



The 1st National Alport Family Support Day

Meeting report

**Saturday
1 December
2012 10am-5pm**

**Westminster Boating
Base, 136 Grosvenor
Road,
London SW1V 3JY**

An informal, family event created by those living with Alport Syndrome and generously supported by a number of individual donations. Also many thanks to the generous funding by the organisations below:

**BRITISH KIDNEY
Patient ASSOCIATION**
improving life for kidney patients

Kidney Research UK
Funding research to save lives

**ACTION FOR
ALPORTS
CAMPAIGN**
*Breaking Through
Rare Kidney Diseases*
Kidney Research UK

 **RARE DISEASE | UK**

The National Alliance for people with rare diseases & all who support them

“A truly excellent day which surpassed all expectations. I learned so much that would be incredibly helpful in terms of knowing what to expect and how to deal with it etc. Covered a vast amount of information in a very efficient manner”. “Very informative and good to share experiences and that I am not on my own” (Patient comments)

Introduction from Susie and Jules

We dreamt up the idea for this day whilst sitting on a picnic table in the grounds of Bowood House. We were having such a fun day – the chatter over the picnic was about amazing achievements – grade 8 musicians, singers, rugby players and the silly stories about dealing with hearing aids, blood tests and some of the horrors we had all been through but could laugh about now. The chatter laughs and jokes about what is ‘normal’ for us was such an uplifting experience to share, we vowed to get others together to do the same.

The First National Alport Family Support Day was a great success for all. It was the result of a small group of families working in partnership with the Rare Diseases Working Group for Alport Syndrome, whom we would like to thank for their support and encouragement throughout the design and development of the day: Professor Colin Baigent, Deborah Fielding, Professor Frances Flinter, Susie Gear, Michael Nation, Professor Neil Turner.

Our thanks also go to the amazing group of expert speakers and helpers who so generously gave up a whole Saturday (some flying in specially from abroad) to be with us in London: Catherine Cabantous (France), Deborah Fielding, Steve Fry, Oliver Gross (Germany), Ossie Fernando, Frances Flinter, Sharon Lagas (USA), Brigid MacArdle, Moin Mohamed, Chris Patch, Julie Tippet, and Neil Turner. Special thanks go to:

- Melinda Edwards & Caron Lawson - ran a breakout for the young people
- Emma Field, Heather Sizeland and Tull Kempe - looked after the children and scored 5+++ (out of a possible 5!) from the families
- Olive Media Group - filmed the speakers.

Their commitment and contribution to the day made it a big success:

The report attached summarises the feedback from the individuals and families who attended the event and the appendices give the detailed feedback

Susie Gear and Jules Skelding, Organisers, Alport Meetings

The First National Alport Family Support Day – 1 December, London

Summary of the day and the feedback we got from the patients and families

Context

1. Overall profile of the group attending

Approximately 106 people attended (including approx. 26 children), plus 26 clinicians and specialist helpers:

<i>Groups</i>	<i>Number attending</i>
Clinicians/researchers/representatives from organisations/helpers	26
Families (majority attended had Alports or were carriers)	28 families
Individuals (about half of them brought a friend)	16 individuals with Alports

<i>Breakdown of patient groups</i>	<i>Age range</i>	<i>Number attending</i>
Adults (balance of male/female)	66+	6
Adults (balance of male/female)	31-65	57
Adults (balance of male/female)	22-30	4
Teenagers/young adults	13-21	13
Children	0-12	26

- Note numbers approximate as a couple of families brought extra people with them
- Majority of geographical areas were covered – South west, South east, Midlands, Borders, Scotland. Covered most socio-economic groups and some were not native English speakers

2. Agenda designed to suit patient needs and room set up designed to encourage open discussion with our speakers

Everyone who registered was sent a form to complete on what they wanted to hear about at the event and to rank the topics of most importance to them. See appendix 1 for the full summary of topics that people expressed an interest in hearing about. This feedback was used to design the agenda to suit their needs and included sessions: introducing Alport Syndrome and how it impacts the kidneys; transplantation; genetics; hearing; eyes; study on ACE inhibitors; and inputs on recent research into Alport Syndrome by Sharon Lagas (Alport Syndrome Foundation, USA) and Deborah Fielding (Action for Alport's Campaign). A couple of patients also spoke of their experiences: Julie Tippett and Steve Fry (recently transplanted) who shared the patient/family perspective on the two initial topics of kidneys and transplantation respectively. The honesty and frankness of these two sessions set the tone for the question and answer sections after each speaker. Other valuable patient/family stories and perspectives were shared as part of these more informal parts of the agenda. The design of the 'circle' format of the room was an important factor in creating a 'safe environment' for people to speak freely about their experiences. See a copy of the agenda for the full day in Appendix 2.

