



a brighter future for people living with alport syndrome

June 2014

Newsletter

The Website: www.alportuk.org

There is exciting progress as the coding of the website is complete and we are just putting the finishing touches to the content. Some of this is being written by professionals as it is vital that all the information on the website is correct and up to date so that it can be used by both individuals living with Alport Syndrome and professionals worldwide.

It is going to be the place to go to for help, answers to questions, information on Alport Syndrome, events past and future, fundraising ideas and much much more.

We have many ideas of what will be useful on the website, but if there is anything in particular you would like to suggest, please email us at info@alportuk.org.

Join us in Birmingham on Saturday 21 June!

We will be attending the Rare Disease Patient Information Day held by the nurses at the Queen Elizabeth Hospital Postgraduate Center, in Birmingham. It looks like an interesting event with talks and a chance to ask questions on topics such as the impact of living with inherited diseases, coping strategies, adolescence and transitional care, amongst other things.

We invite you to join Susie and Jules for breakfast before it begins, to meet other people living with Alport Syndrome and discuss what you would like to listen/discuss at the next Alport Information Day we are planning later in the year.

If you are hoping to come please let us know at info@alportuk.org by 6 June 2014 and book yourself in at <http://conferences.uhb.nhs.uk/events/rare-disease-patient-information-day/book-now/>

Be aware that if the numbers are too small, the day will not go ahead.



The workshop was sponsored by:



**Edinburgh
University Research
Fund**



Amgen



The 2014 International Workshop on Alport Syndrome

Earlier this year, 3-5 January 2014, alport uk hosted The 2014 International Workshop on Alport Syndrome in Oxford. Delegates came from around the world: Australia, China, USA, Canada and Europe. We are very grateful to Julie Kiddie who did the initial web search of Alport research to prepare the first draft of the invites. The report of the workshop was written up in *Kidney International*, an international journal which aims to inform the renal researcher and practicing nephrologists on all aspects of renal research. Attached is a summary of the report for you to read.

It was a hugely successful meeting: fantastic speakers, great conversation and discussion and plans for research in the future. The feedback from all those who attended was exceptional. To have both clinicians and patients in the same room worked well. We had patient groups from Australia, China and America, Holland, Italy, Spain, Portugal and France – all represented in the photo below:



Attending from the UK were Professor Colin Baigent (not pictured), Jules Skelding, Susie Gear, Mike Gear, George Walker, Patrick Walker and Jamie Walker. A couple of additional UK representatives were unable to attend at the last minute and with funding from the British Kidney Patients Association, we were able to video the key speakers. The videos will be available on U-tube and linked to the website when it is up and running.

Exciting outcomes:

- China, Australia, UK and Europe are now going to genetically test for Alport Syndrome using the Leiden Open Variant Database system.
- The UK renal registry is starting not only to take shape but a strategy is being worked on as to how to link it worldwide.
- A new basic science group of clinicians and scientists have joined together and are starting to research together.
- There has been an increase in the number of Alport specific research projects and new collaborations between researchers in different countries.

Renal Registry

One of the important facts coming from the workshop was the need for a renal registry. This will log each Alport patient, his or her medical journey, his or her genetic test results and will be linked to RPV (renal patient view), which many of you already use. It is vitally important for the future of research into Alport Syndrome and for our future health and welfare to be part of this registry. With a rare disease you need large numbers of patients for various reasons. For example: if there is a new drug needing testing, it needs to have a large patient base on which to test it; sharing knowledge; seeing patterns; contacting patients. If you would like to find out more about joining the renal registry, please contact us at info@alportuk.org.



The Scottish Renal Association



UK Kidney Week, May 2014, Glasgow

We were invited by the Renal Association and British Association of Paediatric Nephrologists to speak at the UK Kidney week in Glasgow. The British Renal Society jointly hosts the event each year with the Renal Association. It is attended by renal clinicians, researchers, renal care professionals from all over the UK. There was a specific afternoon session in the main auditorium that focused on Alport Syndrome with three topics:

1. Alport Syndrome: clinical management and therapeutic advances – speaker: David Milford, a Birmingham Paediatric Nephrologist
2. Alport Syndrome: patient journeys - Susie Gear, one of the co-founders of alport uk, represented us.
3. Alports and the structure of the glomerulus – speaker: Neil Turner, Professor of Nephrology, Edinburgh.

