

ANNUAL REPORT AND ACCOUNTS



a brighter future for people living with alport syndrome

For the year ended 31 July 2020



Trustees' Annual Report for the period

| Period start date | | Period end date | |
|-------------------|----------|-----------------|-----------|
| From | 1 8 2019 | To | 31 7 2020 |

Section A Reference and administration details

Charity name alport uk

Other names charity is known by n/a

Registered charity number (if any) 1154774

Charity's principal address PO Box 329

Cirencester

Postcode GL7 9JA

Names of the charity trustees who manage the charity

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

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

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

Names and addresses of advisers (Optional information)

See table of Advisors over the page

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

Section B Structure, governance and management

Description of the charity's trusts

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

Additional governance issues (Optional information)

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

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

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

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

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

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

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

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

Public benefit – statutory declaration by Trustees

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

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

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

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

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

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

alport UK fund four key areas of activity

1. **Support** – Providing support for UK patients and families through a support network, website and information days.
2. **Information** – Working with clinicians, individuals and families to educate them on more effective diagnosis and treatment, for example national guidelines for diagnosis, treatment and the best care for children, teenagers and adults.
3. **Research** – Working with other national patient organisations (eg USA, across Europe and Asia) and clinicians to design, develop and maintain an international research strategy and plan for Alport Syndrome, supported by an alliance of national patient organisations and national patient registries
4. **Collaboration** – Bringing together the scientific community to work

across the different clinical disciplines that specialise in kidneys, ears, eyes, mental health, other rare disease areas with similar issues etc. and working with the national patient organisations or other rare renal disease groups to share best practice with developed and developing countries.

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

Additional details of objectives and activities (Optional information)

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

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

Contribution by volunteers

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

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

- **Wilma Calderwood** for her day-to-day moderation on our closed Facebook page, Alports Warriors, which saw the community double in size during the pandemic.
- **Sam Clarke** for cycling an incredible 4,776.02 miles around Europe, and raising over £20,000 to raise awareness of Alport Syndrome and funds for the 'Don't Wait Fund' to support patients with Alport Syndrome take up a new activity or hobby. Sam managed to cycle from Henley-on-Thames to Albania as the pandemic took hold across Europe. Ingeniously, once back in the UK he then set off from Lands End to John O'Groats to add to the kilometres and continue the challenge. Adventure Man Sam even has his own YouTube channel to share the exciting adventure on his bike and his experiences of living with Alport Syndrome:
<https://www.youtube.com/channel/UCQJsO-IW8UvINcqHZU5qXAq>.
- **Alice Turner** for her tireless energy, enthusiasm and fundraising work, ideas and help with running Alport UK and supporting what fundraising activities could be done during the pandemic and for keeping us all positive during a very worrying year. Alice also has a forensic knack of putting our annual accounts together and tracking down all receipts and invoices to make the accountant's role much easier as he prepares the annual accounts.
- **Anna Mackay** for working with us remotely, whilst based in Portugal, to develop ideas for the Alport Syndrome Alliance, explore contacts in Sweden and be the main operational support co-ordinating speakers and moderators for The 2019 International workshop on Alport Syndrome in Italy. She kept us smiling and the workshop ran incredibly smoothly.
- **Rebecca Moule** for volunteering for us for a number of months, whilst on furlough. Rebecca set up the process and recruited the team to run the Alport Online Workshops during the pandemic and she came to Siena to run the logistics for the workshop. Working with Anna Mackay and the local team in Siena, the workshop ran without a hitch and everyone loved every aspect of it as Rebecca had thought of every detail and had back up strategies for any issues.
- **Carole Taylor**, the grand-daughter of Cecil Alport who kindly made contact with us and set up a campaign, using social media to raise awareness of Alport Syndrome using Verses for Alport (versesforalport.com) and capturing fun rhymes and light-hearted poems on a number of topics.
- **All those who raised money for us this year** – every penny makes a difference and this year people were very limited with what they could do to raise funds and increase our income. Particular thanks to:
 - **The Matthews family** who asked for donations to Alport UK in memory of Mrs Sonja Sinclair.
 - **Sarah Forrester and the Committee of the 2019 Kick Up Your Heels** gathering in Cirencester.
- **And a number of people who wish to remain anonymous** but to whom we are very grateful for their support and encouragement.

We wish to thank our Scientific Advisory Committee for fitting in so much time this year particularly to advise us on how to support the community as the pandemic took hold whilst they were all also very busy on clinical wards helping with renal issues. They answered all queries within 24 hours, ensuring the community remained as calm as possible at such a worrying time for renal patients. This amazing contribution was also having already given us a lot of their time in the previous year helping us prepare for and deliver The 2019 International Workshop on Alport Syndrome (which took place in Siena Italy 22-24 October 2019). We are so very grateful to the scientific community for their help to answer all questions and emails as and when they arose from patients or other scientists. Very many thanks to our UK Scientific Advisory Group:

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

Alport online workshops – during the pandemic, we were overwhelmed with additional help from people who chose to volunteer for alport uk whilst stuck at home unable to work or go into the lab. A small working group of volunteers was formed which included: **Rebecca Moule** and **Harriet Carter** (who both volunteered for us whilst on furlough), **Susie Gear**, **Louise Hopkinson**, **Professor Rachel Lennon**, **Professor Jeffrey Miner**, **Sophie Emler** and **Richard Naylor**. We are so grateful for the quick thinking and inspiration from this group who together came up with the idea of running a series of **Alport online workshops**, using Zoom, which were provided for the international Alport community (patients and scientists) by Alport UK and with set up costs kindly funded by Kidney Research UK and special thanks to **Sandra Currie** for quickly realising the value of the opportunity for patients.

