

Newsletter December 2013

Exciting progress for Alport Syndrome in the UK: December update

This update on our news is going out to people living with Alport Syndrome, clinicians and health workers, families and friends who asked for us to keep them in touch with our progress.

It is a while since our last update as there is a lot happening in the UK and internationally relating to Alport Syndrome. These are exciting times and we are thrilled to be able to share the headlines about our progress with you:

1. **Alport UK is the new name for our patient-led registered charity.** Alport UK is dedicated to facilitating a support and information network for all those affected by Alport Syndrome. Please note our new and permanent email address has changed to info@alportuk.org.
2. **One of our first activities, as a new charity, is to get your views on priorities for research into Alport Syndrome by completing a survey** that will be sent out to you in the next day or so. Watch out for an email from us and Survey Monkey; it will only take 5 minutes to fill in.
3. **The 2014 International workshop on Alport Syndrome will be held at Oxford University, 3-5 January 2014** – we are keen to get some help both at Oxford and ferrying our international visitors to and from the airport. Please get in touch if you are free to help on that weekend?
4. **Edinburgh (September 2013) was the venue for our Second Information Day** with 80 people attending. Watch out for news of our next Information Day in 2014 to be held somewhere in the middle of the UK. Let us know at info@alportuk.org if you know of a suitable venue and/or can offer resources to help organise the day.
5. **Our website, www.alportuk.org, is in development** – take a look at the holding page.
6. **We now have a closed Facebook page, ‘Alport Warriors’,** to share ideas and is managed by Wilma Calderwood. Please email info@alportuk.org if you would like to be involved.
7. **The UK’s Renal Association (professional network for nephrologists) invited us to talk about Alport Syndrome** – to give the patient ‘view’, explain the charity and to talk about how to improve services for patients with Alport Syndrome across the UK.
8. **Some of our supporters have started fundraising for us by getting their school friends and families to donate to Alport UK.** A group of the mums and dads at one school have produced a cook book to say ‘thank you’ to those supporting us. The book makes good presents for Christmas. Let us know if you would like to donate and we can send you some copies of the book. Maybe you can do some fund raising locally?

We hope you agree with us, that this is a great start to create a brighter future for people living with Alport Syndrome. If you are interested, there is further information on each of these topics below.

1. **Alport UK is the new name for our patient-led registered charity.** Alport UK is dedicated to facilitating a support and information network for all those affected by Alport Syndrome.

Alport UK is finally (as of a couple of weeks ago) a registered charity, registered charity number 1154774. This is fantastic news as not only are we 'kosher' and can join various groups of patient organisations to lobby for better information, support and services for people with Alport Syndrome, but when any of us fundraise for Alport UK we can receive gift aid, which adds an enormous 22% to any funds donated by UK tax payers. We have also received very generous donations from various individuals and businesses now we are a fully-fledged charity. Please contact us at info@alportuk.org, if you know of anyone who would like to contribute or donate to the charity.

You may remember that last year we asked a number of individuals and families to tell us what our new organisation should focus on. Our vision and mission for Alport UK is based on what you told us was needed:

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** – through the information days (which a lot of people have already experienced), Facebook page and our website when it is fully up and running.
- **Be a conduit for high quality, accessible information** – mainly through our website, as we develop it, but also through a group of named clinicians who have agreed to help answer queries.
- **Raise the profile of Alport Syndrome in the scientific community** – through a network of named clinicians (that Jules has kindly set up) at each renal unit in the UK and speaking at key scientific events, contributing to discussions on rare diseases etc.
- **Contribute to the international research agenda** – co-ordinating a group of international patient organisations and international scientists to put together a shared International research strategy for Alport Syndrome – the international workshop in Oxford is our first event to get the scientists together to start this process.
- **Collaborate on the development of a UK patient registry and alliance of international patient registries** – collaborate with the people developing patient registries.

All this work is done through volunteers, working on Skype, so our overheads are minimal. We need to raise money to develop our website, fund more information days and fund research. If you are interested in getting involved or supporting us with activities or fund raising, please email Susie and Jules at info@alportuk.org or call us on 01793 847264.