In the session on 'Patient journeys', Susie:

- explained what it can feel like to live with Alport Syndrome
- discussed some of the challenges of the transition between child and adult services and how it comes at a complicated time for Alport patients
- shared the experiences of patients designing and running an international workshop on Alport Syndrome



Alport Warriors

Wilma Calderwood champions our closed Facebook page, Alport Warriors. At time of print there are over 60 members and lots of good conversations going on – and sharing of advice and knowledge and tips, such as never taking ibuprofen even if you are a carrier.

If you are not yet a member and would like to be, please log on to [facebook.com](https://www.facebook.com) and ask to become a member. Wilma will let you in!

Events and fundraising ideas

Charity Race Night

raising money for Alport UK
on Friday 13th June 2014
at Ayr United Hospitality Suite
7pm for 7.30pm

Ticket price includes buffet and disco.
Ticket price £5 each.

alport^{uk}
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Wilma Calderwood is putting on a fundraising event in Ayr, Scotland. It is a charity race night on Friday 13 June. Should you want to attend this fun evening let us know and we can put you in touch with Wilma, or you can find her on Alport Warriors. We wish we were nearer!

If you have any ideas or any events coming up, let us know. We can help promote on Alport Warriors and on our website. We are having t-shirts made and balloons stamped with our logo. We are having leaflets printed with information about Alport Syndrome and gift aid forms and we can also offer a checklist of things to remember when hosting an event. We will have a specific page on our website dedicated to all fundraising activities and even a photo of 'fundraiser of the month!'

Please do send us in pictures of your events and let us know what you are up to.

FROG IN THE BOG



and other recipes from the
St Hugh's kitchen

The cookbook – Frog in the Bog

Our new bubbly team member Alice Turner has taken it on herself to keep up sales of Frog in the Bog. She has managed to persuade hotels and bookshops to stock this little gem. It really does have delicious and easy recipes. Should you like a copy at £10 (plus £2.50 postage and packing), or would like to help sell please contact us at info@alportuk.org. Please make any cheques payable to 'Alport UK Schools'.

We also have the template for the cookbook, so if you would like to do one at your school, let us know and we will give you the outline.

So far the money raised for alport uk from this fantastic book is over £4,000, which is just wonderful news.

Fundraising

You may want to host a fundraising event, or do a sponsored bike ride or coffee morning. alport uk would be very grateful for any money raised. Where would the money go? You can choose. Whatever you raise can go towards something you would like to pay for. We have set up separate bank accounts for our different activities: 'meetings' is one that pays for the information days we run to get people together; 'research' pays for the International workshops and research projects; alport uk is a general account

that funds more general activities such as membership of the European organisations that fund rare disease activities and research.

If you raised:

£10 - could contribute towards an individual in financial difficulties attending an Alport Information Day.

£20 – could help alport uk send out information packs to those who cannot access the information online.

£50 – could fund our annual membership of FEDERG, a new Federation of European Rare Disease patient groups lobbying for more European funding for research OR help provide the tea and cakes at an Alport Information Day.

£100 – could pay to write more pages of useful information on Alport Syndrome for the website OR the childcare at an Alport Information Day.

£1000 – this would pay towards videoing three patient stories and putting them on the website. Or could pay for a web based information leaflet on a topic such as genetics.

£10,000 – could pay for a researcher for 4-6 months, to do vital research eg understanding more about what happens to Alport kidneys that causes the kidney membrane to leak protein.

£25,000 could go towards The next International Workshop on Alport Syndrome, now planned for 2015, which increases the number of research proposals and accelerates the progress we make in finding solutions to help people living with Alport Syndrome. Evidence of this is from the workshop in January.

The money raised does not go on salaries or expenses for the staff at alport uk, we are all volunteers.

Request for Volunteers

We could really do with your help.... If you have any spare time and have any skills, whether it is reviewing newly drafted information leaflets to check they are simple and easy to understand, selling cookbooks or doing accounts, do let us know. We would love more folk to get involved with alport uk.

And finally...

You maybe receiving this newsletter via your renal unit. If you would like to be on our mailing list and receive our newsletter and any other information that we send out from the patient support group, please contact us on info@alportuk.org. or write to us at alport uk, PO Box 91, Tetbury, Gloucestershire GL8 0AW.