We are so grateful to the amazing team – all volunteers - who helped us run and deliver The 2019 International workshop on Alport Syndrome in Siena, Italy:

- **Alessandra Renieri, Chiara Fallerini and the team at the Molecular Genetics Unit at Siena University** for hosting the workshop with special thanks to **Professor Alessandra Renieri** the Programme content lead, for making it a very exciting agenda focused on Genetics and gene therapy.
- **A. S. A. L. Onlus (Italian Alport patient organisation)** for jointly hosting the patient meeting in Siena in advance of the workshop and for getting 50 Italian patients there including some young people who contributed to the activities of the Media team.
- **Professor Frances Flinter** for being counsel on the preparation of the scientific agenda and running of the workshop.
- **Rebecca Moule** for stepping in to organise and run the logistics.
- **Anna Mackay** for organising all the slides and speakers.
- **Sam Clarke and Remy Archer** for filming the workshop and Sam Clarke for producing two excellent videos to explain what we do and the outcomes at an international workshop.
- **Patrick Walker, Ceri Harrop and Kory Stout** for organising the Media team with the local Italian patient team and for helping the patients write, illustrate and produce a video about new treatments in Alport Syndrome in English, Italian and Chinese!
- **Aura Zealey, Reema Hassan, Noor Hassan, Hashim Hassan** for working together as the Media team with the local Italian patients at the workshop to promote the outcomes of the workshop.

- **Mary Lou McCarthy** for an incredible photographic record of the workshop, including lovely photos of all the speakers and activities.
- **Eleanor Beer** and **Sandra Howgate** for their graphic recording of the workshop.
- **Sophie Bell** for supporting us with the logistics for the The 2019 International workshop.

We wish to thank the Workshop Organising Committee (see list below) for helping us to design and deliver **The 2019 International Workshop on Alport Syndrome**. We are also grateful to our colleagues who run some of the other national patient organisations, such as **Andre Weinstock** (Alport Syndrome Foundation, USA), **Jacqueline van Kempen** (The Netherlands), **Maria José Cacharron** (Spain) and **Daniela Lai** (Italy), **Jessie Zhang and Mr Cai** (China), **Christof Finkler** and **Ute Rosenthal** (Germany), **Dave Blatt** (Australia).

Workshop Organising Committee

for The 2019 International workshop on Alport Syndrome:

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

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

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

Professor Frances Flinter, Consultant in Clinical Genetics, Guy's Hospital, London, UK

Professor Daniel Gale, UCL Centre for Nephrology, London, UK

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

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

Professor Bertrand Knebelman, Necker Hospital, Paris, France

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

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

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

Dr Laura Perin, Saban Research Institute, University of Southern California, USA

Professor Judith Savige, University of Melbourne, Australia

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

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

Professor Roser Torra, Fundació Puigvert, Barcelona, Spain

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

Patient representatives:

Dave Blatt, Alport Foundation of Australia

Maria José Cacharron, Spain

Susie Gear, alport uk

Andre Weinstock, Alport Syndrome Foundation, USA

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

Julia Schifter, Alport Foundation Israel

Christof Finkler, Alport Selbsthilfe, Germany

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

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

- **Kidney Care** (was British Kidney Patient Association) for advice and support, particularly through the pandemic.
- **Kidney Research UK** - with specific thanks to **Sandra Currie** and colleagues for so quickly approving a grant to pay for Alport UK's Zoom webinar subscription when the pandemic hit. We were so grateful to them for recognising we needed urgent help and for their continued support at a time when their own funds became very limited and they had to review their own operations.
- **Alport Syndrome Foundation (USA)** – with specific thanks to Andre Weinstock and Janine Diebel for their continued collaboration on the international research agenda out at the 2019 international workshop in Siena and Joy Toal particularly for connecting and sharing her experience to support patients on Alport Warriors during the pandemic.
- **A couple of charities who wish to remain anonymous** for both their financial support and advice which is very much appreciated.

