



# Aniridia Network

## Aniridia Network Annual Report 2018/2019

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Twitter: **@AniridiaNetUK**

Facebook: **AniridiaNetworkUK**

Aniridia Network is registered charity 1176792 in England & Wales, operating as  
Aniridia Network UK, 22 Cornish House Adelaide Lane Sheffield S3 8BJ

# **Services & Information**

# Enquiries & Information

- Corrected and advised RNIB to revise their Aniridia Factsheet.
- 7 enquiries received in 2018-19
- Successfully appealed a refusal of disability benefits
- Thanks for their assistance to:
  - Melanie Higorani - Medical Adviser
  - Veda Petre - Disability Rights Adviser
  - Lyn Buller - Education Adviser

# Education 2018-19

- A parent asked us to produce a **Information Pack** for new parents and people with aniridia. Thanks to:
  - Jenna Fashiola for the original idea
  - those who provided photos
  - Nikki Hall for proofreading the pack.
- 7 requests for information plus 2 from Canada and Spain
  - Pupil Passports,
  - links to websites,
  - Education & Health Care Plans (EHCP)
  - Early Years Support.
- We welcomed Clive Matthews a SEN Advisor and Advocate as an addition to our Education team.

# Befriending 2018-19

- All new members are contacted by the Befriending Officer when they join. The majority do not take up the offer of finding a buddy
- 2 were successfully linked to other families
- 1 requested contact with a family to help them make a decision about the possible adoption of a baby with aniridia.

In recent years there has been a decline in members asking for buddy support.

Most friendships now appear to be made through our local meet ups, conferences and the Aniridic Family group on Facebook.

# Aniridia Europe

Aniridia Network is a founding member of Aniridia Europe and Katie sits on its board of directors

- Katie represented Aniridia Network at the Aniridia Europe General Assembly.
- Katie represented Aniridia Europe at the European Paediatric Ophthalmological Society Conference 2018 in Budapest, Hungary.
- Veronica, Katie, James, Eleanor, Dave and Aaron attended the 4th European Aniridia Conference in Paris, 24th - 26th August 2018.



ANIRIDIA EUROPE



# Rare Disease Day

- Co-signed a letter, with Rare Disease UK, calling for the government to review and refresh the UK Strategy for Rare Diseases.
- Promoted the Rare Reality social media campaign leading many to post their star and story online

## Patients and families affected by rare diseases call on the Government to review and refresh the UK Strategy for Rare Diseases

We the undersigned call on the Government to urgently review and refresh the UK Strategy for Rare Diseases before the end of 2020, to ensure rare disease patients receive high quality services, treatment and support regardless of where they live in the UK.

The UK Strategy for Rare Diseases is a shared vision for improving the lives of all those with rare diseases, so 'no one gets left behind just because they have a rare disease'. This is an objective we hold to be a hallmark of a fair society.

The UK Strategy for Rare Diseases contains 51 distinct commitments that are designed to improve health and social care for rare disease patients and their families. What was once a landmark document at its time of publication in 2013, is now obsolete as technologies, policies and systems have moved on. Its commitments urgently need updating.

Collectively rare diseases are not rare, 1 in 17 people will be affected by a rare disease at some point in their life - approximately 2.5 million people in the UK. As we approach 2020, the expiration date of the UK Strategy for Rare Disease, time is running out to ensure that we have in place a framework that is fit for purpose, timely, relevant and impactful.

We call on the Government to act now, to review and refresh the UK Strategy for Rare Diseases.



