **Support** – Providing support for UK patients and families through a support network, website and information days.
2. **Information** – Working with clinicians, individuals and families to educate them on more effective diagnosis and treatment, for example national guidelines for diagnosis, treatment and the best care for children, teenagers and adults.
3. **Research** – Working with other national patient organisations (eg USA, across Europe and Asia) and clinicians to design, develop and maintain an international research strategy and plan for Alport Syndrome, supported by an alliance of national patient organisations and national patient registries
4. **Collaboration** – Bringing together the scientific community to work

across the different clinical disciplines that specialise in kidneys, ears, eyes, mental health, other rare disease areas with similar issues etc. and working with the national patient organisations or other rare renal disease groups to share best practice with developed and developing countries.

The activities of alport uk are grounded in the local communities across the UK as we aim to connect up regional groups of individuals and families that are affected by Alport Syndrome. As the possible 2-3,000 individuals impacted in the UK is a small group if looked at on their own, this requires the charity to work internationally with other national patient organisations and clinicians to co-ordinate activities and research across a far bigger group of patients, particularly those with 10,000 or 100,000 patients in countries such as USA and China.

#### **Additional details of objectives and activities (Optional information)**

You **may choose** to include further statements, where relevant, about:

- policy on grant making;
- policy programme related investment;
- contribution made by volunteers.

## Contribution by volunteers

**alport uk mostly relied on voluntary help to run the activities over this period as for the previous seven years. Our community often reflect and remark the journey we've been on and the remarkable progress alport uk makes and their ability to support patients and deliver professional international events that appeal to all stakeholders.**

**We are incredibly grateful to the volunteers for this remarkable progress, especially for the many contributions from the following key and very motivated people:**

- **Wilma Calderwood** for her day-to-day moderation on our closed Facebook page, Alports Warriors, which saw the community double in size during the pandemic.
- **Sam Clarke** for cycling an incredible 4,776.02 miles around Europe, and raising over £20,000 to raise awareness of Alport Syndrome and funds for the 'Don't Wait Fund' to support patients with Alport Syndrome take up a new activity or hobby. Sam managed to cycle from Henley-on-Thames to Albania as the pandemic took hold across Europe. Ingeniously, once back in the UK he then set off from Lands End to John O'Groats to add to the kilometres and continue the challenge. Adventure Man Sam even has his own YouTube channel to share the exciting adventure on his bike and his experiences of living with Alport Syndrome:  
<https://www.youtube.com/channel/UCQJsO-IW8UvINcqHZU5qXAq>.
- **Alice Turner** for her tireless energy, enthusiasm and fundraising work, ideas and help with running alport uk and supporting what fundraising activities could be done during the pandemic and for keeping us all positive during a very worrying year. Alice also has a forensic knack of putting our annual accounts together and tracking down all receipts and invoices to make the accountant's role much easier as he prepares the annual accounts.
- **Anna Mackay** for working with us remotely, whilst based in Portugal, to develop ideas for the Alport Syndrome Alliance, explore contacts in Sweden and be the main operational support co-ordinating speakers and moderators for The 2019 International workshop on Alport Syndrome in Italy. She kept us smiling and the workshop ran incredibly smoothly.
- **Rebecca Moule** for volunteering for us for a number of months, whilst on furlough. Rebecca set up the process and recruited the team to run the Alport Online Workshops during the pandemic and she came to Siena to run the logistics for the workshop. Working with Anna Mackay and the local team in Siena, the workshop ran without a hitch and everyone loved every aspect of it as Rebecca had thought of every detail and had back up strategies for any issues.
- **Carole Taylor**, the grand-daughter of Cecil Alport who kindly made contact with us and set up a campaign, using social media to raise awareness of Alport Syndrome using Verses for Alport ([versesforalport.com](http://versesforalport.com)) and capturing fun rhymes and light-hearted poems on a number of topics.
- **All those who raised money for us this year** – every penny makes a difference and this year people were very limited with what they could do to raise funds and increase our income. Particular thanks to:
  - **The Matthews family** who asked for donations to Alport UK in memory of Mrs Sonja Sinclair.
  - **Sarah Forrester and the Committee of the 2019 Kick Up Your Heels** gathering in Cirencester.
- **And a number of people who wish to remain anonymous** but to whom we are very grateful for their support and encouragement.

**We wish to thank our Scientific Advisory Committee** for fitting in so much time this year particularly to advise us on how to support the community as the pandemic took hold whilst they were all also very busy on clinical wards helping with renal issues. They answered all queries within 24 hours, ensuring the community remained as calm as possible at such a worrying time for renal patients. This amazing contribution was also having already given us a lot of their time in the previous year helping us prepare for and deliver The 2019 International Workshop on Alport Syndrome (which took place in Siena Italy 22-24 October 2019). We are so very grateful to the scientific community for their help to answer all questions and emails as and when they arose from patients or other scientists. Very many thanks to our UK Scientific Advisory Group:

- **Professor Frances Flinter**
- **Professor Danny Gale**
- **Professor Rachel Lennon**
- **Dr Omar Mahroo**
- **Professor Neil Turner.**

**Alport online workshops** – during the pandemic, we were overwhelmed with additional help from people who chose to volunteer for alport uk whilst stuck at home unable to work or go into the lab. A small working group of volunteers was formed which included: **Rebecca Moule** and **Harriet Carter** (who both volunteered for us whilst on furlough), **Susie Gear**, **Louise Hopkinson**, **Professor Rachel Lennon**, **Professor Jeffrey Miner**, **Sophie Emler** and **Richard Naylor**. We are so grateful for the quick thinking and inspiration from this group who together came up with the idea of running a series of **Alport online workshops**, using Zoom, which were provided for the international Alport community (patients and scientists) by Alport UK and with set up costs kindly funded by Kidney Research UK and special thanks to **Sandra Currie** for quickly realising the value of the opportunity for patients.

**We are so grateful to the amazing team – all volunteers - who helped us run and deliver** The 2019 International workshop on Alport Syndrome in Siena, Italy:

- **Alessandra Renieri, Chiara Fallerini and the team at the Molecular Genetics Unit at Siena University** for hosting the workshop with special thanks to **Professor Alessandra Renieri** the Programme content lead, for making it a very exciting agenda focused on Genetics and gene therapy.
- **A. S. A. L. Onlus (Italian Alport patient organisation)** for jointly hosting the patient meeting in Siena in advance of the workshop and for getting 50 Italian patients there including some young people who contributed to the activities of the Media team.
- **Professor Frances Flinter** for being counsel on the preparation of the scientific agenda and running of the workshop.
- **Rebecca Moule** for stepping in to organise and run the logistics.
- **Anna Mackay** for organising all the slides and speakers.
- **Sam Clarke and Remy Archer** for filming the workshop and Sam Clarke for producing two excellent videos to explain what we do and the outcomes at an international workshop.
- **Patrick Walker, Ceri Harrop and Kory Stout** for organising the Media team with the local Italian patient team and for helping the patients write, illustrate and produce a video about new treatments in Alport Syndrome in English, Italian and Chinese!
- **Aura Zealey, Reema Hassan, Noor Hassan, Hashim Hassan** for working together as the Media team with the local Italian patients at the workshop to promote the outcomes of the workshop.

