Aniridia Network UK

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Annual report for 2014/15

Welcome to our 2014/15 annual report. We are pleased to say that we've had a successful and varied year. We've been able to reach out to new members and participate in several exciting events. Read on for further details.

Patron's Progress

Looking up on the internet what charity Patrons do and who they are, you find that they are often well-known illustrious individuals who fulfil their role in several ways, partly depending on who they are.

- A celebrity can help you raise your public profile by getting you media attention, taking part in fundraising events etc.;
- A politician can help you open doors and make you more credible to many people. Although be careful not to get your organisation involved with any particular party, that you may appear to be campaigning for;
- A scientist or expert in your area of work will lend credibility; and
- An establishment figure (such as a royal) may do all of the above.

(from a document by Community Action Southwark)

Obviously someone like me is not expected to bring glamour to the charity, but you could definitely have several different Patrons – many charities do. They could then bring a spectrum of distinct advantages to ANUK.

In the past year, my main role has been to help with organising speakers for the annual meeting, which was in Bristol in 2014. After some thought and several emails I was able to identify two or three relevant clinicians, with whom I had interacted, who were available on the day. Drs Alex Shortt and Victoria Tovell, who work at Moorfields and the Institute of Ophthalmology on corneal keratopathy talked about their research with Professor Julie Daniels and the Cells for Sight team. They presented details of progress into "Stem Cell Treatment of Aniridia-Related Corneal Disease" Professor Colin Willoughby from Liverpool discussed "Emerging Molecular Therapies for Aniridia". Dr Amanda Churchill, who is a member of our Medical Panel, based in Bristol, joined the panel of experts for a Question and Answer Session.

I found all the talks full of information, but hearing about the life stories of aniridia-affected members and their families is always the most fascinating. There are many ingenious coping strategies revealed in these presentations. As one who has done a lot of research on the genetics of aniridia and the major causative gene, PAX6, it is very interesting to hear how losing the activity of just one copy of the gene has so many effects. It helps us to understand the gene more and teaches us what aspects need further study. Talking to delegates, including parents of patients, also provides insight into what some of the day to day problems are, such as sleeping regular hours.

Later in 2014, in September, I was lucky enough to be invited to the Aniridia Europe conference near Venice, where I met several continental patients and heard interesting talks. One of the delegates was a young man whose unusual PAX6 regulatory mutation (controlling the expression in the lens) we had identified a couple of years earlier. Also present was Jill Nerby Founder and President of Aniridia Foundation International. She is a very impressive figure and has taken on a new role as Congenital Eye Disorder Manager at the ophthalmology department of the University of Virginia hospital. She talked about her role in guiding patients through the complexities of dealing with the clinical management system and much other useful information gathered by many people over the years.

You will be aware of the advances in genetic studies throughout the world. This will bring new insights even into aniridia, where we can find PAX6 mutations in about 85% of newly diagnosed patients. But new genes are being identified in a few previously unsolved cases, which are similar to classical aniridia, but probably distinct in detail. These genes will become public soon. There is also increasing interest from clinicians in studying the sleep disturbances present in some aniridia patients. It always takes too long to get funding and people in place to carry out such studies, but it remains important for all of you to ask for such work to be made possible.

A year in review from the Chair

This year we have focused on consolidating and building on the great achievements and growth we have seen in the past couple of years, in terms of increased membership, a more professional outlook and great fundraising efforts.

We kicked off the year with our Annual Conference 2014 where we welcomed over 60 members in Bristol. The south west was an area of the UK we had not visited before. We were pleased to welcome new members from the south west and further afield as well as many familiar faces. We are hoping to visit another new area, the north east, in 2015 and our conference team are already working hard on plans for this.

The Trustee Board grew from 6 members to our maximum of 9 with us saying goodbye to Nigel Holdstock, welcoming back Craig Anyon and 3 new trustees Mary Cox, Ben Rendle and Chris Moore. This has provided a valuable boost to the organisation and a great injection of new ideas but it has also had its challenges. It has been difficult for Chris and Craig to attend many trustee meetings and we have found a larger Board can become a bit unwieldy. We have therefore been looking at ways we can restructure to become more efficient and productive and allow more members to get involved as volunteers without having to become a trustee. Achieving this will be an important goal for the year ahead.

This goes hand in hand with another important goal, to become a registered charity. An important requirement for this is to have income greater than £5,000 a year. In the previous year we saw our income significantly exceed this target for the first time and we are happy to say we have succeeded in repeating this again this year. This is a vital step towards becoming a registered charity and we would like to thank everyone who donated and took part in fundraising events for us, we couldn't have done it without you!