3. Feedback gathered after the event showed people were ‘very satisfied’ with the day overall

At the end of the day, we asked everyone to fill out a feedback form:

- The high scores for the whole event meant that the group were ‘very satisfied with the day overall’ and the individual contributions by speakers, exceeding all expectations.
- The teenage breakout lead by the paediatric psychologist team of Melinda Edwards and Caron Lawson scored a full set of 5s and the childcare was scored over 5!

See Appendix 1 for more detail about how the feedback was gathered.

See Appendix 3 for the detailed feedback on each individual session.

Key messages about the overall day

- 1. The day achieved its’ objectives:** Improved patient management and support through shared information, enabled people to connect, tested the need for an Alport UK patient and family organisation and future activities

Patient and family comments:

- *“The day has been amazing. We are so glad we came and that the day has been possible. We no longer feel alone.”*
- *“Learnt a lot about Alports from the presentations and talking to the experts. Good to talk to others who were affected. Very satisfied. “ (Teenager)*
- *“Very useful to hear patients/families perspectives on the disease. Very well organised and delivered.”*
- *“Loved every minute. Fab day for all the family. Learnt so much. Kids entertained. Food fantastic. Drinks available all day. Thank you so very much.”*

- 2. Overall, people were very satisfied with the Family Support Day,**

Patient and family comments:

- *“It was a perfect day. Well done to all involved”*
- *“Thank you! I look forward to the future”*
- *“Fantastic day. Let us know details of next one, please”*
- *“Amazing! Incredibly useful. Thanks so much to everyone involved for all the hard work involved in putting it together. Much appreciated”*
- *“My head is full of so much knowledge”*
- *“Just what we needed”*
- *“Very satisfied. I think that the microphones could have been used a bit more, but overall very good (teenager)”*
- *“It was a really interesting and informative day. It was also very well organised. Thank you”*
- *“Excellent. Well done”*
- *“Very informative and good to share experiences and that I am not on my own”*

- 3. The highest scoring session was the teenagers/young adult breakout** in the afternoon with Melinda Edwards where the “group focused on developing helpful tips for young people or those caring for them”.

Melinda and Caron's summary comments:

- *"We were very impressed with the ideas that group members came up with and the openness they had with sharing their ideas with each other."*
- *"The group appeared to enjoy sharing experiences and decided that they were happy to share their ideas with the rest of the conference through making a short video, which was presented at the end of the day."*
- *"We talked about further meetings and there was interest do this annually. We also wondered whether there could be a more immediate connection between the young people such as a Facebook page where they could share experiences and ask questions in a more informal and direct manner."*
- *"We felt that they were a really impressive group of young people and thoroughly enjoyed meeting them all. Everyone had ideas to contribute and the older members were really good role models for the younger ones in the group."*

See Appendix 4 for the full report of the session.

Patient and family comments:

- *"Well done for producing the DVD – excellent advice!"*
- *"Helped her to meet people her own age who understand" (Mother of a teenager)*
- *"Lovely to have them involved"*
- *"Fun, informative, helpful listening to other people going through the same thing as you (teenager)"*

4. All the speakers scored highly – content and style of presentation was excellent – perfectly pitched at the right level for the audience

Some of the patient and family comments across the range of sessions:

- *"Head is spinning with all the new information"*
- *"Very interesting. Clearly very knowledgeable in this field"*
- *"Very informative"*
- *"Radar sounds incredible"*
- *"Learnt a lot about transplantation, very reassuring (teenager)"*
- *"Good speaker. Perhaps something on the opt-out system. Transplantation in Spain is much greater. They have opt-out thought it took them 20 years to make a difference to transplantation rates"*
- *"Very good presentation and down to earth"*
- *"Gained more knowledge on transplantation and second transplants in particular as son is waiting for second transplant"*
- *"Very simply explained"*
- *"Very valuable as we have not heard any new information since diagnosis 11 years ago"*
- *"Fantastic. Helpful. Given us a greater understanding"*
- *"Very good speaker. Answered all the questions and cleared up confusion around who develops Alports and why"*
- *"Able to comprehend this very important aspect and encouraged to think more about it"*

- *“Very interesting insight. Would like our children to be more thoroughly examined”*
- *“Fascinating. Clear information”*
- *“Although not an Alport’s expert specifically, offered a great overview of the effects on hearing”*
- *“I am able to understand exactly what this meant to Alport sufferers”*
- *“Now going to try to convince my son to get a hearing aid”*
- *“Brilliant presentation. This was the area I didn’t know much about before today”*
- *“Very valuable as our daughter is having eye problems”*
- *“Information was very detailed and clearly laid out”*
- *“Extremely informative. Discovered possible misdiagnosis from local optician of macular degeneration. Will be seeking a referral to Moin Mohamed by my GP”*
- *“Best report. Exciting to know he is trying to get other countries to add patient groups to his German prospective trial. More power to him – to include a UK group of patients soon”*
- *“Brilliant work”*
- *“I knew nothing about this so was SO grateful to hear about this research”*
- *“Fantastic. Amazing”*
- *“More, more, more!”*
- *“Great to be able to get involved”*
- *“Great to hear about the work being done and eager to get involved”*

See Appendix 3 for the detailed comments for each session.