- **Mary Lou McCarthy** for an incredible photographic record of the workshop, including lovely photos of all the speakers and activities.
- **Eleanor Beer** and **Sandra Howgate** for their graphic recording of the workshop.
- **Sophie Bell** for supporting us with the logistics for the The 2019 International workshop.

We wish to thank the Workshop Organising Committee (see list below) for helping us to design and deliver **The 2019 International Workshop on Alport Syndrome**. We are also grateful to our colleagues who run some of the other national patient organisations, such as **Andre Weinstock** (Alport Syndrome Foundation, USA), **Jacqueline van Kempen** (The Netherlands), **Maria José Cacharron** (Spain) and **Daniela Lai** (Italy), **Jessie Zhang and Mr Cai** (China), **Christof Finkler** and **Ute Rosenthal** (Germany), **Dave Blatt** (Australia).

#### **Workshop Organising Committee**

##### **for The 2019 International workshop on Alport Syndrome:**

**Professor Colin Baigent**, MRC Scientist, Hon Consultant in Public Health, Oxford, UK

**Professor Constantinos Deltas**, University of Cyprus, Molecular Medicine Research Center, Nicosia, Cyprus

**Professor Jie Ding**, Department of Pediatrics, Peking University First Hospital, Beijing, China

**Professor Frances Flinter**, Consultant in Clinical Genetics, Guy's Hospital, London, UK

**Professor Daniel Gale**, UCL Centre for Nephrology, London, UK

**Professor Oliver Gross**, Department of Nephrology and Rheumatology, Georg-August-Universität Göttingen, Germany

**Professor Clifford Kashtan**, Department of Pediatrics, University of Minnesota, USA

**Professor Bertrand Knebelman**, Necker Hospital, Paris, France

**Professor Rachel Lennon**, Wellcome Trust Centre for Cell-Matrix Research, University of Manchester, UK

**Associate Professor Julian Midgley**, Department of Paediatrics, Alberta Children's Hospital, Canada

**Professor Jeffrey Miner**, Washington University in St. Louis, USA

**Dr Laura Perin**, Saban Research Institute, University of Southern California, USA

**Professor Judith Savige**, University of Melbourne, Australia

**Professor Alessandra Renieri**, Professor of Medical Genetics, Director of Medical Genetics Unit, Azienda Ospedaliera Universitaria Senese viale Bracci 2, Siena, Italy

**Associate Professor Michelle Rheault**, Department of Pediatrics, University of Minnesota, USA

**Professor Roser Torra**, Fundació Puigvert, Barcelona, Spain

**Professor Neil Turner**, Professor of Nephrology, University of Edinburgh and Consultant Nephrologist, Royal Infirmary of Edinburgh, UK.

#### **Patient representatives:**

**Dave Blatt**, Alport Foundation of Australia

**Maria José Cacharron**, Spain

**Susie Gear**, alport uk

**Andre Weinstock**, Alport Syndrome Foundation, USA

**Daniela Lai**, A.S.A.L., Associazione Sindrome di Alport, Italy

**Julia Schifter**, Alport Foundation Israel

**Christof Finkler**, Alport Selbsthilfe, Germany

**Jessie Zhang and Mr Cai**, Chinese patient group, China.

**We also very much value the funding and support of a number of important organisations and charities:**

- **Kidney Care** (was British Kidney Patient Association) for advice and support, particularly through the pandemic.
- **Kidney Research UK** - with specific thanks to **Sandra Currie** and colleagues for so quickly approving a grant to pay for Alport UK's Zoom webinar subscription when the pandemic hit. We were so grateful to them for recognising we needed urgent help and for their continued support at a time when their own funds became very limited and they had to review their own operations.
- **Alport Syndrome Foundation (USA)** – with specific thanks to Andre Weinstock and Janine Diebel for their continued collaboration on the international research agenda out at the 2019 international workshop in Siena and Joy Toal particularly for connecting and sharing her experience to support patients on Alport Warriors during the pandemic.
- **A couple of charities who wish to remain anonymous** for both their financial support and advice which is very much appreciated.

There are also a number of people we would like to recognise for their contributions to our projects. Although we pay them for the project work they do, each has given way more time and ideas than they charge us for. Their continued support we very much appreciate:

- **Eleanor Beer** and **Sandra Howgate** – translate the complex scientific information into easy-to-understand graphics.
- **Jane Keightley** – for her marketing advice and on-going support to build the brand of Alport UK to raise its' profile along with communicating and engaging people in our aims and objectives and core activities. We also very much appreciate Jane's writing and editorial advice that sets the written tone for all our communications.
- **Robina Newman** – for her thoughtful brand and design work on various materials and generally helping us to create a bright and distinctive identity that sets the visual tone for our activities.
- **Clare Charrington** – for her organisation and administrative support running alport uk.
- **Sylvie Lloyd** – for her analytical work on researching the potential background and structures for an Alport Syndrome Alliance.
- **Davina Liddell** – for her administrative work in preparing us for the 2019 international workshop and the analysis of the feedback after it.
- **Penny Norrie** – for her work in helping us prepare the materials for the 2019 international workshop.
- **Harriet Carter** – who so ably then ran the process to deliver the series of Alport Online workshops once her furlough ended.

### Summary of the main achievements of the charity during the year

The achievements of alport uk this year build from last year and are summarised under the headings of our key objectives and areas of activity below. Overall, our main outcome is to create a more positive and brighter future for individuals and families living with Alport Syndrome. Being a rare and therefore small community, we aim to deliver sustainable strategic change for Alport Syndrome, using virtual networks and limited resources to effectively support patients and develop treatments for Alport Syndrome. Positivity is the main ingredient for all the support we offer – we aim to inspire and encourage people living with Alport Syndrome to be optimistic and understand there can be a brighter future.

Measuring our performance and listening to patient feedback on what works and adjusting what we do is vital: **Parents with a young daughter recently diagnosed with Alport Syndrome:** *“...always hugely impressed with you and the team for effort, organization, enthusiasm, info, results etc – well done it is so appreciated by us all out in the Alport community!”*

### The philosophy that underpins our performance

The Six Pillars of Wellbeing – long established as framework to think about mental health and wellbeing - is a useful structure to encourage positive outcomes for individuals and families living with Alport Syndrome. The Six Pillars that inspire our activities:

- **Stress management** – keeping the community calm and informed with the latest information, so they can become more independent, strong and resilient over time
- **Nutrition** – inspiring the community to eat healthily to protect their kidneys for as long as possible and when on restricted diet, explore new foods they can eat
- **Community** – connect to reduce the feeling of isolation caused by having a rare disease that few others either know or understand
- **Sleep** – ensure the community members can have a routine with good sleep to enable them to deal with the rollercoaster journey that some individuals and families face as part of living with a rare disease and coping with critical events along the way, such as hearing declining, kidney failure and eye issues.
- **Exercise** – we know cardio vascular exercise is good for the kidneys. It is also vital to rebalance the chemical impact brought on by the feeling of anxiety that overwhelms some patients living with the fact that their kidneys may fail at some unknown time in the future
- **Meaningful activity** – encourage individuals, families and researchers to connect around a shared objective of helping our community in some way, whether it be volunteering for our community, advocating, fundraising, collaborating on research or useful information or sharing stories to help others living with Alport Syndrome.

