

# ANNUAL REPORT AND ACCOUNTS



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

For the year ended 31 July 2021

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

## Section A Reference and administration details

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

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

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

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

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

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

See table of Advisors over the page

| Type of adviser                                                                 | Name                      | Address                                                                                                                                                                          |
|---------------------------------------------------------------------------------|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <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>                                                               | Professor Frances Flinter | Emeritus Professor of Clinical Genetics, Guy's & St Thomas' NHS Foundation Trust<br>Genetics Department, 7th floor Borough Wing, Guy's Hospital, Great Maze Pond, London SE1 9RT |
| <b>Eye specialist</b>                                                           | Dr Omar Mahroo            | St Thomas' Hospital Campus, 3rd Floor South Wing Block D, Westminster Bridge Road, London SE1 7EH                                                                                |
| <b>PR, Communication and Marketing</b>                                          | Jane Keightley            | JK Branding and Communications Limited                                                                                                                                           |
| <b>Accountant</b>                                                               | David Cuthbertson         | Shilton Accounting Services Ltd                                                                                                                                                  |
| Name of chief executive or names of senior staff members (Optional information) |                           |                                                                                                                                                                                  |
| Susie Gear, Chief Executive                                                     |                           |                                                                                                                                                                                  |
|                                                                                 |                           |                                                                                                                                                                                  |

## Section B Structure, governance and management

### Description of the charity's trusts

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

### Additional governance issues (Optional information)

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

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

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

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

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

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

## Section C Objectives and activities

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

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

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

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

#### Public benefit – statutory declaration by Trustees

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

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

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

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

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

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

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

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

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

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

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

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

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

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

## Contribution by volunteers

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

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

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

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

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

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

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

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







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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

**Patient representatives:**

**Dave Blatt**, Alport Foundation of Australia

**Maria José Cacharron**, Spain

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

**Susie Gear**, alport uk

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

**Julia Schifter**, Alport Foundation Israel

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

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

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

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



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

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

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

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

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

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







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



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



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

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



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

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

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

### The philosophy that underpins our performance

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

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

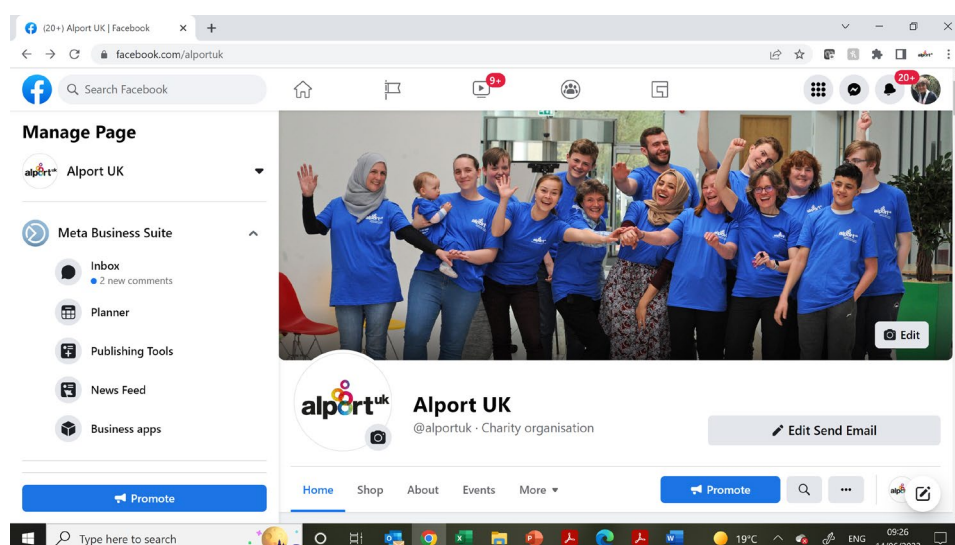
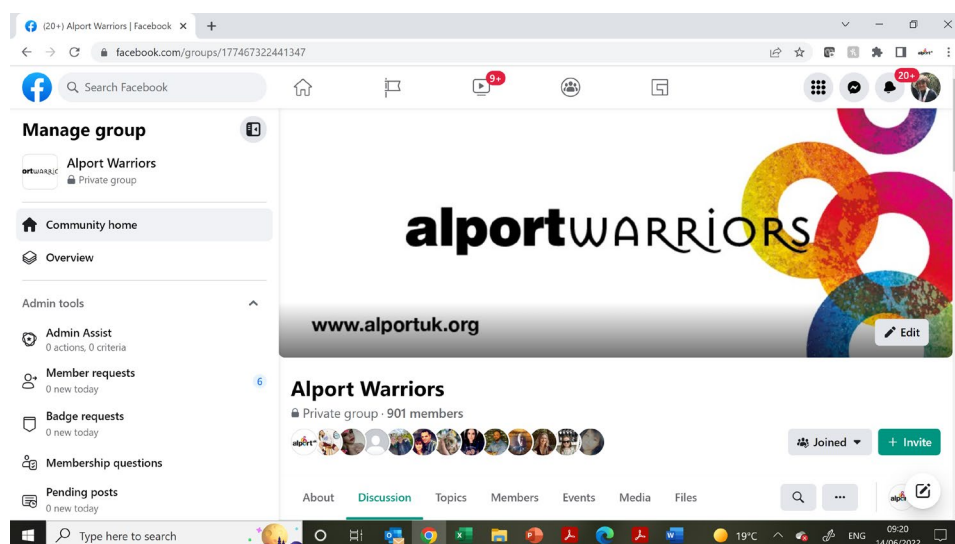
### As a tiny charity we are very clear what we can do