Together with counterparts from across Europe we have been working to strengthen Aniridia Europe. I represented Aniridia Network UK at the 2nd European Medical Conference on Aniridia held in Italy in September 2014 which was a unique opportunity for doctors and researchers from across Europe and further afield to come together and focus purely on aniridia and related conditions. We hope this will become a regular biannual event. We were also invited to take part in an Aniridia Youth Exchange Summer Camp to be held in Italy in August 2015. This event brought together young people between the ages of 13 and 25 from across Europe with aniridia including up to 8 young people from the UK. One of those young people, Lois Turner, travelled to Italy this summer to represent the UK in the planning process. We advertised this event regularly, but we have been a little disappointed at the lack of interest from our members. The event is not only a chance to see some beautiful sights and enjoy some great outdoor activities but also a chance for young people to meet others with aniridia, share experiences and learn from each other in an informal setting. We are hoping this will be a springboard to launch more activities and events for young people with aniridia in the UK. Tim Broome kindly volunteered to be a UK leader for the trip and actively looked for participants from outside our current membership. We am looking forward to hearing all about the event from Tim, Lois and the other participants.

Of course as well as these big events we have been quietly working away on our everyday activities. These include answering your enquiries with help from our Medical Panel and other Advisors, publishing aniridia news and articles on our blog and social media, helping our volunteers with fundraising and distributing our hospital leaflets, promoting Rare Disease Day and representing the interests of aniridia patients as part of organisations such as the Genetic Alliance and Rare Diseases UK.

I would like to thank all our trustees, volunteers and fundraisers for their hard work throughout this year. By working together I am sure we can achieve even more next year.

Membership

We have gained many new members though fewer than previously. We've grown rapidly in recent years so perhaps we are approaching a peak, at least based on our current dispositions.

Category	**2012/ 13**	**2013/ 14**	**2014/ 15**	**Year on year increase 2013-14**	**Year on year increase 2014-15**	**% of estimated affected people in the UK**
familial aniridia	83	114	134	37%	18%	
sporadic aniridia	73	94	116	22%	23%	
aniridia but origin unknown	87	87	84	0%	-3%	
Total with aniridia	243	295	330	21%	12%	23%
Traumatic aniridia	0	2	2	20	0%	0%
WAGR	22	31	34	41%	10%	51%
None/ unknown	187	237	265	27%	12%	
Total	452	565	635	25%	12%	

Note: Increases in familial and sporadic cases may be due to clarification of type from unknown

James continues to manage membership. His diligent research and persistence has led to several new affiliations.

Despite his efforts however, we have still not found a volunteer to be a dedicated Membership Officer. As a result, plans to improve the quality and structure of our contact data have not been possible.

A new volunteer has offered to develop our database which James and Keith, our Database Officer are overseeing.

Communications

Social media

The growth of our social media has continued but slower, in-line with membership.

	Followers						
				Year on year increase			
Site	2012/13	2013/14	2014/15	2013-14		2014-15	
Facebook	383	531	607	148	39%	76	14%
Twitter	282	416	517	134	48%	101	24%

l57% of our Facebook followers are in the UK and 18% are in the USA. 72% are female.

We frequently post aniridia news, announcements and appeals. We also share posts from Rare Disease Day, Nystagmus Network etc. This informs our followers and strengthens relationships with those organisations. Our best performing posts were about personal stories and research. They reached 1,638 views and were Liked by 20 people.

We have promoted and participated in the Aniridic Family group on Facebook. It has become the most active aniridia community online, a fantastic international resource for instant support, advice and making connections.

Facebook helps us stay in touch with members, and they with each other. Through it we hear of medical issues and treatments, achievements and challenges. Our Board members actively engage with these to help and learn things that can be useful for others.

Twitter meanwhile is primarily useful for receiving news and communicating with relevant organisations.

James currently manages social media but we really need an outgoing, enthusiastic Social Media Officer to build on this success.

Website

Usage of our website has increased:

- Visitors: 7,870;
- Views 15,750 (+21%);
- Blog posts: 37 (+2).

Blog subjects were mainly patients and parents accounts of dealing with aniridia plus news of fundraising and research. Videos of the presentations given at Conference 2014 have also been published on YouTube and embedded into blog posts by James. As usual we make most content public, to benefit everyone, but reserve personal stories exclusively for ANUK members. Thank you to all those who provided content. We appeal to everyone to send us their stories.