### As a tiny charity we are very clear what we can do

Supporting a rare disease that impacts 1 in 10,000 in a population is a challenge as there are few people who have it, who want to research it or fund it. So as a charity we think wisely about how we use our strengths, capabilities and resources and how to collaborate to complement these. Our volunteers have strong capabilities in delivering commercial innovation and collaboration across virtual networks of international

stakeholders around the world. Some examples of the principles that guide what we do in five key areas of our work:

1. **Support network:** with a small isolated patient community with such differing needs, we like to deliver **personal support in a timely way that delivers practical advice** and solves practical issues. alport uk's role is to empathise, understand the needs/issues, advocate for patients (and researchers) and support delivery of solutions. With our limited resources, this often means facilitating patient/researcher access to resources. For example, alport uk facilitates patients getting the right diagnosis via genetic testing, understanding treatment options or facilitating the grant application process for holiday breaks via Kidney Care's grant system. alport uk also writes letters of support for researchers to facilitate grant applications for Alport research.
2. **Provision of information:** with a diverse community and a very complex condition to explain, we try out different ways to provide information in a **variety of formats that suit different stakeholders**. With many of the community facing critical medical decisions as young adults, increasingly we use **short videos, social media and engaging activities to enable the patient community to engage in formats and content they find valuable**. For example, we encourage young adults to become our 'media team' at events, to engage in content, choose what is important and create videos and social media content themselves. See the video patients created about clinical trials and new treatments: <https://youtu.be/JRsJtUu8Lh8>. This was translated into 3 other languages by the patients working together on the script. We also publish **scientific information in the appropriate international journals so that it is peer reviewed and globally available** for researchers, clinicians and patients.
3. **Support research:** with limited funds and fundraising capability, we choose to focus our efforts to **inspire and facilitate collaborative behaviours such as information and resource sharing to facilitate and accelerate innovative ways of working and the development of new treatments and knowledge**. For example, we **facilitate the international research community coming together to share and exchange ideas through a series of in person and online international workshops**. This strategy aims to create a vibrant international research community that attracts more researchers and pharmaceutical or biotech companies interested in developing new treatments. These activities complement the activities of our colleagues in organisations such as:
  - Kidney Research UK – who raise money to fund specific UK Alport and kidney research projects eg elements of Rachel Lennon's lab based at Manchester University.
  - Alport Syndrome Foundation in the USA – who raise money to provide vital 'seed funding' for Alport research at an early stage of development.
4. **Support of a UK research registry:** with significant investment made by Kidney Care UK and Kidney Research UK into The **National Registry of Rare Kidney Diseases (RaDaR)** – the UK Renal Association's initiative designed to pull together information from patients with certain rare kidney diseases - alport uk support this vital project by **encouraging patients, clinicians and renal units to upload long-term clinical data into this database to enable**

**Natural History Studies in the future to progress Alport**

**Syndrome research.** This will give a much better understanding of how Alport Syndrome affects people. It will also speed up research. The value for:

- Alport patients:
    - Access to their clinical data online via Patient View, an online system which records blood and urine results, medications and clinic letters.
    - Ability to be contacted about future potential research studies or patient information events
    - Contribute to the increase in knowledge about their condition
  - Clinicians:
    - Share knowledge with other colleagues
    - Use RaDaR as part of a research study or clinical trial.
5. **Fundraising:** with so few people in the UK impacted by Alport Syndrome, awareness of the condition is limited and traditional fundraising by the public typically focuses on the key health areas of cancer, heart conditions etc. **We heartily encourage individuals and families living with Alport Syndrome to fundraise when inspired to do so, by providing support, encouragement and branded merchandise** (eg t-shirts, badges, wrist bands, shaking tins etc) to enable them to achieve whatever challenge motivates them. This means that **we raise significant funds for each major project or a programme of activities by applying for grants from larger charities or from pharmaceutical companies.** We support large fundraising events each year eg a dinner with an auction, a major activity eg swimming the channel or cycling round Europe etc.

**Highlights: achievements and performance this year****The pandemic: an opportunity to connect and engage**

The second half of alport uk's financial year was particularly challenging as the pandemic hit the world in early 2020. Vulnerable kidney transplant or dialysis patients and many Alport patients were advised to shield at home and the closed Facebook community – Alport Warriors - doubled in size from 350 members to over 750 members with members joining from all over the world, trusting and appreciating the excellent advice we get from our colleagues in the NHS. Each year we are contacted by more and more people as they are diagnosed with Alport Syndrome. This year, we had double the number of people contacting us for advice and specifically relating to COVID and the impact on renal patients. As we work as a 'virtual' organisation anyway, alport uk was able to easily respond to this increase in requests and with more of the community online – patients and researchers – more people were able to help each other. This engagement from the wider community was so valuable for all and so alport uk thrived in a really positive way, despite the pandemic. It was an opportunity for more to engage and more got value from this engagement.

**Support network proactively increased during the pandemic**

As many Alport patients were asked to urgently isolate in March 2020 due to COVID, ahead of the UK population understanding what was going on, our support activities dramatically changed. We were very

grateful to our Alport colleagues in China (Professor Jie Ding particularly) and Professor Colin Baigent who warned us of the emerging situation in Wuhan and helped us be ahead of the questions as they arose from the community. This set us up to be proactive in our advice for people living with Alport Syndrome, and was invaluable in keeping the community as calm as possible through a very worrying few months.

Before the charity existed in 2013, with Alport Syndrome affecting 1 in 10,000 people, it was typical that a family diagnosed with Alport Syndrome would never have met or talked to anyone outside their own family impacted by the condition. There was no support network and no mechanism for connecting individuals and families. People felt isolated. Through regular National Alport Information Days, our web site and closed Facebook page, support networks developed and each year the community feels stronger, more connected and able to deal with issues as they arise and particularly as we work through challenges together. People don't feel alone anymore. This infrastructure proved invaluable in supporting patients through the early unknown stages of the pandemic.

