



Aniridia Network

Aniridia Network UK Annual Report 2016/17

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Facebook: [AniridiaNetworkUK](https://www.facebook.com/AniridiaNetworkUK)

Charity registration

- At the 2015 AGM members voted to dissolve Aniridia Network UK unincorporated association (ANUK UA), and create a new one to allow us to register as a charity
- Implementation has been delayed until autumn 2017

Management Roles

- James
 - Chief Executive
 - Head of Communications and Membership
- Katie
 - Head of Services and Information
- Emily
 - Head of Finance and Funding
- Martin
 - Head of Volunteering and Development

Services & Information

Befriending

- 13 individuals/families made contact with the Befriending Scheme or were contacted when they became members.
- 3 did not respond to emails.
- 1 preferred to continue to make links through Facebook.
- 6 were successfully linked to other families
- 3 requested links to Education support or other services

Education 2016-17

- We have aniridia pupil passport templates for children aged 0-18 years
- We produced ***Aniridia 0-16 Months VI Guidance for Practitioners***, based on the Department of Education Early Years Framework.
- We had 3 requests for information e.g. Pupil Passports, Links to websites and Early Years Support.

Enquiries

- 12 enquiries received in
- Advice provided on a range of topics e.g. cataract and cornea operations, risk of inheriting aniridia, APD and assistance with applying for disability benefits
- Thanks to Melanie Higorani (Medical Adviser) and Veda Petre (Disability Rights Adviser) for their assistance

Aniridia Europe

- Attended the 3rd European Aniridia Conference was held 27th-28th August 2016, Duisburg, Germany
- Sent representatives to several ophthalmology conferences across Europe. Katie and James represented AE and ANUK at the European Paediatric Ophthalmological Society Conference 2017 in Oxford, UK.
- Supporting Aniridia Day 2017



Patron's Report

- August 2016 attended 3rd European Aniridia Conference, Duisberg:
- Suggested setting up of a database where Aniridia Network members can record details of the progress of their eye condition, as well as their PAX6 mutation. This could help establish closer links between genetics and outcomes.
- What do members think?

Rare Disease Day

- Shared Rare Disease Day 2017 campaigns on social media
- [@PourHouseShrews](#) sold a awesome themed milkshake whose price included £1 donation



Events

- Conference 2016
- London meet up 2016
- Ireland Conference 2017



Conference 2016

- Another successful conference with 70 adults and 16 children attended the very accessible London venue in 2016. The event included an exhibition, food and creche
- Organised by member Mary Cox and family
- We continue to receive positive feedback with most people saying they are satisfied with the conference event.
- Sessions:
 - Morning - VI cricket and tandem cycling –
 - Afternoon – Various presentations including:
Accounts of living with Aniridia from a couple of members, Living Paintings presentation, attending university to mention a few.
 - Evening – social event

Ireland 2017

- April 2017 saw the first half day meeting of Aniridia Network's Irish group.
- 30 attended.
- Day consisted of various presentations with Q&As for some of the speakers and plenty of time for chatting and networking.
- Eleanor Burke who organised the meeting continues to work at developing the group and keeping the trustees informed of its development/progress.

Finance & Funding

Finances

Opening Balance - £12,010.04

Closing Balance - £22,350.03

- Advance ticket sales for the May 2016 conference came to £2,650.37. Costs for the May 2016 conference totalled £830.10.
- £6,056.13 was deposited on 15 March 2017 as a closing balance from ANUK COOP bank account.
- Income from donations for the year was £1,134.13. The board had agreed to focus on increasing this for the next financial year 2017/18

Key Financial Activities

- Centralising Funds
 - Coop account closed
 - Transfer of Paypal funds
- Preparation for becoming Aniridia Network
- QuickBooks
 - Allocation of income/ expenses
 - Accounts preparation

Communications & Membership

Membership statistics

- Only a fraction of people with aniridia in the UK have contacted ANUK. Of course many more may have accessed our information without us knowing.
- New members are usually families with new-born cases of aniridia.
- James continues to manage membership but we need a dedicated volunteer to recruit and retain members.
- James and Keith are working on General Data Protection Regulation compliance and other database improvements

Liaison/Public Relations

We sent representatives
to:


- Genetic Alliance UK
Annual General Meeting.
- UK Genetic Disorders
Leadership Symposium
2017



Website

- 11,435 page views
- 5831 visitors
- 21 blog posts

Down compared to previous years



Aniridia Network UK

Home Blog Events About us Services Support us About Aniridia Links

← Thanks to the person in front Kids complete Mini Great North Run in aid of aniridia →

2016 Paralympians with aniridia

Posted on [September 18, 2016](#) by [Aniridia Network UK](#)

Athletes with aniridia competed at the Rio 2016 [Paralympic Games](#).

- [Mary Fisher, New Zealand](#) won gold in 100m backstroke S11 with a world record time and 4th or 6th in freestyle swimming at other lengths
- [Amanda Dennis, USA](#) won bronze with her goalball teammates
- [Simon Richards, Canada](#) achieved the quarter finals with his goalball squad. [Read more](#) and [watch a video](#) about Simon.
- [Cailin Currie, USA](#) came 10th and 15th in the 400m and 100m freestyle swimming S13 race. Read a [local news article about Cailin](#).

Do you know any others with aniridia who took part?

-

For more inspiring stories read our previous article about [people with aniridia at the London 2012 and previous Paralympic Games](#)

Goalball Athlete - Amanda Dennis



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We recommend
JULBO Kids sunglasses with loop SP4



BOOK: Aniridia and WAGR

Email broadcasts sent

- London meet up 2016
- March 2017 news

Social media

- Monitored and promoted mentions of 'aniridia'
- Promoted and engaged in Aniridic Family Facebook group
- Streamed and published recordings of Conference 2016 on Periscope/YouTube

Site	2015/ 16	2016/ 17	Year on year increase			
			2015-16		2016-17	
Facebook	705	779	98	16%	74	10%
Twitter	597	679	80	15%	82	14%

Volunteering & Development

Volunteering

- Volunteering continues to be our main means of providing certain roles to fulfil specific supports and functions of the organisation.
- Important roles needing to be filled at this time are a Membership Officer, Volunteer Coordinator and a trustee position.
- There are still many other opportunities, listed on the website, that are in need of volunteer support whether long term or short term tasks, and we welcome all levels of help.
- Due to lack of offers from the membership of the organisation, which has been the historical way we've obtained our volunteers, we are having to now externally advertise for certain roles.

Volunteers thank you

We would like to thank all our volunteers for their work over the year:

- Liz Atkinson
- Eleanor Burke
- Lyn Buller
- Mary Cox
- Dave McKay
- Keith Spink
- Glen Turner
- David Woodward

Trustee Board

- Ben Rendle stepped down in September 2016
- Emily Nash was co-opted in March 2017 after an appeal for volunteers with financial skills
- We would like to thank our trustees for their work over the year:
 - Katie Atkinson (Chair)
 - James Buller
 - Martin Fleming