

# 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

Postcode

### 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 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 (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation
Trustee selection methods (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.

<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 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.</li> <li>• 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.</li> <li>• Our public facing social media eg Facebook and Instagram pages are run by Susie Gear, Hannah Russell and some of the younger Alport Warriors.</li> <li>• 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).</li> <li>• 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.</li> </ul> <p>Trustees' consideration of the major risks &amp; procedures to manage them:</p> <ul style="list-style-type: none"> <li>• <b>Support</b> – 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</li> </ul>
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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

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 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.

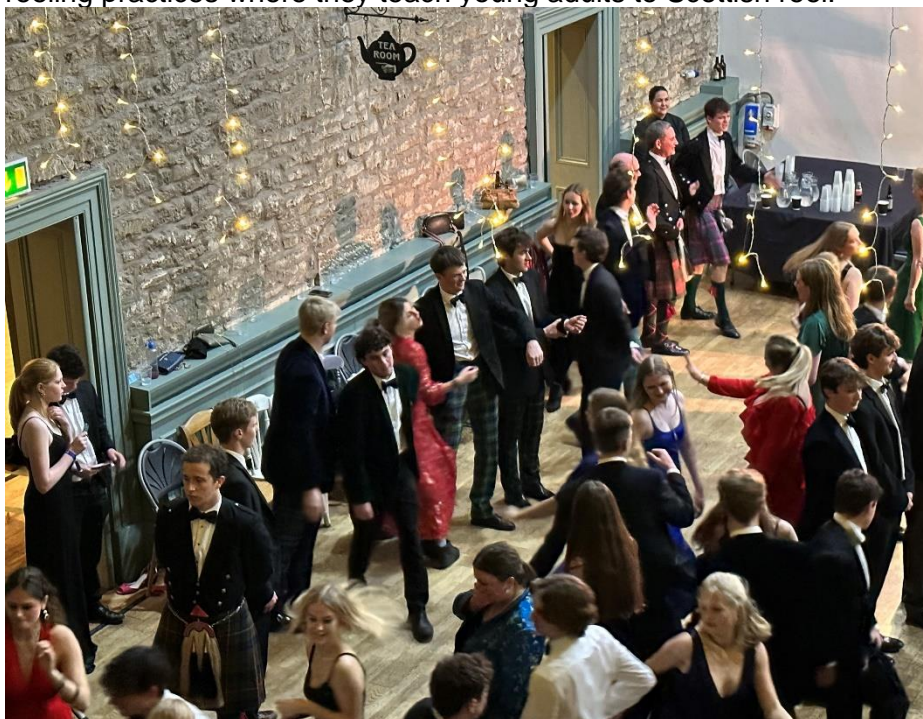


- **Disa Hunter**, who raised £2,580 and raised awareness of Alport Syndrome and Alport UK at her pop-up shop in Shetland in November 2023. Her family, friends and the Shetland community donated clothes, toys and other items, which Disa sold in her pop-up shop.



- **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>



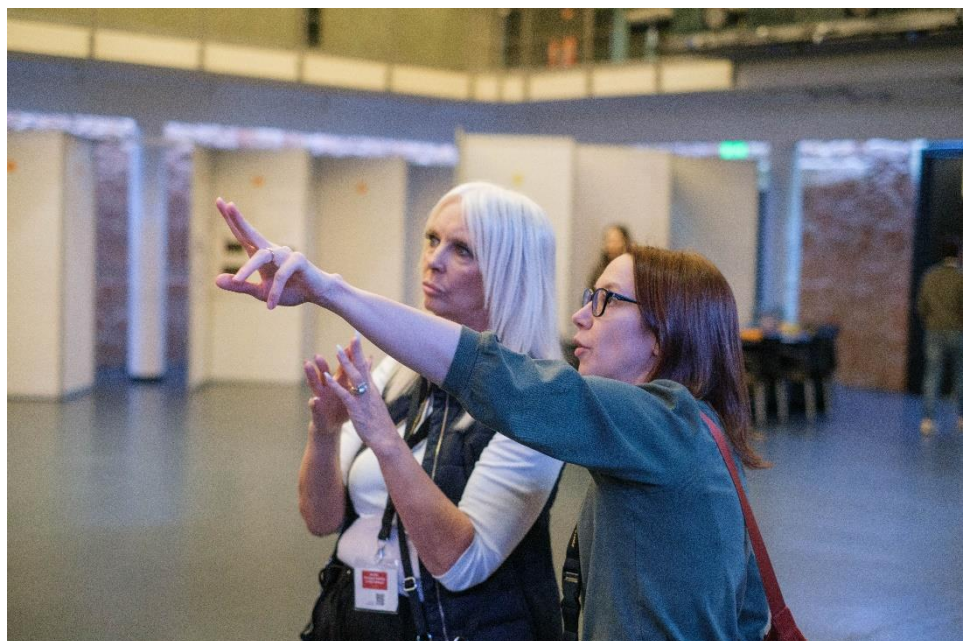
Sam Clarke filming at The 2024 International workshop on Alport Syndrome in Nicosia, Cyprus. See links above for examples of the 2-minute videos he makes.

- **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 0.0001	1 in 2300	Reference <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 - <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

A poster for a one-day workshop on Alport Syndrome in Singapore. The background shows a modern building at sunset. Logos for NUS, Alport Syndrome Alliance, and National University Hospital are at the top. A cartoon of two children is in the top right. The text is centered in white boxes.

**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.

Organised by:

A poster for the 2025 International Workshop on Alport Syndrome in Beijing. The background is a scenic view of the Great Wall of China at sunset. The text is in white boxes.

**Save the date!**

**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 Cirencester Gloucestershire GL7 3PX
Trustees:	Professor Colin Baigent Professor Danny Gale Susie Gear Emeritus Professor Frances Flinter Professor Rachel Lennon Amanda McLean Tim McLean Alice Turner Emeritus Professor 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 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**

	<b>Restricted</b>	<b>Unrestricted</b>	<b>Total</b>	<b>2023</b>
<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 balance	Incoming resources	Outgoing resources	Balance 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>