**Young woman in her 20s with a young daughter, both impacted by Alport Syndrome and mother needing a transplant urgently,** commenting about young adult workshop: *"It was really good to not feel so alone."*

**Young male patient from Georgia with no support locally,** but joins the online workshops to understand more about Alport Syndrome: *"Thank you so much. Really appreciate what you guys are doing."*

Some of the key support network achievements over the year:

- At the time of writing our Facebook Alport Warriors increased to over 800. The community quickly doubled during lockdown as people sought information online. Some members are regular contributors and the conversations are becoming more specific as people feel more connected as a community that is getting to know each other better and value each other's thoughts and opinions. The topics discussed include COVID, kidney donation, transplant successes, successes at the annual Transplant games, celebrating birthdays, links from other Alport Facebook sites, fundraising things, and a range of questions about Alport Syndrome, its' symptoms and side effects. There was one very touching story of a teenager who attended our first information day in London with his parents. The teenager met one of our inspirational and celebrated patients who has now had three transplants. After the teenager had their transplant, the two of them met up again at the Transplant games and shared a picture on Facebook. Connection with others who are in a similar situation is clearly valued by some people in the Alport community. Connection is not valued by all, so we aim to provide support for individuals or families in other ways to suit their needs.  
**Following the support we gave the parent of a young Alport patient facing kidney failure and living in unsuitable accommodation** for their condition: *"Hi, I just wanted to let you know that the council have agreed to fully refurbish (patient name)'s wet room after it went to a panel meeting last week...Thank you ever so much for your continued help and support."*
- We continued the dissemination of information and support from the first five Alport Information Days held in London (December 2012), Edinburgh (September 2013) and Birmingham (February 2015) and Manchester (November 2015), London (January 2017) and

Manchester (2019) for both patients and carers, including:

- Sending out information electronically – there was a high number of enquiries about information for women and girls living with Alport Syndrome.
- Answering enquiries emailed to us at [info@alportuk.org](mailto:info@alportuk.org) and phone calls sent to our landline number of 01793 847264 and putting people in touch with experts to answer their questions or with other families to share stories and experiences.
- Eg **A Dad contacted us as daughter wanting to start IVF and concerned about whether her side of the family has inherited Alport Syndrome like her cousin and wanting advice on best way to get a diagnosis in the COVID environment:** *“Thanks Alport UK – and to the Professor for the prompt & concise response. Your advice is crystal clear.... Thanks again for your help.”*
- When patients contact us for advice on specific topics, we put them in touch with the relevant clinicians, experts. Initially, much of this was done via email, but now we connect people through Alport Warriors, our phone line and email. Alport Warriors is our closed Facebook page where people share experiences of living with Alport Syndrome. **Parent of one young Alport patient facing transplant who we connected up with another young person who recently had a transplant:** *“Thank you. We have seen a big change in our son since he started talking about his worries and the extra support seems to be what he needs now.”*

#### Provision of information

With the help of our scientific advisors, we got advice early as the pandemic emerged and were able to keep one step ahead of the barrage of questions with daily posts on our closed Facebook page – Alport Warriors - to the community to answer queries as they arose. We posted the same information on the Alport Syndrome Foundation’s USA Facebook page in parallel as they have a number of UK patients as members. The USA Facebook page admins were incredibly supportive and we worked together to make sure that the international community benefited from the practical advice we got from our scientific advisors. This timely information reduced the anxiety in the community at a very challenging time. As everyone’s circumstances were different, we provided specific information to help patients work out their own risk levels and the necessary personal actions they needed to take to protect themselves from the virus. This built-up personal confidence and resilience as people took control of their own situations. This approach informing people to enable them to take control and build resilience was vital as our community has so many differing needs, many different age groups, are in differing stages of renal failure, undergoing different types of renal replacement therapy and many patients and family member were also from other countries seeking what advice they could get. We are very proud of the alport uk team, how they anticipated queries, increased the advice and information to enable people to stay as calm as possible, including sourcing food banks and writing letters to employers to explain the needs of their employees with Alport Syndrome. We are incredibly proud of the patients, their positive and pragmatic approaches to looking after themselves and helping each other across the community at a very concerning time.

Sometimes it was most helpful to connect young people to mentor each other when facing particularly challenging times such as declining kidney

failure and transplants: **Parent of one young Alport patient facing transplant** who we connected up with another young person who recently had a transplant: *"Thank you. We have seen a big change in our son since he started talking about his worries."* **Young Alport patient needing a transplant:** *"I think it's not actually as bad as it sounds to be fair...it really helped for me to understand what exactly actually goes on"*

During the pandemic, with most of our community – individuals and families living with Alport Syndrome and all the Alport researchers – isolating or working in their homes, we created **Alport Online Workshops, a series of online workshops featuring topics impacting patients and the latest Alport research from all over the world:** <https://tinyurl.com/y9cuhgby>. The first workshop was about COVID and the impact on kidney patients. The online audience was over 70 people, but the video was put onto YouTube after and received over 450 views. Subsequent workshop topics, requested by patients wanting more information, included for example: Alport eyes, Alport genetics and work by lab researchers in Manchester and USA. During the pandemic and various national lockdowns, the Alport online workshop team went on to produce a total of 20 online workshops including a 'Drop in' session one evening: **Mother with a teenager daughter with Alport Syndrome:** *"I think it's lovely just to have coffee type chats over zoom for the Alport Community however many join. Wishing you all at Alport U.K. a lovely weekend after all your hard work, as a family affected by Alport, we very much appreciate it!"*

With our young adult group, as the most critical group facing declining kidney function just at the time they are trying to leave home, build careers etc, their feedback increasingly indicates that short videos are the most useful way of sharing information. We now use these short videos to explain Alport Syndrome and share patient stories. Our most shared videos include three filmed and produced for alport uk by filmmaker, Sam Clarke who is also a young person living with Alport Syndrome:

- **Fighting failure:** Sam Clarke, prepared for his challenge to cycle round Europe <https://youtu.be/1A1adCj-cvo>. We use this video for newly diagnosed patients as it explains the challenges of living with Alport Syndrome but Sam ably inspires patients with the fun activities that he does such as sky diving, cycling and generally having fun. This is such an important message for young patients.
- **Patients inspire Alport Syndrome research**, a collaboration between alport uk and University of Manchester: <https://www.youtube.com/watch?v=77p7nzKz6nc>
- **Highlights from The 2019 International workshop on Alport Syndrome**, Siena, October 2019: <https://youtu.be/QH8mDTmKaVU>

A very successful **series of two-minute animated videos were written, illustrated and produced by a group of our young people with Alport Syndrome for their peers**. The writing of the videos and working with the clinicians to make them scientifically accurate was a valuable process for the young people to engage in understanding Alport better as sometimes they can be in denial about what is important to keep them healthy or sources of support. Topics included:

- Why Alport research is important <https://youtu.be/TU0m6gGvTFY>
- Alport Community <https://www.youtube.com/watch?v=5qJEtmhcCIU>
- Alport Syndrome: Know your numbers <https://www.youtube.com/watch?v=jtkmJdwG0nE>
- Kidney transplants and Alport Syndrome <https://www.youtube.com/watch?v=Gd4yB9PVnM0&t=52s>

- Update on clinical trials and potential treatments for Alport Syndrome (written in English and translated into Italian, German and Chinese by the young patients with Alport Syndrome) at The 2019 International workshop in Siena, Italy <https://youtu.be/JRsJtUu8Lh8>