5. People felt very satisfied with the quality of the information provided before the day

Patient and family comments:

- *“Excellent. Very informative. Everything I needed to know”*
- *“Initial information was very good. A reminder email in the week before would have been reassuring”*
- *“Well informed through email”*
- *“Great direction and good information available before the day”*

6. People were very satisfied with the quality of the venue and facilities eg childcare

Patient and family comments:

- *“Excellent venue – wonderful to have a view rather than the usual conference room outlook onto brick walls and air conditioning units”*
- *“My daughter wanted to take Emma (one of the nannies) home!”*
- *“Food was lovely. Childcare was fantastic”*
- *“Extremely good location, easy to get to and excellent hospitality and facilities”*
- *“Very well run day. Good facilities”*

But the sound projection needs to be better thought through next time with better facilities.

During the day, we let the patients' and families' interest in the topics drive the time we spent on things, being flexible with the agenda. This meant that we did not have as much time as hoped for the breakouts. Everyone was so engaged in the plenary circle format that we decided to cover the topics briefly with the whole group. This meant that they were not covered in the level of detail necessary and we must address these topics at future events, for example:

- Parents of children with Alport Syndrome
- Planning for Action for Alport's Campaign
- Developing a website for Alport information
- Developing a support network for Alport patients.

7. The main session that didn't score so highly (due to mixed scoring) was the networking

The mix of patient and family comments explain the mix of scores:

- *"We seemed to stay in our family group (our fault)"*
- *"Fantastic to have the opportunity to talk to the experts about specific queries – they were all incredibly friendly and helpful"*
- *"Amazing food. Great to chat to other people. Made friends with a family 20 minutes from us"*
- *"I am an older carrier with a child in his 30s. It was good to talk to older people and hear their experiences in regards to finding their children's diagnosis"*
- *"Talked to other people and families affected. Very good (teenager)"*
- *"Could have done with a bit more time as families tended to stick together and needed a bit longer to chat and start to form relationships. Maybe an email list would help start the contacts before the next get together"*
- *"Many of the families knew each other and a bit daunting to a newcomer to go to join them"*

See Appendix 3 for detailed feedback on each individual session.

Appendix 1: Process to design the agenda and gather feedback after the day

Designing the agenda

Everyone who registered was sent a form to complete on what they wanted to hear about at the event and to rank the topics of most importance to them. We received more than 30 forms back and the most important topic that people wanted to hear about was 'transplantation and organ donation'. Other topics high on the list of what people wanted to hear about were: an overview of research into Alport Syndrome, kidney aspects and genetics. Hearing and eyes were also requested topics, particularly as many people stated that they were not aware of the eye abnormalities that can impact people with Alport Syndrome. See below for the full summary of topics that people expressed an interest in hearing about.

From the 30+ forms that were returned completed, in order of priority:

1	Transplantation and organ donation
2	Overview of research into Alport Syndrome
3	Kidney aspects
4	Genetics
5	Symptoms
6	Medication
7	Hearing aspects
8	Introduction to Alport Syndrome
9	Supporting children
10	Eye aspects
11	Meeting clinicians
12	Where to find support
13	Networking – meeting other families
14	Family stories eg 'how to live life to the full'
15	Raising money for research
Other	Renal diet Mental health/depression in kidney patients Hearing aids for young people and support to pay for them (NHS behind ear not best for young people or business people) Ivf.

This feedback was used to design the agenda to suit their needs and included sessions: introducing Alport Syndrome and how it impacts the kidneys; transplantation; genetics; hearing; eyes; study on ACE inhibitors; and inputs on recent research into Alport Syndrome by Sharon Lagas (Alport Syndrome Foundation, USA) and Deborah Fielding (Action for Alport's Campaign). A couple of patients also spoke of their experiences: Julie Tippett and Steve Fry (recently transplanted) who shared the patient/family perspective on the two initial topics of kidneys and transplantation respectively. The honesty and frankness of these two sessions set the tone for the question and answer sections after each speaker. Other valuable patient/family stories and perspectives were shared as part of these more informal parts of the agenda. The 'circle' format of the room created a 'safe environment' for people

to speak freely about their experiences. See a copy of the agenda for the full day in Appendix 2.

Process to gather feedback after the event

At the end of the day, we asked everyone to fill out a feedback form:

- 26 forms were completed in detail – one for most of the family groups, plus 5 forms from speakers (who did not score their own sessions)
- People had to score each session (Scale of 1 = not satisfied, 5 = very satisfied) and were also invited to add comments.
- The average scores of the majority of the sessions, including individual speakers were above 4.5. From past experience of running events such as these, it can be a challenge getting scores higher than 4.5 as it only requires a couple of people to give lower scores to bring the overall average scores down. So the scores from this event are very high demonstrating its' overall success.
- These high scores for the whole event meant that the group were very satisfied with the day overall and the individual contributions by the speakers.
- The teenage breakout lead by the paediatric psychologist team of Melinda Edwards and Caron Lawson scored a full set of 5s and the childcare was scored over 5!