We have not had capacity to develop the website or its medical information as we hoped. More volunteers would be very useful.

Email broadcast

- 346 subscribers;
- approximately 50% open rate; and
- mainly read using mobile devices, predominantly iOS.

James used our email broadcast system to distribute our winter newsletter, the #IrisSelfie campaign and Conference 2015 announcement. We also sent targeted invitations for our meet-ups. This is important because social media posts only reach a portion of our members.

We need feedback on how to make our direct communications more engaging. We also need volunteers to improve the email and post output.

Financial report

The total income for ANUK in the year 2014-2015 was £8,963.44 a 20.38% increase on 2013-2014 which had a total income of £7,446.

This increase in income was thanks to some fantastic fundraising totalling over £4,000.00.

The total cost of running ANUK in the year 2014-2015 was £1,644.64. The biggest cost being the annual conference.

Overall this was a fantastic year financially for ANUK and will contribute to a very stable year in 2015-2016.

Events

James arranged 3 meet-ups for patients and parents. The events in Leicester, Milton Keynes and Newcastle were hosted by Katie, Andrew, James and Kelly. They were useful but not well attended.

The Aniridia Europe Youth Camp held in summer 2015 was extensively publicised. At the time of writing one adult and two young people are going from the UK for 10 days of activities near Venice.

We advertised a Genetic Alliance UK event in Cardiff to establish a local support group for people affected by rare eye diseases. At least two member households are now involved.

We'd like members to tell us what kind of events they would like and to help make them happen.

Rare Disease Day 2015

Together James and Jessica at Aniridia Foundation International ran an awareness and fundraising campaign anchored on Rare Disease Day. They orchestrated a global meme of posting a photo of one's eye along with a donation pledge and nomination plus #IrisSelfie and #RareDisease. It worked really well sparking off lots of interesting conversations.

ANUK received nearly £200 in donations. £80 came via an SMS donation system, set up late in the initiative. This was mainly thanks to the insisting and dynamism of Elly Chaplet. The percentage of donations to pictures was somewhat disappointing.

Looking at what we could have done better. We struggled to get people to post photos with irises as well as of aniridia. So the campaign's reach was limited. In trying to both educate and stimulate it was not simple enough.

Also our needs and purposes are unclear to many and hard to articulate in a few works, compared to say "....to beat cancer". Our wordy calls to action therefore worked well on Facebook. However viewing the pictures was often restricted by privacy settings. By contrast it was difficult to do it all in the 140 characters on the public medium of Twitter.

Based on its late performance, enabling SMS donations from the start could well have made a big difference to the virility and profitability. This was shown when we re-used it with a different campaign on Mother's Day.

James found it a real pleasure to work with Jessica. They played off each other's variations and refinement of the messaging to get the best effects. They plan to devise a similar scheme involving other countries next year.

Volunteering

ANUK owes its existence to the amazing efforts of its volunteer officials. They deliver all our services and infrastructure in their spare time. We are extremely grateful for everything they do for the benefit of our members.

Our newest volunteers are:

- Kelly – assisting with Conference 2015 in Newcastle;
- Tracy & Krystnya - creating a patient passport to use in hospitals; and
- Jerry - Improving our contacts database.

However the number of people, their skills and time they give to ANUK activities continues to be the biggest limitation for the organisation. Some have not been able to spend as much time as would be necessary to achieve as much as we'd like, or in the timescales desired. At the same time appeals for additional volunteers are answered but the offers to help have often not been followed through. This all affects our (perceived) effectiveness which has negative consequences.

As well as more people doing stuff, we need someone dedicated to recruiting and managing volunteers.

Liaison/Public Relations

We put a journalist in touch with Susan, resulting in a great article about her daughter's aniridia in Pick Me Up magazine.

We worked with Genetic Alliance UK to produce an aniridia briefing for the Human Fertilisation and Embryology Authority (HFEA) to inform their decision on licensing pre-implantation genetic diagnosis.

We advocated for members to sign up to the CoRDs Patient Registry to facilitate research into aniridia and WAGR.

We advertised for young people to take part in US research into how aniridia genes affect sleep.

Enquiries and advisers

We received around 16 enquiries by email and one enquiry through Facebook, plus five by phone in the past year. These enquiries only account for the direct enquiries that we receive, we are aware of others that are made unofficially through Facebook threads or direct messages to the trustees and officers. Enquiries this year have largely covered genetics (sometimes in combination with other conditions) both sporadic and inherited, corneal conditions – stem cell deficiency, scraping, treatment options, benefits, surgery, education and included referrals from other groups.