When someone is diagnosed with Alport Syndrome, some of the regional genetics units e.g. at Guy's Hospital and some of the paediatric renal units e.g. at Manchester University Hospital, have a small leaflet giving some summary details about the condition and our alport uk leaflets. Beyond this, there is an array of information one can find on the web, but it is hard to decipher what is medically correct or up to date. On our website is:

- **A summary leaflet for Alport UK** to encourage people to get in touch with us – this is now handed out at the genetics units when people are newly diagnosed with Alport Syndrome. It was also sent out, along with laminated posters with our contact details on, to all the main adult and paediatric renal units around the country to advertise where to find out information about Alport Syndrome
- **A dictionary of scientific terms** to help patients learn more about the biology of Alport Syndrome, so when their clinicians explain things, they understand a bit more about what they are talking about as it is so hard to pick much up in a short clinic appointment.
- **Definitions of related rare renal diseases** – Nephrotic Syndrome, IgA Nephropathy, Membranous Nephropathy and Focal Segmental Glomerular Sclerosis (FSGS) that sometimes overlap with Alport Syndrome or people can be diagnosed with more than one disease or if people are misdiagnosed.
- **Videos available through our website** ([www.alportuk.org](http://www.alportuk.org)) and a special section on Alport Syndrome on [www.healthtalk.org](http://www.healthtalk.org) (<http://www.healthtalk.org/peoples-experiences/long-term-conditions/alport-syndrome/topics>) of our key experts talking about specific aspects of Alport Syndrome. Topics are varied about all aspects of living with Alport Syndrome and include: Genetics, An introduction to Alport Syndrome, Hearing and hearing aids, caring for people with Alport Syndrome, medication, women with Alport Syndrome etc.
- **Our website remains an invaluable resource.** We are currently fundraising to improve our website [www.alportuk.org](http://www.alportuk.org) to update and make the information clearer and more accessible and to answer the questions we have received over the last year or so through our closed Facebook page, Alport Warriors. **Mother contacted us about vaccination for a 19-year-old daughter with Alport Syndrome and on strong medication:** *"Thank you for putting my mind at rest. I got your contact details from the Alport UK website. My daughter said it's not really her thing joining groups. Shame, as I think it's really good that support is out there. Thank you for your support."*
- **Information about new clinical trials** that patients can sign up is shared through our website 'Latest news' section, through our closed Facebook page (Alport Warriors) and through directly emailing our database of patients.

### The support of research

With limited funding for research, alport uk's strategy is use our small amount of funding to facilitate an Alport research collaborative plus support and encouragement for the research community in working together to create a vibrant research community that attracts more researchers and pharmaceutical companies interested in developing new

treatments.

The major programme for the first half of the year was to deliver our fourth 'in person' international workshop – The 2019 International workshop on Alport Syndrome in Siena, co-hosted with the Italian national Alport patient association – A.S.A.L. Onlus – and Professor Alessandra Renieri's wonderful genetics team at Siena University. With participation from patients and scientists all over the world, the Siena workshop focused on genetics and gene therapy and was the largest collaboration to date with the international Alport community delivered entirely by alport uk volunteers in collaboration with the team in Italy – the key achievements are listed below including the collaborative effort on sponsorship to provide the funds to make the workshop possible.

A specialist international 'Alport mutations/variants workshop' was then held in London in February 2020 for all those involved in lab testing and diagnosing Alport Syndrome around the world to collaborate on and publish international guidelines and clinical standards to improve diagnosis. Professor Judy Savige from Australia lead the effort, with over 50 experts participating in person from all over the world just before the UK went into Lockdown, supported by alport uk.

When lockdown happened and with many patients shielding at home and the alport researchers unable to get into the lab, people had time on their hands and we quickly formed a small working group to create a series of Alport online workshops. The first workshop, delivered on 12 May 2020 focused on answering COVID questions and explained the new arrangements for Alport genetic testing as the lab facilities moved from Guy's in London to Bristol. The workshops were run monthly thereafter with a few extras fitted in on topics people were particularly keen to hear about eg eye complications in Alport syndrome. The workshops featured scientists from all over the world. **From a patient advocacy person in another country:** "...congratulations for the Alport workshops. It is a fantastic way to keep connected and continue learning about Alport Syndrome."

Over the year:

279 participants from 33 different countries participated in the first 14 online workshops

38 speakers presented 42 of the latest research projects from 8 different countries.

15 moderators contributed from 3 different countries and we aim to increase the diversity for the next set of workshops

So far, the videos on YouTube, <https://tinyurl.com/y9cuhgby>, received 1,786 views.

The researcher and clinician participants represented a range of different disciplines: basic science, lab technicians, adult and paediatric nephrology, clinical and laboratory genetics, pathology, ophthalmologists, transplant surgeons, dialysis specialists, academics.

Some of the workshops featured specific labs and were an opportunity for early career researchers to present their work to the international Alport community and get feedback and questions. In the spirit of 'collaboration' – such an important principle of alport uk's strategic direction – the pandemic actually enabled us to accelerate our progress, share more research to a wider audience and at a reduced cost compared with the four 'in person' workshops delivered previously. The lock-in format of the 'in person' workshops meant the community had

spent plenty of time getting to know each other over the last 6 years and this investment in enabling the community to 'get to know each other' and collaborate paid off as we worked online. Busy clinicians, battling to deliver frontline care to patients in hospitals all over the world, still made time to join us online and connect.

After their presentations, a number of the researchers fed back stories to alport uk about how the workshops 'furthered their science'. Presenting researchers confirmed that members of the Zoom audience on their workshop reached out to them via email to:

- set up new collaborations
- initiate new collaborative research projects and
- provide vital new input to current projects.

The online workshop format was a catalyst for new research, thanks to the pandemic and the inspiration of the team who devised the format:

**Professor Rachel Lennon, Professor Jeffrey Miner, and two members of the Lennon lab - Louise Hopkinson and Richard Naylor.**

alport uk is incredibly grateful particularly to Louise and Richard, who worked from home whilst unable to get into the lab, and helped us identify new research to feature, created material to post on social media, participated in the discussions and helped 'translate' some the difficult terms into a dictionary of layman's terms to make the science more accessible for patients with no science background.