The 1st National Alport Family Support Day

Agenda

**Saturday
1 December 2012
10am-5pm**

**Westminster Boating Base,
136 Grosvenor Road,
London SW1V 3JY**

An informal, family event created by those living with Alport Syndrome and generously supported by a number of individual donations and the organisations below:

**BRITISH KIDNEY
Patient ASSOCIATION**
improving life for kidney patients

Kidney Research UK
accelerating research to save lives



RARE DISEASE | UK

The National Alliance for people with rare diseases & all who support them

Introductions

Be prepared with a few words to introduce yourself at the beginning of the event, so we can meet everyone, including:

1. Your name and nearest village/town
2. A short sentence (8 words) about one of the interesting or fun things you have done this year.

Short talks with question and answers:

- **Introduction to Alport, kidneys and RADAR** - Neil Turner
- **Transplantation and organ donation** - Ceste Fernando
- **Genetics** - Frances Flinter

Lunch

Teen/young adult breakout group to meet in gallery room next door

Short talks with question and answers:

- **Hearing** - Eriq MacArdle
- **Eyes** - Moh Mohamed
- **Overview of the latest research** – Sharon Lages, Julie Kiddie and Deborah Fielding
- **Early Pro-test** - Oliver Gross

Breakouts:

- **1 Parents of children with Alports** – Chris Patch
- **2 Planning for Action for Alports** – Deborah Fielding
- **3 Developing a website for Alport information** – Steve Fry
- **4 Developing a support network** – Julie Tippet and Katie Fry
- **5 Ideas for an international conference on Alport research** – George Walker and Julie Kiddie

All back in the main room

- **Breakouts report back**
- **Check out**

We will provide packs of hand outs at the end

If you need additional electronic copies, please mail Susie Gear and Jules Skelting at meetings@alport.info or call 01793 847 264

Appendix 3: detailed comments on each individual session from the feedback forms

Objectives for the First National Alport Family Support Day									
<ul style="list-style-type: none"> Improved patient management and support (for both children and adults) of Alport Syndrome - through shared information, knowledge, expertise and personal experiences across the community Enabled people to connect and have the space for a conversation – patients, families, clinicians Tested the need for an Alport UK patient and family organisation/support group and/or future activities eg useful information (website?), future meetings and what for etc? Developed outcomes and ideas for International Alport meeting to bring together scientists involved in relevant research and interested in doing future research into Alport Syndrome 									
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					1	2	3	4	5
How satisfied were you that these Family Support Day objectives have been achieved?								4.9	
Comments									
<ul style="list-style-type: none"> <i>“Excellent meeting – good balance between Alport families, patients and clinicians and scientists. A website clearly would be an enormous benefit – but quite a job to set up”</i> <i>“Fantastic day”</i> <i>“Wonderful day. I hope people found it helpful – it was certainly very interesting”</i> <i>“I found the day very informative after having the disease for 50 years and seeing many specialists”</i> <i>“It has been a very positive experience meeting other families and professionals each on a different journey but all with a shared goal. It feels like the beginning of something very exciting”</i> <i>“Really informative”</i> <i>“A truly excellent day which surpassed all expectations. I learned so much that would be incredibly helpful in terms of knowing what to expect and how to deal with it etc. Covered a vast amount in a very efficient manner!”</i> <i>“It has been nice to meet other people in a similar circumstance and professionals who can explain things without Google”</i> <i>“The day has been amazing. We are so glad we came and that the day has been possible. We no longer feel alone”</i> <i>“Brilliant day. Thank you for such great information and organisation.”</i> <i>“Amazing day! So good to meet everyone. Made some contacts for on-going advice, thanks!”</i> <i>“Excellent, well organised, thank you so much =)”</i> <i>“The few questions/concerns that we had were answered/addressed brilliantly”</i> <i>“Learnt a lot about Alports from the presentations and talking to the experts. Good to talk to others who were affected. Very satisfied (teenager)”</i> <i>“I think it was very good to meet other people with Alports and talk about shared experiences. It would be great if the support and care from health professionals and their general knowledge of them improve because of this”</i> <i>“Very good introduction to Alports and each other”</i> <i>“Thank you so much. The best event for me!”</i> <i>“A fantastic informative day – thank you so much for organising this. It must have taken a lot of work which was definitely worth it. I hope you think so!”</i> <i>“Very useful to hear patients/families perspectives on the disease. Very well organised and delivered”</i> 									

- *"I came to support a friend, who got some very useful information about genetic testing and also got some useful information regarding treatment available from different sources"*
- *"Very informative. Gained a lot more knowledge of genetics. Overall going home much more informed on all aspects of Alports"*
- *"Very interesting and informative"*
- *"Brilliant chance to meet people and hear stories, know what information is available"*
- *"Loved every minute. Fab day for all the family. Learnt so much. Kids entertained. Food fantastic. Drinks available all day. Thank you so very much"*

Preparation

How well were you prepared for attending the Family Support Day?