We have received requests from other groups for volunteers and been passed information on the experiences of different families.

We were able to handle our enquiries in an effective manner, as three people were involved in responding to enquiries this year, rather than two. This was a particular bonus because of the decreasing level of sight of one of the people who normally handles the majority of enquiries.

We were able to answer most of the enquiries within ANUK, but others were passed on to our advisers. The advisers continue to be an invaluable resource for the trustees, officers and members of ANUK, for which we thank them enormously. Even as people with aniridia, we are always learning something new from our advisers. We are lucky with our advisers, whenever we ask for help or information we always receive a great response.

The Aniridic Family group on Facebook continues to be a place to ask questions and get advice. The well-informed patients and parents there are very helpful. We monitor the posts and contribute whenever we can. We signpost enquiries originating from abroad to the group and to Aniridia Foundation International.

We have been tagged in other groups.

Education

Our new pupil passports for early years, primary and secondary schools were introduced at the 2014 conference, with presentations from the Westwood family and Lyn Buller, Education Officer. After the conference there were nine requests for passports.

In October 2014 we were contacted by a teacher who had a new pupil in her class with aniridia. She became a member of ANUK and expressed her gratitude for the passports examples and the educational advice she received.

Fundraising

ANUK had a fundraising target of £4,500 for the year starting at conference in June 2014. This was the minimum we needed to raise but more would be welcome and enable us to do more.

We got off to a good start at conference with the sale of merchandise and the raffle raising £344.15 between them. A number of conference attendees and their families were inspired to raise money in various ways. Sponsored events proved again to be great money raisers with Kirsty Brunskill completing the Salford swim and a hair day raising in all £2,155. Caryl Roberts passed on £100 raised by friends having a party. Victoria Tovell raised £115 with a cake sale. Harry Atkinson completed the York Marathon raising £683 Riley Blissett completed a sponsored “blind day” raising a great £1007. The Atkinson family again collected at a local Sunday Market in North Yorkshire raising £244. There were a number of other events completed by our members and we are thrilled with the response and would like to thank everyone concerned.

We also received a very generous £1250 from the FDQT bike team after they had completed the Ride London 100 biking event. Many thanks to all the riders involved and to Elly Chapple for facilitating this.

Our Patron Veronica successfully negotiated a donation of £1000 in return for advice. Special thanks to her for this super donation.

We have a small number of people giving a regular monthly amount, but it is a valuable source of income for us and is an area we need to grow.

Other smaller amounts have come in from T-shirt sales, sales of old clothes and other one off donations.

Gift Aid from sponsored events needs to be pursued as it is a growing area of income for us. We have also had more success with commissions from on line shopping through Give as You Live/Everyclick with a number of members using the site when shopping on line. These are both areas that we are looking to improve on in the coming year and we are now trialling "Just Giving" to expand our profile.

The two collection boxes out in large workplaces have not been returned. Our Christmas Raffle was a great way of getting in touch with members and raised £421 but only a small profit. We need to review whether these are worthwhile. We are registering with the NCVO charity raffle and this could be a better option for us.

As it stands at the end of May 2015 we have raised over £5898 pounds from events and sales and there may be more by conference. Donations, monthly giving and Everyclick have risen, there is some outstanding.

We would like to take this opportunity to thank everyone for all their efforts and hope we can keep the momentum going.

Aniridia Europe

Over the past year Katie Atkinson has represented the UK on the Board of Aniridia Europe. She was re-elected to continue in this role until 2016 at the Aniridia Europe General Assembly held in Venice on 21st September 2014. As part of this role Katie has participated in Board meetings held approximately every 2 months via Skype.

Aniridia Europe's biggest achievement during 2014 was hosting the 2nd European Conference on Aniridia which took place at the Venice Eye Bank, Mestre, Italy on the 19th to 20th September 2014. This event was organised primarily by Aniridia Italy in conjunction with the Venice Eye Bank Foundation. The event brought together medical professionals, both clinicians and researchers from a variety of specialties, and from across Europe, Russia and North America, all with an interest in aniridia. The first 1.5 days of the conference consisted of presentations by many of the attendees outlining their latest research, medical and surgical techniques for treating various aspects of aniridia. These presentations were intended for a professional audience although members of the various aniridia associations were welcome to sit in.