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



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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

Some of the key support network achievements over the year:

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



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

**Patient feedback included:**

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

**Provision of information**

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

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

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

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

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

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

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

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

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

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

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

### Supporting or driving research?

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

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

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

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



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

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

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

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

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

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

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

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

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

Feedback from patients:

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

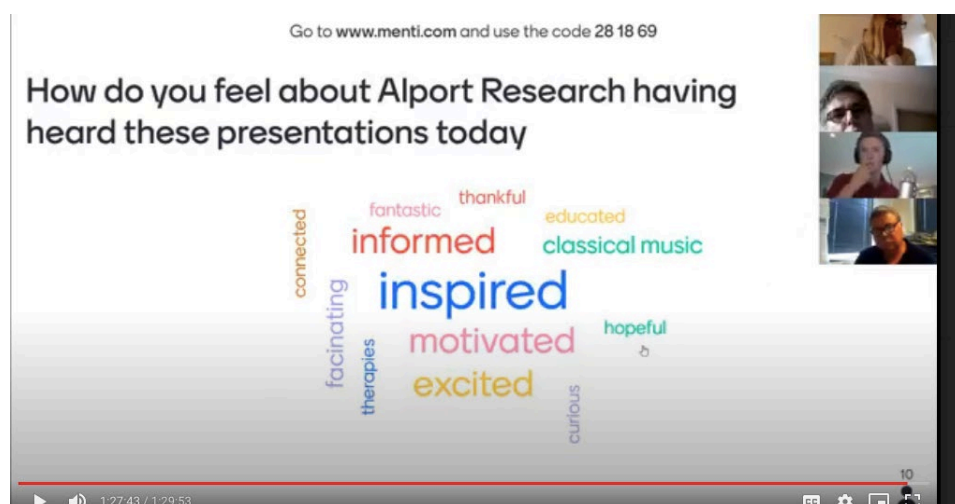
*"It was reassuring that such research is carrying on."*

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

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

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

**Feedback from the Hearing workshop:**



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

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

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



**Feedback from Chat and emails:**

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

**Alport research indicators in 2019**

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

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

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

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

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

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

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

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

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

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

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

## Section E

## Financial review

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

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

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

### Details of any funds materially in deficit

No funds in deficit

### Further financial review details (Optional information)

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

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

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

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

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

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

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

## Section F

## Other optional information

None

# Alport UK

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

Charity number: 1154774

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

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

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

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

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

**Respective responsibilities of trustees and examiner.**

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

It is my responsibility to:

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

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

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

**Independent examiner's statement.**

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

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

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



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

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

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

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

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

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

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

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

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

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



**Susie Gear**

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

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

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

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

**Alport UK**  
Charity number 115774

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

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

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



**Date: 13 June 2022**

**Notes to the financial statements**

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

**1. Accounting policies**

**a. Basis of accounting**

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

**b. Going concern**

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

**c. Fund accounting**

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

**d. Income resources**

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

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

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

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

Investment income is included when receivable.

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

**Notes to the financial statements**

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

**e. Resources expended**

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

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

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

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

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

**2. Staff costs**

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

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

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

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

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

**4. Cash at bank.**

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

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

Accounting fee accrual £1184.00

**6. Movement in funds**

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