Feedback from patients:

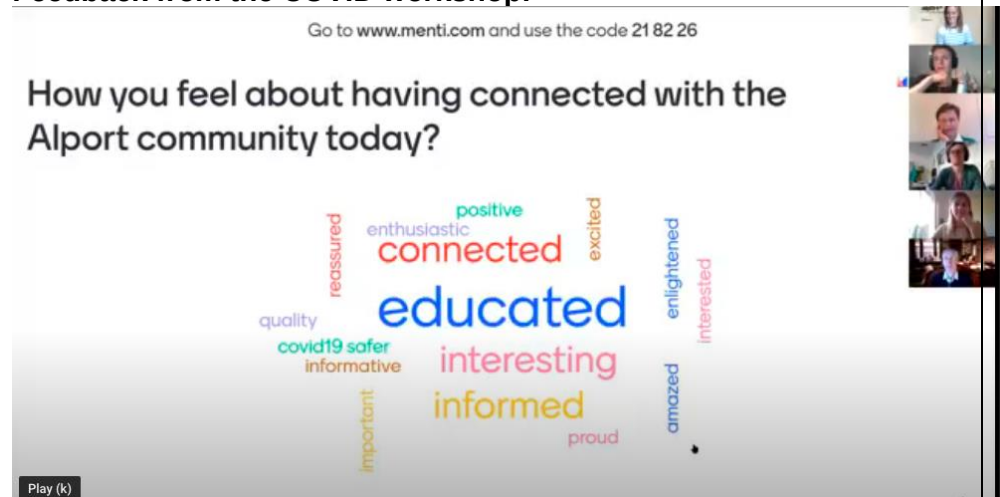
*"It was so enlightening to find out these people (the researchers) are doing their very best on our behalf. I had no idea of the methods used for this kind of research. They seemed to be a happy team too!"*

*"It was reassuring that such research is carrying on."*

*"Fantastic idea and I'm sure the rest of the Alport community would be very interested in seeing this. I did not have a clue so much was going on and to hear all the info has made me feel very hopeful. Many thanks again"*

After each workshop, we invite people to submit one word to express how they feel after a workshop. For example:

**Feedback from the COVID workshop:**



### Feedback from the 'Planning a family' workshop:

## Word Cloud



### Feedback from the 'Flozins as a potential treatment' workshop:

Share your thoughts on todays topic!



The science to better understand what causes Alport Syndrome is very complicated. The more we know about the genetics, the more complicated it is with modifier genes impacting the Alport genes creating a vast range of phenotypes. Much of the science was daunting for some patients and the patients provided valuable input to the workshop programme planning for the following year to balance the programme with other topics to feature more patient-friendly science relating to transplantation, dialysis, hearing etc.

## Alport research indicators in 2019

In the 1990s, groups of leading clinicians, academics and scientists regularly met to discuss topics related to Alport Syndrome. They published a number of key papers about Alport Syndrome, but the regular meetings stopped. In 2012, alport uk commissioned a web audit of people publishing material on Alport Syndrome through to the current day and prepared a report on the status of research into Alport Syndrome. This report was used to identify the missing areas of activity and needs for research including:

- A shared international strategy and plan for Alport Syndrome research
- New research ideas and projects to develop new treatments and therapies and more research generally

- Ways to reengage the leading experts in Alport Syndrome
- Co-ordination of national patient registries
- The need to engage the pharmaceutical industry in developing new treatments
- How alport uk could complement the current contributions of other national patient organisations, for example the Alport Syndrome Foundation who currently run an excellent programme of seed funding for Alport research, commissioning projects each year
- How Alport Syndrome is a model renal disease and that new treatments developed for Alport Syndrome could help other patients living with renal disease.

In 2019, to check on the performance of our investment to get researchers together through these workshops, alport uk circulated a simple survey with the Workshop Organising Committee members and their research teams (ie not the full Alport research community, just some of the key members) to understand the impact of the international workshops, emphasis on collaboration and how much research is now being done. Overall the numbers indicate a very healthy research community to whom we are incredibly grateful for all they do to help with the awareness and understanding of Alport Syndrome by delivering:

- 131 publications with the majority in international journals
- 18 book chapters
- 38 major grants to fund the ongoing research.
- over 90% of the projects and publications were collaborative efforts.

These survey results confirmed to alport uk that our efforts to drive collaboration and accelerate research are delivering the results we need.

To continue the collaborative international workshops in Oxford (2014) Göttingen, Germany (2015) and Glasgow, Scotland (2017), alport uk facilitated the delivery of a fourth workshop in the series: **The 2019 International Workshop for Alport Syndrome** in Siena, Italy. Even the preparation work, for the workshop in itself, further consolidated interactions among the various stakeholder groups and addressed the progress being made to move forward with focus on the shared mission to find a long-term multi-target therapy for Alport Syndrome resulting in a lifelong delay of renal failure. In Siena at the 2019 workshop, there were 146 participants including 38 patients and representatives from 12 pharmaceutical companies who came together to continue the progress on a research strategy and collaboration effort. Outputs from the workshop included:

- 46 abstracts highlighting the latest Alport research – a significant growth from the last workshop.
- Drafted a workshop summary ready to publish in a genetics publication.
- A graphic book charting the progress of the science to share with patients and illustrate the work going forward.
- An increased number of countries engaged with new communities emerging in pathology and across eastern Europe eg Croatia, Poland and the Baltic region.
- Further consolidated interactions among the various stakeholder groups and addressed upcoming steps to move forward on the shared mission.
- 12 pharmaceutical or biotech companies participated, a number who are researching Alport Syndrome and some planning or considering clinical trials
- Five pharmaceutical and two hearing aid companies sponsored the workshop.

After this fourth important workshop to reconnect the Alport Syndrome

research community, alport uk intended to restart the conference calls with the international workshop organising committee to share progress, keep the researchers engaged in delivering the agenda agreed at the workshop and start planning the fifth and sixth workshops in Beijing, China and Calgary, Canada respectively. However, when the pandemic hit and with most of our Workshop Organising Committee being kidney doctors, the doctors were needed on the wards to help with the kidney complications that COVID caused. So, the Alport Online Workshops were started instead and plans started for an Online International workshop for 2021.

### **Support of a UK research registry**

In parallel to alport uk being set up, the Renal Association established a working group on Alport Syndrome, funded jointly by Kidney Research UK and Kidney Care (previously British Kidney Patient Association) to support the development of a national renal registry of patients, called RaDaR which is linked to a system that patients can access, called Renal Patient View. Some of the trustees from alport uk contribute to the working group on an ongoing basis to devise ways of promoting RADAR to patients and clinicians across the UK. At the time of writing, RaDaR has over 800 patients registered as having Alport Syndrome. alport uk specifically contribute to the support of this UK research registry of patients and an international alliance of patient registries by:

- Promoting the importance of RaDaR and Renal Patient View to patients at Alport information days, along with information about the value of RaDaR to research
- Making the research registry a central part of the national contribution to international efforts to collaborate on research coming out of the 2014, 2015, 2017 and 2019 International Workshops on Alport Syndrome and proposing to make it one of the key topics for 2021.
- Continuing the development of the UK's contribution to an international alliance of Alport Syndrome research. An 'alliance' is necessary as there are not enough patients in the UK for Clinical trials and so pharmaceutical companies will want to do trials in a number of different countries to try new therapies.

If anyone reading this annual report is interested in more information or to get involved or support us with activities or fund raising, please email Susie Gear and Julia Skelding at [info@alportuk.org](mailto:info@alportuk.org) or call us on 01793 847264.