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

- **Eleanor Beer** and **Sandra Howgate** – translate the complex scientific information into easy-to-understand graphics.
- **Jane Keightley** – for her marketing advice and on-going support to build the brand of Alport UK to raise its' profile along with communicating and engaging people in our aims and objectives and core activities. We also very much appreciate Jane's writing and editorial advice that sets the written tone for all our communications.
- **Robina Newman** – for her thoughtful brand and design work on various materials and generally helping us to create a bright and distinctive identity that sets the visual tone for our activities.
- **Clare Charrington** – for her organisation and administrative support running alport uk.
- **Sylvie Lloyd** – for her analytical work on researching the potential background and structures for an Alport Syndrome Alliance.
- **Davina Liddell** – for her administrative work in preparing us for the 2019 international workshop and the analysis of the feedback after it.
- **Penny Norrie** – for her work in helping us prepare the materials for the 2019 international workshop.
- **Harriet Carter** – who so ably then ran the process to deliver the series of Alport Online workshops once her furlough ended.

Summary of the main achievements of the charity during the year

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

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

The philosophy that underpins our performance

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

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

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

Supporting a rare disease that impacts 1 in 10,000 in a population is a challenge as there are few people who have it, who want to research it or fund it. So as a charity we think wisely about how we use our strengths, capabilities and resources and how to collaborate to complement these. Our volunteers have strong capabilities in delivering commercial innovation and collaboration across virtual networks of international

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

1. **Support network:** with a small isolated patient community with such differing needs, we like to deliver **personal support in a timely way that delivers practical advice** and solves practical issues. alport uk's role is to empathise, understand the needs/issues, advocate for patients (and researchers) and support delivery of solutions. With our limited resources, this often means facilitating patient/researcher access to resources. For example, alport uk facilitates patients getting the right diagnosis via genetic testing, understanding treatment options or facilitating the grant application process for holiday breaks via Kidney Care's grant system. alport uk also writes letters of support for researchers to facilitate grant applications for Alport research.
2. **Provision of information:** with a diverse community and a very complex condition to explain, we try out different ways to provide information in a **variety of formats that suit different stakeholders**. With many of the community facing critical medical decisions as young adults, increasingly we use **short videos, social media and engaging activities to enable the patient community to engage in formats and content they find valuable**. For example, we encourage young adults to become our 'media team' at events, to engage in content, choose what is important and create videos and social media content themselves. See the video patients created about clinical trials and new treatments: <https://youtu.be/JRsJtUu8Lh8>. This was translated into 3 other languages by the patients working together on the script. We also publish **scientific information in the appropriate international journals so that it is peer reviewed and globally available** for researchers, clinicians and patients.
3. **Support research:** with limited funds and fundraising capability, we choose to focus our efforts to **inspire and facilitate collaborative behaviours such as information and resource sharing to facilitate and accelerate innovative ways of working and the development of new treatments and knowledge**. For example, we **facilitate the international research community coming together to share and exchange ideas through a series of in person and online international workshops**. This strategy aims to create a vibrant international research community that attracts more researchers and pharmaceutical or biotech companies interested in developing new treatments. These activities complement the activities of our colleagues in organisations such as:
 - Kidney Research UK – who raise money to fund specific UK Alport and kidney research projects eg elements of Rachel Lennon's lab based at Manchester University.
 - Alport Syndrome Foundation in the USA – who raise money to provide vital 'seed funding' for Alport research at an early stage of development.
4. **Support of a UK research registry:** with significant investment made by Kidney Care UK and Kidney Research UK into The **National Registry of Rare Kidney Diseases (RaDaR)** – the UK Renal Association's initiative designed to pull together information from patients with certain rare kidney diseases - alport uk support this vital project by **encouraging patients, clinicians and renal units to upload long-term clinical data into this database to enable**

Natural History Studies in the future to progress Alport

Syndrome research. This will give a much better understanding of how Alport Syndrome affects people. It will also speed up research. The value for:

- Alport patients:
 - Access to their clinical data online via Patient View, an online system which records blood and urine results, medications and clinic letters.
 - Ability to be contacted about future potential research studies or patient information events
 - Contribute to the increase in knowledge about their condition
 - Clinicians:
 - Share knowledge with other colleagues
 - Use RaDaR as part of a research study or clinical trial.
5. **Fundraising:** with so few people in the UK impacted by Alport Syndrome, awareness of the condition is limited and traditional fundraising by the public typically focuses on the key health areas of cancer, heart conditions etc. **We heartily encourage individuals and families living with Alport Syndrome to fundraise when inspired to do so, by providing support, encouragement and branded merchandise** (eg t-shirts, badges, wrist bands, shaking tins etc) to enable them to achieve whatever challenge motivates them. This means that **we raise significant funds for each major project or a programme of activities by applying for grants from larger charities or from pharmaceutical companies.** We support large fundraising events each year eg a dinner with an auction, a major activity eg swimming the channel or cycling round Europe etc.

Highlights: achievements and performance this year**The pandemic: an opportunity to connect and engage**

The second half of alport uk's financial year was particularly challenging as the pandemic hit the world in early 2020. Vulnerable kidney transplant or dialysis patients and many Alport patients were advised to shield at home and the closed Facebook community – Alport Warriors - doubled in size from 350 members to over 750 members with members joining from all over the world, trusting and appreciating the excellent advice we get from our colleagues in the NHS. Each year we are contacted by more and more people as they are diagnosed with Alport Syndrome. This year, we had double the number of people contacting us for advice and specifically relating to COVID and the impact on renal patients. As we work as a 'virtual' organisation anyway, alport uk was able to easily respond to this increase in requests and with more of the community online – patients and researchers – more people were able to help each other. This engagement from the wider community was so valuable for all and so alport uk thrived in a really positive way, despite the pandemic. It was an opportunity for more to engage and more got value from this engagement.