Scale: 1 = not satisfied; 5 = very satisfied

1	2	3	4	5
			4.6	

How satisfied were you with the quality of the information provided before the day?

Comments

- *"Very informed"*
- *"Covered everything, hard questions"*
- *"Good info beforehand"*
- *"Very satisfied. Good talks from experts (teenager)"*
- *"It would be interesting to know about people who did not respond to the letter about the support day. There were a lot of parents of children with Alports. Are there older people who were not represented so much as they didn't come?"*
- *"Excellent. Very informative. Everything I needed to know"*
- *"Initial information was very good. A reminder email in the week before would have been reassuring"*
- *"Well informed through email"*
- *"Great direction and good information available before the day"*

Sessions at the Family Support Day

Please evaluate below the importance and quality of contribution made to the Family Support Day objectives by each element of the day

How valuable was this session to your understanding of the Alport community?

Scale: 1 = not satisfied; 5 = very satisfied

1	2	3	4	5
			4.8	

Introductions and check in

Comments

- *Very friendly reception on arrival"*
- *"Fantastic"*
- *"Very warm welcome. The map was a great idea"*
- *"Very friendly"*
- *"Very friendly and helpful. Maybe if people had said about who in their family had Alports and the reason they had attended eg for support, for information etc"*
- *"Set out the day well"*

How valuable was this session to your understanding of Alport syndrome?										
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					1	2	3	4	5	
Introduction to Alport, kidneys and RADAR – Neil Turner								4.9		
Comments						<ul style="list-style-type: none"> • <i>“First rate”</i> • <i>“I would like to know if after transplantation he has come across anyone who has developed Coeliac and epilepsy and Osteoporosis in the same year through medication for keeping the transplant. I have had it 17 years”</i> • <i>“Head is spinning with all the new information”</i> • <i>“Very interesting. Clearly very knowledgeable in this field”</i> • <i>“Very informative”</i> • <i>“Radar sounds incredible”</i> • <i>“Excellent”</i> • <i>“Very good. Very informative (teenager)”</i> • <i>“Very good speaker and answered questions well. Maybe a bit more on the likelihood of carriers to show symptoms?”</i> • <i>“Very interesting”</i> • <i>“Explained clearly and concisely and well received”</i> • <i>“Very informative. Now have much more knowledge”</i> 				

How valuable was this session to your understanding of transplantation and organ donation?										
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					1	2	3	4	5	
Transplantation and organ donation – Ossie Fernando								4.7		
Comments						<ul style="list-style-type: none"> • <i>“Very informative and worrying!!”</i> • <i>“Very interesting. I learnt a lot”</i> • <i>“Good talk – but families need to know more and hear more about the shortage of kidneys and efforts to get more donations. Eg why not have ‘presumed’ consent for organ donation?”</i> • <i>“My husband had a transplant 4 years ago”</i> • <i>“Very informative”</i> • <i>“Learnt a lot about transplantation, very reassuring (teenager)”</i> • <i>“Good speaker. Perhaps something on the opt-out system. Transplantation in Spain is much greater. They have opt-out thought it took them 20 years to make a difference to transplantation rates”</i> • <i>“Very good presentation and down to earth”</i> • <i>“Gained more knowledge on transplantation and second transplants in particular as son is waiting for second transplant”</i> 				

How valuable was this session to your understanding of Alport syndrome?										
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					1	2	3	4	5	
Genetics – Frances Flinter								4.9		
Comments						<ul style="list-style-type: none"> • <i>“Particularly useful for our current family circumstances”</i> • <i>“A lot clearer”</i> • <i>“Very interesting. Would like to speak in more depth about our particular case”</i> • <i>“Very simply explained”</i> • <i>“Very valuable as we have not heard any new information since diagnosis 11 years ago”</i> • <i>“Very interesting information”</i> • <i>“Fantastic. Helpful. Given us a greater understanding”</i> 				

- *“Very good speaker. Answered all the questions and cleared up confusion around who develops Alports and why”*
- *“Really interesting overview”*
- *“Able to comprehend this very important aspect and encouraged to think more about it”*
- *“This was the most useful session as a carrier with a son with Alports and a daughter planning on starting a family”*

How valuable was the networking over lunch?