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

Reserves from fundraising are kept in separate Barclays bank savings accounts, labelled for their specific use. For example, for:

- Information Days (Alport UK Meetings)
- Development of information, website and marketing material (Alport UK)
- Facilitating the International Workshops on Alport Syndrome (Alport UK Research)
- Research commissioned by Alport UK (Alport UK Schools)

### Details of any funds materially in deficit

No funds in deficit

### Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

alport uk's principal sources of funds this year were again more diverse than in the previous year:

- Personal donations
- Limited personal fund-raising activities such as running events, hosting charity evenings, cake sales etc.
- Just Giving and Virgin Money Giving pages of sponsorship for various activities that our community get involved in to raise funds for alport uk – this year Sam Clarke's amazing efforts raised over £20,000 for a new fund we will call the 'Don't Wait Fund' to support patients taking up a new sport or hobby.
- Social media fundraising pages eg Facebook
- PayPal payments/donations to Alport UK
- Sales of Christmas cards, t-shirts and badges
- Standing orders from a couple of very supportive patient families
- Customised shaking tins located in retail venues
- Donations from larger charities or foundations for specific activities and particular thanks to Kidney Care UK and to Kidney Research UK
- Grants given by a number of pharmaceutical companies to fund The 2019 International workshop on Alport Syndrome: alport uk are very grateful to the support from Sanofi Genzyme, Regeneron, Retrophin (now Traveo Therapeutics), Novartis, REATA Pharmaceuticals and two hearing aid companies Audibel and Audiomedical Solutions.
- Income from the registrations for The 2019 International workshop on Alport Syndrome
- One of our Trustees loaned us a sum to partly fund the next stage of the healthtalk.org project and a number of expenses in the early stages of the charity. The loan is interest free and there is no deadline to pay it back, just when funds are available.

As funds were all allocated to specific activities that support our key objectives this year, there was no opportunity for investment during this accounting period.

## Section F

## Other optional information

# Alport UK

## Report and Financial Statement For the year ended 31<sup>st</sup> July 2020

Charity number: 1154774

Shilton Accounting Services  
1<sup>st</sup> Floor, 1 The Clock House  
Brize Norton Road  
Carterton  
OX18 3HN

**Alport UK**  
**Charity number: 1154774**  
**Legal and administrative information**

Charity name: Alport UK  
Charity registration number: 1154774  
Type of organisation: Charitable Unincorporated Organisation

Registered office and business: PO Box 329  
Cirencester  
Gloucestershire  
GL7 9JA

Trustees: Colin Baigent  
Jules Skelding  
Daniel Gale  
Susie Gear  
Frances Flinter  
Rachel Lennon  
Neil Turner

Accountants: Shilton Accounting Services  
Certified Practising Accountants  
1<sup>st</sup> Floor, 1 The Clock House  
Brize Norton Road  
Carterton  
OX18 3HN

**Alport UK**  
**Charity number: 1154774**  
**Independent Examiner's report to the Trustees of Alport UK**

I report on the accounts of the Charity for the year ended 31<sup>st</sup> July 2020 which are set out below.

**Respective responsibilities of trustees and examiner.**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under section 43(2) of the Charities Act 1993 (the 1993 Act) and that an independent examination is needed.

It is my responsibility to:

- a) Examine the accounts (under section 43(7)(b) of the Act.
- b) To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 43(7)(b) of the Act.
- c) To state whether particular matters have come to my attention.

**Basis of independent examiner's report.**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence which would be required in an audit and consequently I do not express an audit opinion on the accounts.

**Independent examiner's statement.**

In connection with my examination, **no** matter has come to my attention

1. Which gives me reasonable cause to believe that in any material respect, the requirements of a) to keep proper accounting records in accordance with section 41 of the 1993 Act and b) to prepare accounts which accord with the accounting records and to comply with the requirements of the Act, have not been met.
2. To which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

David Cuthbertson – ICPA Cert Acc (Open)  
Shilton Accounting Services  
Honeystone Cottage  
Ladburn Lane  
Shilton  
OX18 4AJ  
30/12/2020

**Alport UK**  
**Charity number: 1154774**  
**Director's report for the year ended 31<sup>st</sup> July 2020**

The trustees present their report and financial statement for the year ended 31<sup>st</sup> July 2020.

**Objects** – The relief of sickness and the promotion of health of those people suffering from Alport Syndrome, in particular, but not exclusively by:

- a) The establishment and facilitation of a support network for Alport Syndrome patients, carriers, their families and carers;
- b) The provision of information on Alport Syndrome;
- c) The support of research into Alport Syndrome both in the UK and internationally;
- d) The support of a research registry in the UK and an international alliance of national registers.

**Governing document** – the charity is governed by a constitution based upon a Charity Commission document that was adopted on 27<sup>th</sup> November 2013. A copy of the full governing document can be obtained from the charity.

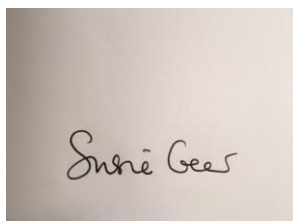
**Trustees** - The overall responsibility of the organisation rests with the Board of Trustees. The selection of Trustees is designed to supplement the existing skills and expertise of the board and is governed by an informal skills assessment. The appointment of trustees is made in accordance with the constitution.

**Risk assessment** – Disclosure and Barring checks are carried out for all appropriate trustees, staff and volunteers. The Trustees have examined the major strategies, business and operational risks which the charity faces and confirm that systems have been established to enable regular reports to be produced so that the necessary steps can be taken to minimise these risks.

**Public benefit statement** – Alport UK is a patient-led organisation dedicated to facilitating a support and information network for all those affected by Alport Syndrome. Our vision is to ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life. This creates public benefits in health and community cohesion.

**Reserves policy** – The Trustees are actively trying to build reserves, with a view to being able to fund further research and to strengthen its support structure.

This report was approved by the Trustees on 27 February 2021 and signed on its behalf by

A rectangular box containing a handwritten signature in black ink. The signature appears to read 'Susie Gear'.

**Susie Gear**

**Alport UK**  
Charity number 115774

**Statement of Financial Activities (including Income & expenditure Account)**  
**For the year ended 31<sup>st</sup> July 2020**