The afternoon of the second day was dedicated to a session aimed specifically at patients and their families where a panel of professionals summarised the key messages of the conference in less technical language and answered questions from the audience. The event was extremely valuable in bringing together so many doctors and researchers who all have an interest in aniridia so that they can learn from each other and encourage more collaboration. The UK was well represented amongst the medical professionals with amongst others our patron Veronica van Heyningen and Julie Daniels from our Medical

Panel both giving talks. Katie also attended the event in order to represent Aniridia Network UK.

The other major project for Aniridia Europe over the past year was the planning of a summer camp of outdoor activities for young people with aniridia and their siblings from across Europe. This took place in Italy in the summer of 2015. The programme for the trip has been designed and developed by young people themselves with Lois Turner representing the UK on the planning trip to Italy during summer 2014. The aim of the summer camp is to allow young people with aniridia to meet, bond, share experiences and learn from each other whilst having fun. There were places for 8 young people from the UK plus 2 adults to assist with running the event. The large majority of the costs were funded from an "Active Youth" grant with the remainder covered by ANUK. We recruited 1 adult and 2 young people to participate from the UK. We advertised the event to all our members but did not received as much interest as we had anticipated.

Aniridia Europe has expanded its membership so that it now includes:

- 10 associations as full members (Bulgaria, Finland, France, Germany, Italy, Norway, Russia, Spain, Sweden and the UK);
- 7 reference persons as affiliated members (Belgium, Croatia, Denmark, Greece, Poland, Portugal, Serbia);
- Contacts with patients in Hungary, Kazakhstan, Lithuania, Malta, the Netherlands, Romania, Switzerland, and Ukraine.

Aniridia Europe has also been contacted by people living in African and Asian countries, such as Egypt and Iran.

During 2014, a brochure was developed by Ivana Kildsgaard, with input from the Board members. The medical text was contributed to and revised by Dr. Tor Paaske Utheim and Dr. Barbara Käsmann-Kellner from the Aniridia Europe Scientific Committee. It is based on existing medical texts that were completely rearranged to address both patients and doctors. The text is accurate and well grounded, and it is likely to serve the purpose of having text stable enough not to need changes in the short term. The graphic layout is designed to make it readable and effective. 3,000 copies have been printed with financial support from Aniridia Europe's sponsor HumanOptics. Copies are available to all the member associations for distribution to patients and doctors. A PDF of the leaflet is also available on the Aniridia Europe website.

The aim of developing a European research project on aniridia remains a high priority and was discussed regularly by the Board of Directors. Two more people, Ivana Kildsgaard (Sweden) and Didier Colle (Belgium), were involved because of their specific skills in preparing and submitting projects within the European framework. A document was developed to establish priorities and strategies. Clearly such a project is a long-term goal and it requires that a lot of conditions are fulfilled, first of all the existence of an effective and well-balanced Scientific Committee.

The work of the Scientific Committee has been slower to get started than was originally hoped, but with the addition of some new members the outlook is more positive. Aniridia Europe has continued to lay the foundations to facilitate a European wide research project on aniridia as soon as possible. In the meantime, Aniridia Europe has collected information and sought ways to cooperate with the existing projects in various countries (e.g. OCT project in Spain, registry of patients in Bulgaria). Aniridia Europe has also partnered with two different research teams applying for European funding to support their research in areas which could benefit aniridia patients. Competition is fierce for this funding and so far one of these projects was turned down at the first stage of the application, the second is still under consideration.

Befriending

Twenty five individuals/families have made contact with the Befriending Service or were contacted by the service when they became members of ANUK, of these:

- 10 did not respond to emails asking if they would like to have a buddy;
- 3 preferred to continue to make links through Facebook;
- 11 were successfully linked to other families; and
- One is in the process of joining ANUK and has recently requested a buddy.

One family was newly arrived from Romania and spoke no English, ANUK was contacted on their behalf by a friend. They were eventually given details of a family living in Romania. Despite several emails we have been unable to find out if this was successful.

A second family, also newly arrived from Romania, were able to speak limited English and Spanish. They were buddied with both English and Spanish speaking families.

A Facebook request for families speaking other languages, who would be willing to be a buddy yielded four people speaking Greek (two people), Polish and Turkish.

It would be advantageous to include languages spoken on the membership form.

Conclusion

We’d like to thank everyone who has contributed to such a great year for ANUK. We hope that the fruits of our volunteers’ hard work this year will act as a firm foundation for us to provide new projects and initiative that help our members.

If you think that you could be a part of the continuing success of ANUK in anyway please get in touch.