



# **Aniridia Network UK Conference 2015**

## **Summary of the ANUK 2014/15 Annual Report**

This is a summary of what's happened in 2014/15. Please see our full report for further details.

### **Membership**

- Our membership has grown by 12% from 565 to 635.
- Diligent, proactive and friendly Membership Officer needed.

### **Financial report**

- ANUK's total income for 2014/15 was £8,963.44.
- Our costs for 2014-2015 were £2,082.

### **Social media**

- Facebook followers up by 14% and on Twitter up by 24%.
- Enthusiastic Social Media Officer needed.

### **Website**

During the year the website had about 7,870 visitors and 37 blog posts were published.

### **Email Broadcast**

We used this method to distribute our winter newsletter, the #IrisSelfie campaign and Conference 2015 announcements.

We also sent targeted invitations for our meet-ups.

We have 346 subscribers to our email broadcast with an open rate of approximately 50%, mostly using mobile devices, predominantly iOS.

## Events

- **Conference 2014**

A successful event with over 60 people attending eight sessions. There was a social event in the evening.

- **Meet-ups**

These took place in Leicester, Milton Keynes and Newcastle. They were useful but not well attended.

- **Aniridia Europe summer camp**

A youth camp of 10 days of activities near Venice was planned for the summer of 2015.

- **Rare Disease Day 2015**

ANUK and AFI ran an awareness and fundraising campaign. #IrisSelfie and #RareDisease.

## Volunteering

- ANUK owes its existence to the amazing efforts of its volunteer officials.
- Dedicated volunteer recruiter and manager needed.

## Liaison/PR

- An article about a member's daughter's aniridia was published in Pick Me Up magazine.
- ANUK worked with Genetic Alliance UK to produce an aniridia briefing for the Human Fertilisation and Embryology Authority (HFEA).
- We advocated for members to sign up to the CoRDs Patient Registry.

## Enquiries and Advisers

16 enquiries were received by email, one enquiry through Facebook, plus five by phone in the past year.

## **Education**

- Our new pupil passports for early years, primary and secondary schools were introduced in 2014.
- A teacher who had a new pupil in her class with aniridia is now a member of ANUK.

## **Medical**

Consultant Paediatric Ophthalmologist Jay Self has joined the medical panel.

## **Fundraising**

- ANUK had a target of £4,500 for the 2014/15.
- As at the end of May 2015 we had raised over £5,898. The Trustees would like to thank everyone for all their efforts.

## **Aniridia Europe**

- The 2nd European Conference on Aniridia was held at the Venice Eye Bank, Mestre, Italy on the 19th to 20th September 2014 for medical professionals from a variety of specialties and countries,
- 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.
- Aniridia Europe has expanded its membership so that it now includes: 10 associations as full members, 7 reference persons as affiliated members. Aniridia Europe has also been contacted by people living in African and Asian countries.
- During 2014, a brochure was developed. 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

## **Befriending**

- 25 requests were made to the Befriending Scheme or were contacted when they became ANUK members.
- Two of the contacts were families newly arrived from overseas.
- A Facebook request for families speaking other languages, yielded Greek, Polish and Turkish speakers.