2. **One of our first activities is to get your views on priorities for research into Alport Syndrome by completing a survey** that will be sent out to you in the next day or so. Watch out for an email from us and Survey Monkey; it will only take 5 minutes to fill in. This is what the email will look like:

From: "meetings@alport.info via surveymonkey.com" <member@surveymonkey.com>
Subject: Alport UK Research Survey
Body: We are conducting a survey, and your response would be appreciated.

Here is a link to the survey:
<https://www.surveymonkey.com/s.aspx>

This link is uniquely tied to this survey and your email address. Please do not forward this message.

Thanks for your participation!

There are 6 questions. The whole survey will take 5 minutes of your time. We would be grateful for your responses. It is based on the survey that people filled in at the Edinburgh meeting as a 'pilot' for us. The questions focus on 'What are the research priorities of people with Alport Syndrome, their care providers and clinicians?'

You will be invited to share your ideas on what research Alport UK (and the international community of researchers on Alport Syndrome) should focus on in the future. The focus on research aims to improve the treatment and quality of life of people with Alport Syndrome. Your responses will be used to identify the top research priorities for professors, doctors and clinicians involved in Alport research.

This survey needs to be completed by 19 December. Participation is voluntary and all responses are anonymous.

The final list of research priorities will be presented to researchers and organisations that fund research in January 2014 at the International workshop on Alport Syndrome in Oxford. If you have any questions concerning your rights as a possible participant in this research, please contact: Susie Gear (info@alportuk.org).

3. The 2014 International workshop on Alport Syndrome will be held at Oxford University, 3-5 January 2014 – we are keen to get some help both at Oxford and ferrying our international visitors to and fro to the airport. Please get in touch, if you are free to help on that weekend?

As some of you may know through the messages on Facebook etc., on 3-5 January 2014 we are setting up an international workshop for Alport Syndrome. As of today we have 80 medical professionals: professors, doctors, researchers and importantly patient representatives from national patient groups from all round the world coming to Oxford to start the process of research in Alport Syndrome. The countries represented include: Australia, Canada China, France, Germany, Hong Kong, Italy, Portugal, Singapore, Spain, Sweden, UK, USA. Julie Kiddie was the person who started us on the journey by doing an internet search for all those working on Alport Syndrome all round the world. From that, we put together 'The Workshop Organising Committee' (see list below) who join us on monthly conference calls to set the agenda and agree the programme of speakers. Everyone of the group has been an

inspiration to us with lots of extra advice on Skype calls in between on monthly calls. We have a lot to thank them for.

Workshop Organising Committee for the **The 2014 International workshop on Alport Syndrome**

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

Professor Jie Ding, Department of Pediatrics, Beijing, China

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

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

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

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

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

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

Mr Moin Mohamed, Consultant Ophthalmic Surgeon, St Thomas' Hospital, London, UK

Professor Judith Savige, University of Melbourne, Australia

Dr Judy Taylor, Consultant Paediatric Nephrologist, Evelina Children's Hospital, London, UK

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

Representatives from the following national Alport family support organisations:

Dave Blatt, Alport Syndrome Foundation, Australia

Susie Gear and **Jules Skelding**, Alport support group, UK

Sharon Lagas, Alport Syndrome Foundation, USA

Daniel Renault, AIRG France/Europe

With the help of some fantastic clinicians in the UK (Professor Colin Baigent, Professor Frances Flinter, Dr Danny Gale, Professor Neil Turner) and the Kidney Foundation of Canada and Kidney Research UK, plus a couple of anonymous donors, we have already raised an amazing £55,000 towards the costs of getting the international group together; it is a hugely important event for the future of Alport Syndrome.

What can you do to help? We have people that are flying in from all over the world to be picked up from airports and brought to Oxford - can you help?

We need help with putting name badges together for everyone, packing up folders of information, hosting people at the event etc. Please get in touch with us at research@alport.info if you can help in any way. We are applying to the British Kidney Patients Association (BKPA) to see if we can get support for people with accommodation expenses.

