



Aniridia Network UK Conference 2014

Summary of the year 2013/14 for ANUK

This is a summary of what has happened in the financial year 2013/14 for Aniridia Network UK (ANUK). The full Annual Report 2013/14 is available on the information desk and the ANUK website.

Membership

- Membership has increased significantly over the last year. The number of people in our database has grown by 25% from 452 to 566 members.
- Keith, our Database Officer, is continuing to develop our membership database and train people to use it.
- ANUK needs a diligent, proactive and friendly Membership Officer to manage the membership. If you think you can help us in this area, please get in touch.

Financial report

- ANUK's total income was £7,446 (£3,675 for 2012/13).
- Total operating costs amounted to £5,349 (£3,457 for 2012/13).
- Full details of ANUK's finances for the year are in the annual accounts. A copy is available on the information desk and the ANUK website.

Social media

- ANUK continued strong growth in its social media channels. Facebook followers increased by 39% and Twitter followers increased by 48%.
- ANUK supports the Aniridic Family group on Facebook.

- An outgoing and enthusiastic Social Media Officer is needed to build on this success. If you think you can help with this please get in touch.

Website

- The ANUK website received about 130,000 visits.
- 35 blog posts were published.
- Phil Stringfellow, a freelance web designer (psdesignuk.com), is very kindly providing pro-bono services to develop a new website.

Newsletters

- Members were sent spring, summer and two winter e-mail newsletters, plus invitations to the Bristol meetings.
- Any comments, suggestions or feedback on the newsletters or how they are delivered are welcome.

Events

- **Conference 2013**

- Conference 2013 was the largest and most successful event ANUK has staged to date with over 60 people attending.
- Eleven sessions were held during the day.
- Six exhibition stands from visiting organisations provided useful information to delegates.
- A social evening with food and a lesson in visually impaired tennis followed the conference.

- **Bristol meet-up**

An informal meet-up at the Marriott hotel in Bristol was held in October 2013 as a fringe event to the Nystagmus Network Open Day.

- **Cornea Connect**

Several trustees and members attended Cornea Connect where researchers and patients came together for a greater understanding of each other's position.

- **Limbal Stem Cell Deficiency impact measurement patient focus group**

Scientists are establishing a system to measure the effectiveness of treatment for cornea disease in people with aniridia – caused by limbal stem cell deficiency.

Sarah attended to represent ANUK members.

Volunteering

- ANUK owes its existence to the amazing efforts of its volunteer officials.
- Someone dedicated to recruiting and managing volunteers is needed. Get in touch if you or someone you know could help with volunteer management.

Liaison/PR

- ANUK is assisting a TV production company in finding participants for a TV programme featuring aniridia.
- Genetic Alliance UK has used our name for two campaigns for better health services for people affected by rare conditions such as aniridia.

Enquiries and advisers

- There were 15 enquiries received and answered via email, Facebook or phone.
- ANUK thanks its advisers for their enormous help in continuing to be an invaluable resource for the organisation and its members.

Mobility and daily living

Three professional rehabilitation officers have joined the advisers team to advise on mobility and daily living issues.

Education

Lyn has produced pupil passport templates to explain children's conditions and needs in early years, primary and secondary schools.

Disability Rights

Advice has been given by Veda on housing, employment support allowance and direct payments.

Medical

Consultant Paediatric Ophthalmologist Jay Self has joined the medical panel.

Fundraising

- ANUK set a fundraising target of £3,500 for the year and used various methods to accomplish the goal.
- T-shirt sales and the Conference 2013 raffle raised £313.
- Sponsored events
 - Phil's triathlon raised £568.
 - Caryl's bike ride from Caernarfan to Cork.
 - Charles's fun day/cake sale raised £168.
 - Liz collected £419 at a Sunday market.
- £1,000 was donated by Shine The Light On Aniridia raised from the Ride London 100 biking event.
- Several people donated monthly to ANUK, providing a valuable source of income.
- Substantial one-off donations were received from individuals plus smaller amounts from T-shirt sales and sales of old clothes.
- Gift aid and Give As You Live provided income
- Over £5,000 had been raised by the end of Mar 2014.
- The ANUK trustees thank everyone for all their efforts and hope the good efforts will continue.

Aniridia Europe

- A meeting took place in Germany at the end of May 2013.
- Recent focus has been on improving the medical treatment of aniridia through research and collaboration.
- The Italian aniridia association has been working over for the past two years to organise the second European conference on aniridia which will take place in Venice, Italy in September 2014.
- The European Board has been working on developing a Europe-wide list of aniridia experts and people with aniridia which will be the first step in creating a European aniridia registry.
- Aniridia Europe has also launched its first non-medical project. An application has been made for "Active Youth" funding to organise a summer camp of outdoor activities for young people with aniridia and their siblings from across Europe. This will take place in Italy in the summer of 2015.

Befriending

Twelve individuals and families made contact with the Befriending Scheme or were contacted when they became ANUK members.

Conclusion

Overall, 2013/14 was a very successful year for Aniridia Network UK. There is still much progress that can be made in 2014/2015.