Support network proactively increased during the pandemic

As many Alport patients were asked to urgently isolate in March 2020 due to COVID, ahead of the UK population understanding what was going on, our support activities dramatically changed. We were very

grateful to our Alport colleagues in China (Professor Jie Ding particularly) and Professor Colin Baigent who warned us of the emerging situation in Wuhan and helped us be ahead of the questions as they arose from the community. This set us up to be proactive in our advice for people living with Alport Syndrome, and was invaluable in keeping the community as calm as possible through a very worrying few months.

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

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

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

Some of the key support network achievements over the year:

- At the time of writing our Facebook Alport Warriors increased to over 800. The community quickly doubled during lockdown as people sought information online. Some members are regular contributors and the conversations are becoming more specific as people feel more connected as a community that is getting to know each other better and value each other's thoughts and opinions. The topics discussed include COVID, kidney donation, transplant successes, successes at the annual Transplant games, celebrating birthdays, links from other Alport Facebook sites, fundraising things, and a range of questions about Alport Syndrome, its' symptoms and side effects. There was one very touching story of a teenager who attended our first information day in London with his parents. The teenager met one of our inspirational and celebrated patients who has now had three transplants. After the teenager had their transplant, the two of them met up again at the Transplant games and shared a picture on Facebook. Connection with others who are in a similar situation is clearly valued by some people in the Alport community. Connection is not valued by all, so we aim to provide support for individuals or families in other ways to suit their needs.
Following the support we gave the parent of a young Alport patient facing kidney failure and living in unsuitable accommodation for their condition: *"Hi, I just wanted to let you know that the council have agreed to fully refurbish (patient name)'s wet room after it went to a panel meeting last week...Thank you ever so much for your continued help and support."*
- We continued the dissemination of information and support from the first five Alport Information Days held in London (December 2012), Edinburgh (September 2013) and Birmingham (February 2015) and Manchester (November 2015), London (January 2017) and

Manchester (2019) for both patients and carers, including:

- Sending out information electronically – there was a high number of enquiries about information for women and girls living with Alport Syndrome.
- Answering enquiries emailed to us at info@alportuk.org and phone calls sent to our landline number of 01793 847264 and putting people in touch with experts to answer their questions or with other families to share stories and experiences.
- Eg **A Dad contacted us as daughter wanting to start IVF and concerned about whether her side of the family has inherited Alport Syndrome like her cousin and wanting advice on best way to get a diagnosis in the COVID environment:** *“Thanks Alport UK – and to the Professor for the prompt & concise response. Your advice is crystal clear.... Thanks again for your help.”*
- When patients contact us for advice on specific topics, we put them in touch with the relevant clinicians, experts. Initially, much of this was done via email, but now we connect people through Alport Warriors, our phone line and email. Alport Warriors is our closed Facebook page where people share experiences of living with Alport Syndrome. **Parent of one young Alport patient facing transplant who we connected up with another young person who recently had a transplant:** *“Thank you. We have seen a big change in our son since he started talking about his worries and the extra support seems to be what he needs now.”*

Provision of information

With the help of our scientific advisors, we got advice early as the pandemic emerged and were able to keep one step ahead of the barrage of questions with daily posts on our closed Facebook page – Alport Warriors - to the community to answer queries as they arose. We posted the same information on the Alport Syndrome Foundation’s USA Facebook page in parallel as they have a number of UK patients as members. The USA Facebook page admins were incredibly supportive and we worked together to make sure that the international community benefited from the practical advice we got from our scientific advisors. This timely information reduced the anxiety in the community at a very challenging time. As everyone’s circumstances were different, we provided specific information to help patients work out their own risk levels and the necessary personal actions they needed to take to protect themselves from the virus. This built-up personal confidence and resilience as people took control of their own situations. This approach informing people to enable them to take control and build resilience was vital as our community has so many differing needs, many different age groups, are in differing stages of renal failure, undergoing different types of renal replacement therapy and many patients and family member were also from other countries seeking what advice they could get. We are very proud of the alport uk team, how they anticipated queries, increased the advice and information to enable people to stay as calm as possible, including sourcing food banks and writing letters to employers to explain the needs of their employees with Alport Syndrome. We are incredibly proud of the patients, their positive and pragmatic approaches to looking after themselves and helping each other across the community at a very concerning time.