Scale: 1 = not satisfied; 5 = very satisfied

1	2	3	4	5
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Lunch: Networking

			4.1	
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Comments

- *“We seemed to stay in our family group (our fault)”*
- *“Meeting other families with Alports”*
- *“Fantastic to have the opportunity to talk to the experts about specific queries – they were all incredibly friendly and helpful”*
- *“Amazing food. Great to chat to other people. Made friends with a family 20 minutes from us”*
- *“Spoke to someone approaching transplant. Was good to offer help”*
- *“I am an older carrier with a child in his 30s. It was good to talk to older people and hear their experiences in regards to finding their children’s diagnosis”*
- *“Excellent to talk to others. Fantastic opportunity. Thank you!”*
- *“Talked to other people and families affected. Very good (teenager)”*
- *“Could have done with a bit more time as families tended to stick together and needed a bit longer to chat and start to form relationships. Maybe an email list would help start the contacts before the next get together”*
- *“Many of the families knew each other and a bit daunting to a newcomer to go to join them”*
- *“Nice to speak with others dealing with Alports”*
- *“Great talking to others gaining different perspectives etc”*

How valuable was this session to your understanding of Alport syndrome?

Scale: 1 = not satisfied; 5 = very satisfied

1	2	3	4	5
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Hearing – Brigid MacArdle

			4.6	
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Comments

- *“Interesting”*
- *“Loved the video”*
- *“This is an area that definitely need more research and more collaboration between organisations”*
- *“Very interesting insight. Would like our children to be more thoroughly examined”*
- *“Interesting”*
- *“We could and should have heard more about types of hearing aid – the importance of audiology assessments and new digital aids”*
- *“Fascinating. Clear information”*
- *“Very valuable”*
- *“Good explanation. Needs more on the impact of having hearing aids on how people perceive you. Also the development of hearing aids. I have listened to my husband’s hearing aids and they are rubbish! The sound is tinny. Surely with advanced technology, they can be better than that?”*
- *“Although not an Alport’s expert specifically, offered a great overview of the effects on hearing”*
- *“I am able to understand exactly what this meant to Alport sufferers”*

- *"Now going to try to convince my son to get a hearing aid"*

How valuable was this session to your understanding of Alport syndrome?					
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					
1	2	3	4	5	
			4.8		Eyes – Moin Mohamed
Comments					
<ul style="list-style-type: none"> • <i>"I hope people volunteer for the research"</i> • <i>"An area most people seemed not to know about – more detail about treatments in future meetings"</i> • <i>"Interesting"</i> • <i>"Really good practical information"</i> • <i>"Would like our children to be seen at St Thomas's"</i> • <i>"Brilliant presentation. This was the area I didn't know much about before today"</i> • <i>"Very valuable as our daughter is having eye problems"</i> • <i>"Information was very detailed and clearly laid out"</i> • <i>"Good content, but delivery could have been clearer"</i> • <i>"Extremely informative. Discovered possible misdiagnosis from local optician of macular degeneration. Will be seeking a referral to Moin Mohamed by my GP"</i> • <i>"Good talk. Also very good that you can be involved in research to improve understanding of Alports, and be directly involved. I think this was probably the best speaker for that reason"</i> • <i>"Good to hear about this as haven't had info on it before"</i> • <i>"Very good and clear presentation in layman's terms"</i> • <i>"Son has undergone replacement lenses in both eyes so this was very interesting"</i> 					

How valuable was this session to your understanding of research into Alport syndrome?					
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					
1	2	3	4	5	
			4.7		Overview of the latest research – Sharon Lagas, Julie Kiddie and Deborah Fielding
Comments					
<ul style="list-style-type: none"> • <i>"Huge thanks to all involved!"</i> • <i>"Been great to meet Sharon after emailing her for the last 3 years. Enjoyed all the talks"</i> • <i>"Information was very detailed and clearly laid out"</i> • <i>"More, more, more!"</i> • <i>"Great to be able to get involved"</i> • <i>"Great to hear about the work being done and eager to get involved"</i> 					

How valuable was this session to your understanding of Alport syndrome?					
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					
1	2	3	4	5	
			4.9		Early PRO-TECT Alport trial: use of ACE inhibitors – Oliver Gross
Comments					
<ul style="list-style-type: none"> • <i>"Best report. Exciting to know he is trying to get other countries to add patient groups to his German prospective trial. More power to him – to include a UK group of patients soon"</i> • <i>"Brilliant work"</i> • <i>"I knew nothing about this so was SO grateful to hear about this research"</i> • <i>"Fantastic. Amazing"</i> • <i>"Our daughter started Enalapril about 6-7 years ago"</i> • <i>"Information was very detailed and clearly laid out"</i> • <i>Very interesting. Would like to know more about early intervention – how, when etc"</i> • <i>"Very satisfied"</i> 					