|                          | <b>Restricted Funds</b> |           |              | <b>Unrestricted</b> |               | <b>Total</b>   | <b>2019</b>   |
|--------------------------|-------------------------|-----------|--------------|---------------------|---------------|----------------|---------------|
|                          | Research                | Meetings  | Don't Wait   | General             | Caxton        |                |               |
| <b>Income</b>            |                         |           |              |                     |               |                |               |
| Donations/ Sponsors      | 14,030                  | -         | -            | 31,339              | 8,111         | 53,480         | 57,009        |
| Delegate fees            | 17,060                  | -         | -            | -                   | -             | 17,060         | -             |
| HMRC Gift Aid            | -                       | -         | -            | 402                 | -             | 402            | 2,804         |
| Sale of books etc        | -                       | -         | -            | 164                 | -             | 164            | 254           |
| Exchange differences     | -                       | -         | -            | -                   | 228           | 228            | -             |
| <b>Total income</b>      | <b>31,091</b>           | <b>-</b>  | <b>-</b>     | <b>31,905</b>       | <b>8,339</b>  | <b>71,335</b>  | <b>60,067</b> |
| <b>Expenditure</b>       |                         |           |              |                     |               |                |               |
| Bank & service charge    | 77                      | -         | -            | 597                 | 9             | 683            | -             |
| Direct cost events       | 14,340                  | -         | -            | 17,199              | 13,518        | 45,057         | 7,886         |
| Administration           | 6,281                   | -         | -            | 6,442               | -             | 12,723         | 4,487         |
| Travel & subsistence     | 10,662                  | -         | -            | 1,960               | 1,650         | 14,272         | 12,192        |
| Internet/website         | -                       | -         | -            | 2,026               | -             | 2,026          | 1,408         |
| Marketing                | -                       | -         | -            | 247                 | -             | 247            | 4             |
| Insurance                | -                       | -         | -            | 672                 | -             | 672            | 672           |
| Subscriptions            | -                       | -         | -            | 282                 | -             | 282            | 501           |
| Bursaries/Grants         | 219                     | -         | 255          | -                   | -             | 474            | -             |
| Others                   | 219                     | -         | -            | -                   | -             | 219            | 216           |
| <b>Governance costs</b>  |                         |           |              |                     |               |                |               |
| DBS checks               | -                       | -         | -            | 391                 | -             | 391            | -             |
| Accountants' fees        | -                       | -         | -            | 960                 | -             | 960            | 960           |
| <b>Total expenditure</b> | <b>31,797</b>           | <b>-</b>  | <b>255</b>   | <b>30,777</b>       | <b>15,176</b> | <b>78,005</b>  | <b>28,327</b> |
| <b>Transfers</b>         | <b>(846)</b>            | <b>-</b>  |              | <b>(29,988)</b>     | <b>30,835</b> | <b>-</b>       | <b>-</b>      |
| <b>Net movement</b>      | <b>(1,553)</b>          | <b>-</b>  | <b>(255)</b> | <b>(28,860)</b>     | <b>23,998</b> | <b>(6,671)</b> | <b>31,740</b> |
| <b>Opening balance</b>   | <b>10,074</b>           | <b>94</b> | <b>2,684</b> | <b>54,364</b>       | <b>-</b>      | <b>67,215</b>  | <b>35,474</b> |
| <b>Closing balance</b>   | <b>8,521</b>            | <b>94</b> | <b>2,429</b> | <b>25,503</b>       | <b>23,998</b> | <b>60,544</b>  | <b>67,215</b> |

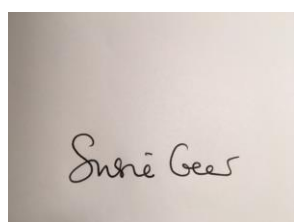
There are no recognised gains or losses other than in the Statement of Financial Activity.

**Alport UK**  
Charity number 115774

**Balance Sheet as at 31<sup>st</sup> July 2020**

|                                            | Notes | 2020   | 2019   |
|--------------------------------------------|-------|--------|--------|
|                                            |       | £      | £      |
| <b>Fixed assets</b>                        |       | -      | -      |
|                                            |       |        |        |
| <b>Current assets</b>                      |       |        |        |
| <i>Cash at bank</i>                        | 4     | 62,464 | 68,175 |
|                                            |       |        |        |
| <b>Total Current assets</b>                | 5     |        |        |
|                                            |       |        |        |
| <b>Current liabilities</b>                 |       |        |        |
| <i>Creditors falling due within 1 year</i> |       | 1,920  | 960    |
|                                            |       |        |        |
| <b>Net current assets</b>                  |       | 60,544 | 67,215 |
|                                            |       |        |        |
| <b>Assets less liabilities</b>             |       | 60,544 | 67,125 |
|                                            |       |        |        |
| <b>Represented by</b>                      |       |        |        |
| <i>Restricted funds</i>                    |       | 11,043 | 12,851 |
| <i>Unrestricted funds</i>                  |       | 49,501 | 54,364 |
|                                            |       |        |        |
| <b>Total funds</b>                         | 6     | 60,544 | 67,215 |
|                                            |       |        |        |

**Signed on behalf of the charity's trustees**



**Date: 27 February 2021**

**Notes to the financial statements**

**For the year ending 31<sup>st</sup> July 2020.**

**1. Accounting policies**

**a. Basis of accounting**

The financial statements have been prepared under the historic cost convention with items recognised at cost or transaction value unless otherwise state in the relevant notes to these accounts. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and reporting by Charities preparing their accounts in accordance with Financial Reporting Standards applicable in the UK and Republic of Ireland (FRS102) issued on 16<sup>th</sup> July 2014 and the Charities Act 2011. The trust constitutes a public benefit entity as defined by FRS102.

**b. Going concern**

The trustees consider that there are no material uncertainties about the trust's ability to continue as a going concern.

**c. Fund accounting**

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subject to restrictions on their expenditure imposed by the donor or through the terms of an appeal.

**d. Income resources**

All incoming resources are included in the statement of financial activities when the charity is entitled to the income and the amount can be quantified with reasonable accuracy. The following specific policies are applied to particular categories of income:

Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of financial activities when receivable.

Grants, where entitlement is not conditional on the delivery of a specific performance by the charity, are recognised when the charity becomes entitled to the grant.

Donated services and facilities are included at the value to the charity where this can be quantified. The value of services provided by volunteers has not been included in these accounts.

Investment income is included when receivable.

Income resources for charitable trading activity are accounted for when earned.

**Notes to the financial statements**

**For the year ending 31<sup>st</sup> July 2020.**

**e. Resources expended**

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

Costs of generating funds comprise of the costs associated with attracting voluntary income and costs of trading for fund raising purposes.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include accountancy and legal fees.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resources. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

**2. Staff costs**

The charity did not employ any staff in the financial year.

**3. Trustee remuneration & related party transactions.**

The trustees all give freely of their time and expertise without any remuneration or other benefit in kind. Expenses incurred on behalf of the charity are reimbursed at cost.

## Alport UK

Charity number: 1154774

### Notes to the financial statements

For the year ending 31<sup>st</sup> July 2020.

#### 4. Cash at bank.

|                                      |                |
|--------------------------------------|----------------|
| Barclays General Account 93696405    | £27,423        |
| Barclays Research Account 93725642   | £7,149         |
| Barclays Meeting Account 83477436    | £94            |
| Barclays Don't wait Account 33742210 | £2,429         |
| Caxton FX                            | £23,998        |
| PayPal                               | £1,371         |
| <b>Total</b>                         | <b>£62,464</b> |

#### 5. Creditors: Amounts falling due within one year

Accounting fee accrual £960.00

#### 6. Movement in funds

|              | Opening<br>balance | Incoming<br>resources | Outgoing<br>resources | Balance<br>31 <sup>st</sup> July 2020 |
|--------------|--------------------|-----------------------|-----------------------|---------------------------------------|
| Restricted   | £12,851            | £31,091               | £32,898               | £11,043                               |
| Unrestricted | £54,364            | £40,244               | £45,107               | £49,501                               |
| <b>Total</b> | <b>£67,215</b>     | <b>£71,335</b>        | <b>£78,005</b>        | <b>£60,544</b>                        |