Sometimes it was most helpful to connect young people to mentor each other when facing particularly challenging times such as declining kidney

failure and transplants: **Parent of one young Alport patient facing transplant** who we connected up with another young person who recently had a transplant: *"Thank you. We have seen a big change in our son since he started talking about his worries."* **Young Alport patient needing a transplant:** *"I think it's not actually as bad as it sounds to be fair...it really helped for me to understand what exactly actually goes on"*

During the pandemic, with most of our community – individuals and families living with Alport Syndrome and all the Alport researchers – isolating or working in their homes, we created **Alport Online Workshops, a series of online workshops featuring topics impacting patients and the latest Alport research from all over the world:** <https://tinyurl.com/y9cuhgby>. The first workshop was about COVID and the impact on kidney patients. The online audience was over 70 people, but the video was put onto YouTube after and received over 450 views. Subsequent workshop topics, requested by patients wanting more information, included for example: Alport eyes, Alport genetics and work by lab researchers in Manchester and USA. During the pandemic and various national lockdowns, the Alport online workshop team went on to produce a total of 20 online workshops including a 'Drop in' session one evening: **Mother with a teenager daughter with Alport Syndrome:** *"I think it's lovely just to have coffee type chats over zoom for the Alport Community however many join. Wishing you all at Alport U.K. a lovely weekend after all your hard work, as a family affected by Alport, we very much appreciate it!"*

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

- **Fighting failure:** Sam Clarke, prepared for his challenge to cycle round Europe <https://youtu.be/1A1adCj-cvo>. We use this video for newly diagnosed patients as it explains the challenges of living with Alport Syndrome but Sam ably inspires patients with the fun activities that he does such as sky diving, cycling and generally having fun. This is such an important message for young patients.
- **Patients inspire Alport Syndrome research**, a collaboration between alport uk and University of Manchester: <https://www.youtube.com/watch?v=77p7nzKz6nc>
- **Highlights from The 2019 International workshop on Alport Syndrome**, Siena, October 2019: <https://youtu.be/QH8mDTmKaVU>

A very successful **series of two-minute animated videos were written, illustrated and produced by a group of our young people with Alport Syndrome for their peers**. The writing of the videos and working with the clinicians to make them scientifically accurate was a valuable process for the young people to engage in understanding Alport better as sometimes they can be in denial about what is important to keep them healthy or sources of support. Topics included:

- Why Alport research is important <https://youtu.be/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) and a special section on Alport Syndrome on www.healthtalk.org (<http://www.healthtalk.org/peoples-experiences/long-term-conditions/alport-syndrome/topics>) of our key experts talking about specific aspects of Alport Syndrome. Topics are varied about all aspects of living with Alport Syndrome and include: Genetics, An introduction to Alport Syndrome, Hearing and hearing aids, caring for people with Alport Syndrome, medication, women with Alport Syndrome etc.
- **Our website remains an invaluable resource.** We are currently fundraising to improve our website www.alportuk.org to update and make the information clearer and more accessible and to answer the questions we have received over the last year or so through our closed Facebook page, Alport Warriors. **Mother contacted us about vaccination for a 19-year-old daughter with Alport Syndrome and on strong medication:** *"Thank you for putting my mind at rest. I got your contact details from the Alport UK website. My daughter said it's not really her thing joining groups. Shame, as I think it's really good that support is out there. Thank you for your support."*
- **Information about new clinical trials** that patients can sign up is shared through our website 'Latest news' section, through our closed Facebook page (Alport Warriors) and through directly emailing our database of patients.

The support of research

With limited funding for research, alport uk's strategy is use our small amount of funding to facilitate an Alport research collaborative plus support and encouragement for the research community in working together to create a vibrant research community that attracts more researchers and pharmaceutical companies interested in developing new

treatments.

The major programme for the first half of the year was to deliver our fourth 'in person' international workshop – The 2019 International workshop on Alport Syndrome in Siena, co-hosted with the Italian national Alport patient association – A.S.A.L. Onlus – and Professor Alessandra Renieri's wonderful genetics team at Siena University. With participation from patients and scientists all over the world, the Siena workshop focused on genetics and gene therapy and was the largest collaboration to date with the international Alport community delivered entirely by alport uk volunteers in collaboration with the team in Italy – the key achievements are listed below including the collaborative effort on sponsorship to provide the funds to make the workshop possible.

A specialist international 'Alport mutations/variants workshop' was then held in London in February 2020 for all those involved in lab testing and diagnosing Alport Syndrome around the world to collaborate on and publish international guidelines and clinical standards to improve diagnosis. Professor Judy Savige from Australia lead the effort, with over 50 experts participating in person from all over the world just before the UK went into Lockdown, supported by alport uk.

When lockdown happened and with many patients shielding at home and the alport researchers unable to get into the lab, people had time on their hands and we quickly formed a small working group to create a series of Alport online workshops. The first workshop, delivered on 12 May 2020 focused on answering COVID questions and explained the new arrangements for Alport genetic testing as the lab facilities moved from Guy's in London to Bristol. The workshops were run monthly thereafter with a few extras fitted in on topics people were particularly keen to hear about eg eye complications in Alport syndrome. The workshops featured scientists from all over the world. **From a patient advocacy person in another country:** "...congratulations for the Alport workshops. It is a fantastic way to keep connected and continue learning about Alport Syndrome."

Over the year:

279 participants from 33 different countries participated in the first 14 online workshops

38 speakers presented 42 of the latest research projects from 8 different countries.