How valuable was this session to meeting others and you sharing what you need?										
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					1	2	3	4	5	
Breakout: Teenagers/young adults – Melinda Edwards										5.0
Comments						<ul style="list-style-type: none"> • <i>Excellent DVD presented back to the group. Good work!"</i> • <i>"Well done for producing the DVD – excellent advice!"</i> • <i>"Helped her to meet people her own age who understand"</i> • <i>"Lovely to have them involved"</i> • <i>"Fun, informative, helpful listening to other people going through the same thing as you (teenager)"</i> • <i>"Great!"</i> 				

How valuable was this session to your understanding of Alport syndrome in children?										
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					1	2	3	4	5	
Breakout: Parents of children with Alport syndrome – Chris Patch									4.1	
Comments						<ul style="list-style-type: none"> • <i>"A major topic of interest to everyone"</i> • <i>"Very important. As parents we worry constantly. So helpful to be with other parents"</i> 				

How valuable was this session to your understanding of the campaign?										
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					1	2	3	4	5	
Breakout: Planning for Action for Alports Campaign – Deborah Fielding									4.7	
Comments						<ul style="list-style-type: none"> • <i>"Spoke with Deborah about fund-raising etc"</i> • <i>"Great to hear of this initiative"</i> • <i>"What a fab lady. Well done Deborah. We would be happy to help raise money"</i> • <i>"It's one of our biggest concerns"</i> • <i>"Very inspiring. Keen to get involved"</i> 				

How valuable was this session to you sharing what information you need?										
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					1	2	3	4	5	
Breakout: Developing a website for Alport information – Steve Fry									4.8	
Comments						<ul style="list-style-type: none"> • <i>"Will be interesting to continue discussions beyond this event"</i> • <i>"Would be very helpful"</i> • <i>"Very informative"</i> • <i>"Excited about the prospect in regards to younger sufferers"</i> • <i>"I am still interested in this though the session didn't happen"</i> • <i>"Great idea"</i> • <i>"I am Stephen's cousin so will be continually involved/informed"</i> 				

How valuable was this session to you sharing what support you need?					
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					
	1	2	3	4	5
Breakout: Developing a support network for Alport patients – Julie Tippet and Katie Fry				4.8	
Comments <ul style="list-style-type: none"> • <i>“Will be interesting to continue discussions beyond this event”</i> • <i>“Would be a great support”</i> • <i>“Katie is married to my cousin, so I will be involved”</i> 					

Venue (Westminster Boating Base) and facilities eg childcare etc					
How satisfied were you with the quality of the following aspects of the venue and facilities?					
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					
	1	2	3	4	5
<i>Main room (Size and ambiance)</i>				4.9	
<i>Catering and service</i>				4.9	
<i>Sound projection and ability to hear speakers</i>			3.8		
<i>Childcare facilities provided – does this help?</i>					5.1
Comments <ul style="list-style-type: none"> • <i>“Excellent venue”</i> • <i>“Food was excellent”</i> • <i>“Excellent venue + location + food. Also kept my teething daughter entertained, so thank you =)”</i> • <i>“Bit cold. Great for children to be able to enjoy themselves”</i> • <i>“Excellent venue – wonderful to have a view rather than the usual conference room outlook onto brick walls and air conditioning units”</i> • <i>“My daughter wanted to take Emma home!”</i> • <i>“Catering and service +++, Childcare facilities ++++”</i> • <i>“The overall day”</i> • <i>“Food was lovely. Childcare was fantastic”</i> • <i>“I could hear, but Richard couldn’t”</i> • <i>“Extremely good location, easy to get to and excellent hospitality and facilities”</i> • <i>“Very well run day. Good facilities”</i> 					

Your overall experience of the First UK Alport Family Support Day					
<i>Scale: 1 = not satisfied; 5 = very satisfied</i>					
	1	2	3	4	5
Overall, how satisfied were you with the Family Support Day?				4.9	
Please make suggestions/comments on how we could improve your overall experience? <ul style="list-style-type: none"> • <i>“It was a perfect day. Well done to all involved”</i> • <i>“Thank you! I look forward to the future”</i> • <i>“Fantastic day. Let us know details of next one, please”</i> • <i>“Amazing! Incredibly useful. Thanks so much to everyone involved for all the hard work involved in putting it together. Much appreciated”</i> • <i>“My head is full of so much knowledge”</i> • <i>“Great. Really appreciate the time and effort everyone put in. =)”</i> • <i>“Enjoyed every minute”</i> • <i>“Fantastic day. Thank you”</i> • <i>“A very informative day”</i> • <i>“Fantastic – thank you so much. Look forward to the next one! =)”</i> 					

- *“Just what we needed”*
- *“Very satisfied. I think that the microphones could have been used a bit more, but overall very good (teenager)”*
- *“It was a really interesting and informative day. It was also very well organised. Thank you”*
- *“Excellent. Well done”*
- *“Smaller groups to discuss certain topics. To be given the opportunity to join research projects”*
- *“Brilliant. Really well organised and informative”*
- *“Very informative and good to share experiences and that I am not on my own”*
- *“Excellent”*

Any other ideas or comments?