4. Edinburgh (September 2013) was the venue for our Second Patient Information Day with 80 people attending

We had a fantastic patients meeting in Edinburgh on 7 September, meeting up with our Scottish patients and families. We had fantastic speakers again, Professor Neil Turner, Professor Frances Flinter plus local people to talk about hearing and transplantation. With it being a slightly smaller group there was good time for questions and answers after each session. It was held the Surgeon's Hall and kindly hosted by Professor Neil Turner with fantastic support from Harriet Gordon and Emma Farrel. We now have another 70 people connected up locally to support each other and connected to our wider national support group.

5. **Our website, www.alportuk.org, is in development** – take a look at the holding page.

Finally we have a home page! We will add more information to the site so it gets better and better. We have huge plans for the website, as you told us in the survey earlier this year that it would be one of the most useful things to help people living with Alport Syndrome. Please do tell us more about:

- what you want to know
- what you want on the site
- what will be the most help to you as an individual or family living with Alport Syndrome.

Steve Fry and others are kindly going to work on the site to develop it further to a really useful information resource for people. Email us at info@alportuk.org with any ideas.

6. **We now have a closed Facebook page, 'Alport Warriors'**, to share ideas. It is managed by Wilma Calderwood. Please email info@alportuk.org if you would like to be involved.

As a result of this wonderful meeting in Edinburgh, a closed Facebook page 'Alport Warriors' has been set up by Wilma Calderwood. It is a very informal support network of people who are living with Alport Syndrome, trying to make a support site for young people to connect, air their views about any concerns or issues, talk privately, hopefully create occasions for social events. Everyone of all ages is encouraged to join. Please email us at info@alportuk.org stating that you would like to be 'invited to join the Alport Warriors' page' and Wilma will 'invite' you in. There might then be a 'teenage only' Facebook page for those teenagers or young adults, who would like to communicate without parents/guardian/family checking it out!

7. **The UK's Renal Association (professional network for nephrologists) invited us to talk about Alport Syndrome** – to give the patient 'view', explain the charity and to talk about how to improve services for patients with Alport Syndrome across the UK.

Susie Gear was invited by the UK's Renal Association to speak at the Royal Society of Medicine to give the patient view of what it is like to live with a rare disease. An amazing speech; it not only moved all the medical professionals invited, but got them thinking. Susie spoke not only from an Alport UK perspective but from a mother's perspective, giving these professionals a reality check as to what life is like, when you a. are a mother, b. are a working mother c. living with Alport Syndrome. Susie has also been invited to give a 'Guest lecture' at the Renal Association's Kidney Week in May 2014. Susie also recently was appointed to the Rare Disease Advisory Group which advises the NHS on services for patients with Rare Diseases.

8. **Some of our supporters have started fundraising for us by getting their school friends and families to donate to Alport UK.**

A group of the mums and dads at one school have produced a cook book to say 'thank you' to those supporting Alport UK with donation. The cook book, called 'Frog

in the bog' (instead of 'Toad in the hole'!) makes good presents for Christmas. Let us know if you would like to donate to Alport UK and we can send you some copies of the book. Maybe you can do some fund raising locally?

So many people have joined in our efforts over the last few months, there has been a lot to do, but a lot achieved, hence our silence; we didn't have a spare moment to sit down and write it up!

We need support and encouragement from you all. We need to know what you want and desire from the charity. We need volunteers to help with activities and fund raising. Please let us know what you can do and how you can help. We are one connected community, so if you can help with expertise in any camp, or have time to prepare nametags, print out packs of information, prepare envelopes, or have time to organise a cake sale, whatever it is, however large or small, we would appreciate you joining us on this journey.

We need you to get involved and help us achieve our ultimate aim, to create a brighter future for people living with Alport Syndrome.

Merry Christmas to everyone



a brighter future for people living with alport syndrome

Registered charity number 1154774, www.alportuk.org

The new charity and meetings are being organised by a group of volunteers – people living with Alport Syndrome: Colin Baigent, Katie Fry, Steve Fry, Susie Gear, Catherine Kent, Julie Kiddie, Thomas Kiddie, Clare Norrie, Jules Skelding, Oliver Skelding, Richard Stanton, Julie Tippet, George Walker

In partnership with the Rare Diseases (UK) Working Group for Alport Syndrome. For more information on rare diseases: www.raredisease.org.uk