15 moderators contributed from 3 different countries and we aim to increase the diversity for the next set of workshops

So far, the videos on YouTube, <https://tinyurl.com/y9cuhgby>, received 1,786 views.

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

Some of the workshops featured specific labs and were an opportunity for early career researchers to present their work to the international Alport community and get feedback and questions. In the spirit of 'collaboration' – such an important principle of alport uk's strategic direction – the pandemic actually enabled us to accelerate our progress, share more research to a wider audience and at a reduced cost compared with the four 'in person' workshops delivered previously. The lock-in format of the 'in person' workshops meant the community had

spent plenty of time getting to know each other over the last 6 years and this investment in enabling the community to 'get to know each other' and collaborate paid off as we worked online. Busy clinicians, battling to deliver frontline care to patients in hospitals all over the world, still made time to join us online and connect.

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

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

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

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

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

Feedback from patients:

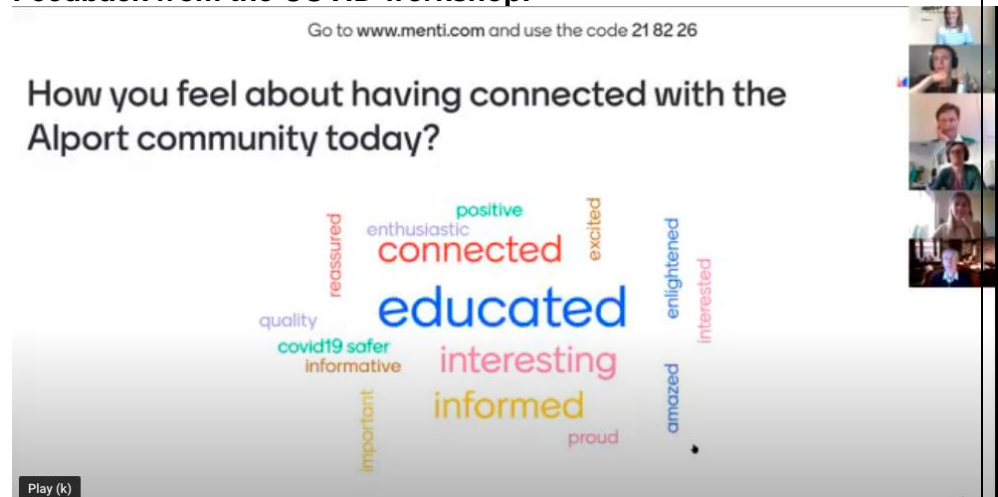
"It was so enlightening to find out these people (the researchers) are doing their very best on our behalf. I had no idea of the methods used for this kind of research. They seemed to be a happy team too!"

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

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

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

Feedback from the COVID workshop:



Word Cloud



Share your thoughts on todays topic!



Alport research indicators in 2019

- A shared international strategy and plan for Alport Syndrome research
- New research ideas and projects to develop new treatments and therapies and more research generally

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

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

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

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

To continue the collaborative international workshops in Oxford (2014) Göttingen, Germany (2015) and Glasgow, Scotland (2017), alport uk facilitated the delivery of a fourth workshop in the series: **The 2019 International Workshop for Alport Syndrome** in Siena, Italy. Even the preparation work, for the workshop in itself, further consolidated interactions among the various stakeholder groups and addressed the progress being made to move forward with focus on the shared mission to find a long-term multi-target therapy for Alport Syndrome resulting in a lifelong delay of renal failure. In Siena at the 2019 workshop, there were 146 participants including 38 patients and representatives from 12 pharmaceutical companies who came together to continue the progress on a research strategy and collaboration effort. Outputs from the workshop included:

- 46 abstracts highlighting the latest Alport research – a significant growth from the last workshop.
- Drafted a workshop summary ready to publish in a genetics publication.
- A graphic book charting the progress of the science to share with patients and illustrate the work going forward.
- An increased number of countries engaged with new communities emerging in pathology and across eastern Europe eg Croatia, Poland and the Baltic region.
- Further consolidated interactions among the various stakeholder groups and addressed upcoming steps to move forward on the shared mission.
- 12 pharmaceutical or biotech companies participated, a number who are researching Alport Syndrome and some planning or considering clinical trials
- Five pharmaceutical and two hearing aid companies sponsored the workshop.

After this fourth important workshop to reconnect the Alport Syndrome

research community, alport uk intended to restart the conference calls with the international workshop organising committee to share progress, keep the researchers engaged in delivering the agenda agreed at the workshop and start planning the fifth and sixth workshops in Beijing, China and Calgary, Canada respectively. However, when the pandemic hit and with most of our Workshop Organising Committee being kidney doctors, the doctors were needed on the wards to help with the kidney complications that COVID caused. So, the Alport Online Workshops were started instead and plans started for an Online International workshop for 2021.