- *“Maybe at future events there could be a discussion purely for carriers of Alports”*
- *“It would be good to have someone from a PCT or a few GPs as they are often the first point of contact and are failing to recognise the symptoms which delay the diagnosis”*
- *“Thank you so much. It has been great”*
- *“Thank you very much for organising this day, it was brill. I wish we had this much earlier in this journey”*
- *“Thank you. Excellent!”*
- *“Just to thank you again and also for keeping me so well informed in the lead up to the day. Knowing what to expect was very helpful. (patient speaker)”*

Appendix 4: Feedback from the teenager/young adult breakout group

Alport Family day- Young People's group

The group focused on developing helpful tips for young people or those caring for them. We were very impressed with the ideas that group members came up with and the openness they had with sharing their ideas with each other.

We have summarised the group discussion under a number of themes.

Sharing experiences

The group gave the young people an opportunity to talk to other people about their condition and share some of their experiences. Many people in the group had never had the opportunity to meet anyone else with Alports. One young boy even thought he was the only person who had been diagnosed with Alports.

Hearing

Group members talked about their experience of having hearing difficulties and the best ideas to give other people with regards to helping. They suggested that it was good to let people know and then to ask people to speak normally and clearly

(for example not to exaggerate mouth movements or speak louder) as this enabled better communication. Some people suggested that using a radio mic in class was also helpful to be able to hear more clearly. The group thought that using a radio mic was particularly useful at school but there were mixed ideas about whether using it socially was helpful or just drew attention to their hearing problems.

The group members shared their expertise of using hearing aids with one group member who did not currently use one, emphasising how easy they were to get used to (to the extent that sometimes they forgot they were even wearing one!). They were able to reassure that hearing aids were secure to wear and would not just fall out. This information was clearly helpful with the young man as he told the group he felt better about starting to wear hearing aids.

The group agreed that it was actually very hard to tell if people were wearing hearing aids as they were very discrete, this emphasized that some people would not know they may have hearing difficulties unless informed and they needed to take responsibility for this.

Although discrete, there were some specific situations where group members were clear they would not want to show the hearing aid, such as when in character in a play. In this situation they showed good creativity in how they might disguise or conceal the hearing aid when needed.

The group also talked about ways of humorously dealing with unwanted attention. One group member suggested telling people 'you are listening to music' and another mentioned he sometimes told people he was a spy and that people communicated with him through his hearing aid!!!

In terms of negative experiences of hearing loss, some young people mentioned that wearing a hearing aid can quite tiring at times as it globally picks up noise and is not able to selectively highlight important sound. We thought this could be a useful tip to mention to teachers to be aware of.

It was also interesting to hear that the group thought that occasionally they could use their hearing disability to their advantage, but we agreed what was said in the group stays in the group!!!

What it meant to have Alports.

The group had very different experiences which related to how long they had been diagnosed for and what level of hearing and renal impairment they already had. It also depended on their knowledge of Alports in later life (related often to who they already knew in their family with Alports).

There was some uncertainty about what the future would hold, with one person believing that having a transplant would be a positive experience as they would no longer need to take medication (this misconception was corrected by someone else in the group.) Another member felt that having an operation such as a transplant, would be a scary experience. It was clear some families were planning for the future including travelling abroad to places now that they may not be able to visit in the future after having a transplant.

There was some uncertainty about the future and how serious Alports was. It was clearly new information to most of the group that there may be visual problems and this is one of the questions they wanted to ask one of the experts later on when they re-joined the conference

Another question one of the young people had was the impact of keeping themselves healthy and whether this would delay the onset of renal failure? This was another question they wanted to bring back to the rest of the conference.

There was considerable expertise in the group about taking tablets which they shared with each other. A very effective tip was to have a routine and it was also mentioned that it gets easier with practice!

It was helpful having other family members in the group as well as young people with Alports, both to hear other family member's experiences and also as we felt it was good for siblings to hear and talk about Alports as it was mentioned that it doesn't get talked about much at home as it has become 'normality'. We validated everyone's roles in the group hearing about everyone's experience of Alports.

We lightly touched on the subject of where Alports came from; there was a very clear genetic/familial connection for all but one group member who thought he was the only person in his family with Alports. It was briefly raised what knowledge parents

had about Alports and different thoughts about this from people in the group whether their parents knew or not when considering to have children and how this would affect them.

The group appeared to enjoy sharing experiences and decided that they were happy to share their ideas with the rest of the conference through making a short video, which was presented at the end of the day. We talked about further meetings and there was interest do this annually. We also wondered whether there could be a more immediate connection between the young people such as a Facebook page where they could share experiences and ask questions in a more informal and direct manner.

We felt that they were a really impressive group of young people and thoroughly enjoyed meeting them all. Everyone had ideas to contribute and the older members were really good role models for the younger ones in the group.

Melinda Edwards

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