Support of a UK research registry

In parallel to alport uk being set up, the Renal Association established a working group on Alport Syndrome, funded jointly by Kidney Research UK and Kidney Care (previously British Kidney Patient Association) to support the development of a national renal registry of patients, called RaDaR which is linked to a system that patients can access, called Renal Patient View. Some of the trustees from alport uk contribute to the working group on an ongoing basis to devise ways of promoting RADAR to patients and clinicians across the UK. At the time of writing, RaDaR has over 800 patients registered as having Alport Syndrome. alport uk specifically contribute to the support of this UK research registry of patients and an international alliance of patient registries by:

- Promoting the importance of RaDaR and Renal Patient View to patients at Alport information days, along with information about the value of RaDaR to research
- Making the research registry a central part of the national contribution to international efforts to collaborate on research coming out of the 2014, 2015, 2017 and 2019 International Workshops on Alport Syndrome and proposing to make it one of the key topics for 2021.
- Continuing the development of the UK's contribution to an international alliance of Alport Syndrome research. An 'alliance' is necessary as there are not enough patients in the UK for Clinical trials and so pharmaceutical companies will want to do trials in a number of different countries to try new therapies.

If anyone reading this annual report is interested in more information or to get involved or support us with activities or fund raising, please email Susie Gear and Julia Skelding at info@alportuk.org or call us on 01793 847264.

Section E

Financial review

Brief statement of the charity's policy on reserves

Reserves from fundraising are kept in separate Barclays bank savings accounts, labelled for their specific use. For example, for:

- Information Days (Alport UK Meetings)
- Development of information, website and marketing material (Alport UK)
- Facilitating the International Workshops on Alport Syndrome (Alport UK Research)
- Research commissioned by Alport UK (Alport UK Schools)

Details of any funds materially in deficit

No funds in deficit

Further financial review details (Optional information)

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

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

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

- Personal donations
- Limited personal fund-raising activities such as running events, hosting charity evenings, cake sales etc.
- Just Giving and Virgin Money Giving pages of sponsorship for various activities that our community get involved in to raise funds for alport uk – this year Sam Clarke's amazing efforts raised over £20,000 for a new fund we will call the 'Don't Wait Fund' to support patients taking up a new sport or hobby.
- Social media fundraising pages eg Facebook
- PayPal payments/donations to Alport UK
- Sales of Christmas cards, t-shirts and badges
- Standing orders from a couple of very supportive patient families
- Customised shaking tins located in retail venues
- Donations from larger charities or foundations for specific activities and particular thanks to Kidney Care UK and to Kidney Research UK
- Grants given by a number of pharmaceutical companies to fund The 2019 International workshop on Alport Syndrome: alport uk are very grateful to the support from Sanofi Genzyme, Regeneron, Retrophin (now Trave Therapeutics), Novartis, REATA Pharmaceuticals and two hearing aid companies Audibel and Audiomedical Solutions.
- Income from the registrations for The 2019 International workshop on Alport Syndrome
- One of our Trustees loaned us a sum to partly fund the next stage of the healthtalk.org project and a number of expenses in the early stages of the charity. The loan is interest free and there is no deadline to pay it back, just when funds are available.

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

Section F

Other optional information

Alport UK

Report and Financial Statement For the year ended 31st July 2020

Charity number: 1154774

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

Alport UK
Charity number: 1154774
Legal and administrative information

Charity name: Alport UK
Charity registration number: 1154774
Type of organisation: Charitable Unincorporated Organisation

Registered office and business: PO Box 329
Cirencester
Gloucestershire
GL7 9JA

Trustees: Colin Baigent
Jules Skelding
Daniel Gale
Susie Gear
Frances Flinter
Rachel Lennon
Neil Turner

Accountants: Shilton Accounting Services
Certified Practising Accountants
1st Floor, 1 The Clock House
Brize Norton Road
Carterton
OX18 3HN

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

I report on the accounts of the Charity for the year ended 31st July 2020 which are set out below.

Respective responsibilities of trustees and examiner.

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

It is my responsibility to:

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

Basis of independent examiner's report.

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

Independent examiner's statement.

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

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

David Cuthbertson – ICPA Cert Acc (Open)
Shilton Accounting Services
Honeystone Cottage
Ladburn Lane
Shilton
OX18 4AJ
30/12/2020

Alport UK
Charity number: 1154774
Director's report for the year ended 31st July 2020

The trustees present their report and financial statement for the year ended 31st July 2020.

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

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

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

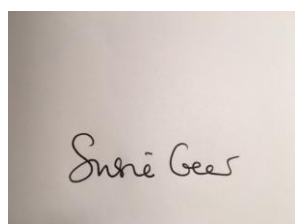
Trustees - The overall responsibility of the organisation rests with the Board of Trustees. The selection of Trustees is designed to supplement the existing skills and expertise of the board and is governed by an informal skills assessment. The appointment of trustees is made in accordance with the constitution.

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

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

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

This report was approved by the Trustees on 27 February 2021 and signed on its behalf by

A photograph of a piece of paper with a handwritten signature in dark ink. The signature is written in a cursive style and appears to read 'Susie Gear'.

Susie Gear

Alport UK
Charity number 115774

Statement of Financial Activities (including Income & expenditure Account)
For the year ended 31st July 2020

| | Restricted Funds | | | Unrestricted | | Total | 2019 |
|--------------------------|-------------------------|-----------|--------------|---------------------|---------------|----------------|---------------|
| | Research | Meetings | Don't Wait | General | Caxton | | |
| Income | | | | | | | |
| Donations/ Sponsors | 14,030 | - | - | 31,339 | 8,111 | 53,480 | 57,009 |
| Delegate fees | 17,060 | - | - | - | - | 17,060 | - |
| HMRC Gift Aid | - | - | - | 402 | - | 402 | 2,804 |
| Sale of books etc | - | - | - | 164 | - | 164 | 254 |
| Exchange differences | - | - | - | - | 228 | 228 | - |
| Total income | 31,091 | - | - | 31,905 | 8,339 | 71,335 | 60,067 |
| Expenditure | | | | | | | |
| Bank & service charge | 77 | - | - | 597 | 9 | 683 | - |
| Direct cost events | 14,340 | - | - | 17,199 | 13,518 | 45,057 | 7,886 |
| Administration | 6,281 | - | - | 6,442 | - | 12,723 | 4,487 |
| Travel & subsistence | 10,662 | - | - | 1,960 | 1,650 | 14,272 | 12,192 |
| Internet/website | - | - | - | 2,026 | - | 2,026 | 1,408 |
| Marketing | - | - | - | 247 | - | 247 | 4 |
| Insurance | - | - | - | 672 | - | 672 | 672 |
| Subscriptions | - | - | - | 282 | - | 282 | 501 |
| Bursaries/Grants | 219 | - | 255 | - | - | 474 | - |
| Others | 219 | - | - | - | - | 219 | 216 |
| Governance costs | | | | | | | |
| DBS checks | - | - | - | 391 | - | 391 | - |
| Accountants' fees | - | - | - | 960 | - | 960 | 960 |
| Total expenditure | 31,797 | - | 255 | 30,777 | 15,176 | 78,005 | 28,327 |
| Transfers | (846) | - | | (29,988) | 30,835 | - | - |
| Net movement | (1,553) | - | (255) | (28,860) | 23,998 | (6,671) | 31,740 |
| Opening balance | 10,074 | 94 | 2,684 | 54,364 | - | 67,215 | 35,474 |
| Closing balance | 8,521 | 94 | 2,429 | 25,503 | 23,998 | 60,544 | 67,215 |

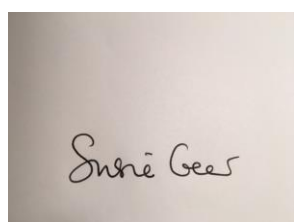
There are no recognised gains or losses other than in the Statement of Financial Activity.

Alport UK
Charity number 115774

Balance Sheet as at 31st July 2020

| | Notes | 2020 | 2019 |
|--|-------|--------|--------|
| | | £ | £ |
| Fixed assets | | - | - |
| | | | |
| Current assets | | | |
| <i>Cash at bank</i> | 4 | 62,464 | 68,175 |
| | | | |
| Total Current assets | 5 | | |
| | | | |
| Current liabilities | | | |
| <i>Creditors falling due within 1 year</i> | | 1,920 | 960 |
| | | | |
| Net current assets | | 60,544 | 67,215 |
| | | | |
| Assets less liabilities | | 60,544 | 67,125 |
| | | | |
| Represented by | | | |
| <i>Restricted funds</i> | | 11,043 | 12,851 |
| <i>Unrestricted funds</i> | | 49,501 | 54,364 |
| | | | |
| Total funds | 6 | 60,544 | 67,215 |
| | | | |

Signed on behalf of the charity's trustees



Date: 27 February 2021

Notes to the financial statements

For the year ending 31st July 2020.

1. Accounting policies

a. Basis of accounting

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

b. Going concern

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

c. Fund accounting

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

d. Income resources

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

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

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

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

Investment income is included when receivable.

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

Notes to the financial statements

For the year ending 31st July 2020.

e. Resources expended

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

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

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

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

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

2. Staff costs

The charity did not employ any staff in the financial year.

3. Trustee remuneration & related party transactions.

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

Alport UK

Charity number: 1154774

Notes to the financial statements

For the year ending 31st July 2020.

4. Cash at bank.

| | |
|--------------------------------------|----------------|
| Barclays General Account 93696405 | £27,423 |
| Barclays Research Account 93725642 | £7,149 |
| Barclays Meeting Account 83477436 | £94 |
| Barclays Don't wait Account 33742210 | £2,429 |
| Caxton FX | £23,998 |
| PayPal | £1,371 |
| Total | £62,464 |

5. Creditors: Amounts falling due within one year

Accounting fee accrual £960.00

6. Movement in funds

| | Opening balance | Incoming resources | Outgoing resources | Balance 31 st July 2020 |
|--------------|--------------------|-----------------------|-----------------------|---------------------------------------|
| Restricted | £12,851 | £31,091 | £32,898 | £11,043 |
| Unrestricted | £54,364 | £40,244 | £45,107 | £49,501 |
| Total | £67,215 | £71,335 | £78,005 | £60,544 |