**I'M ONE OF ONLY  
1600 IN THE UK  
WITH NO EYE  
COLOUR (IRISES)  
DUE TO ANIRIDIA.**

**I'm illuminating  
the rare reality**

# Conference 2018

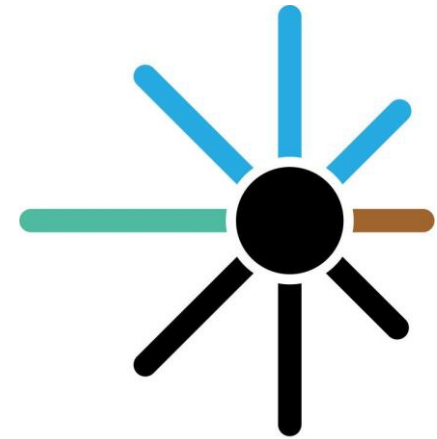
- Another successful conference at Resource For London on 14 April
- 111 adults and 14 children attended
- Sessions included:
  - Keynote by Mariya Moosajee from Moorfield Eye Hospital,
  - Thanos from Liverpool University.
  - Introduction to Access To Work
  - A stirring talk from Fern Lulham about living with aniridia.
  - Effie Papadopoulou about psychological impact of aniridia on parents:
  - Social evening with pizza and an introduction to goalball
- Very positive feedback: 93% satisfaction rating and comments such as:

“The best part was the chance to listen to medical professionals about advances being made and to meet people I had not met before who are living with Aniridia. It made me feel hopeful and positive for the future.”

Thank to Conference Officer Dave Mckay for excellent organisation,



# European Aniridia Conference 2020



European **Aniridia**  
Conference

- We committed to hosting the 5th of this biannual scientific events
- For professionals and patients to discuss the latest treatments and research
- Date set as 14-16 August 2020 at Resource For London
- Scientific committee:  
Veronica Van Heyningen, Sajjad Ahmad, Julie Daniels, Nikki Hall, Mariya Moosajee, Melanie Hingorani
- Organising committee: Dave and James
- Logo designed
- Now seeking speakers and £40,000 funding
- Volunteers and fundraising needed

# £15,000 Research Grant

- Last year we partnered with Fight for Sight to award a £15,000 grant, using fundraised money
- £190,000 was also donated by 2 sets of parents of children with aniridia
- Research has begun at UCL Institute of Ophthalmology

In her laboratory Dr Moosajee will grow cells for up to 17 weeks to make 3D model eyes. These will start with skin samples taken from people with aniridia. The stem cells will, therefore, lack a protein that normally results from the PAX6 gene which is often defective in people with aniridia. Other models will be grown from cells that have normal PAX6 genes.

This will allow them to answer questions such as:

1. What are the early effects on the developing 'optic cup' especially on the retina?
2. Can a drug called amlexanox be used to cause the PAX6 protein to be created and what effect will that have?

# £15,000 Research Grant

Dr Moosajee said

“the study will advance our understanding of PAX6 in early eye development, exploring its effect on retinal differentiation, eye growth and gene expression patterns. Plus it will provide proof-of-concept of amlexanox as a treatment for nonsense-mediated aniridia.

The results will add knowledge and make possible further investigations into other aniridia-related human ocular tissues. If successful, we will endeavour to repurpose amlexanox for aniridia and apply for further funding.”



## **FIGHT FOR SIGHT**

The Eye Research Charity

# **Communications & Membership**

# Membership statistics

Category	Members	Increase since 2018	
familial aniridia	171	11	6%
sporadic aniridia	162	5	3%
aniridia but origin unknown	90	1	1%
<b>Total with aniridia</b>	<b>423</b>	<b>17</b>	<b>4%</b>
Traumatic aniridia	2	0	0%
WAGR	40	0	0%
None/unknown	374	19	5%
<b>Total</b>	<b>839</b>	<b>36</b>	<b>4%</b>

There are an estimated 1400 people with aniridia in the UK.

# Membership statistics

- We estimate about a third of people with aniridia in the UK have contacted Aniridia Network. Of course many more may have accessed our information without us knowing.
- New members are usually families with new-born cases of aniridia.
- Rate of new membership signing ups continues to slow from a high of over 20% per year
- James continues to manage membership but we need a dedicated volunteer to recruit and retain members.

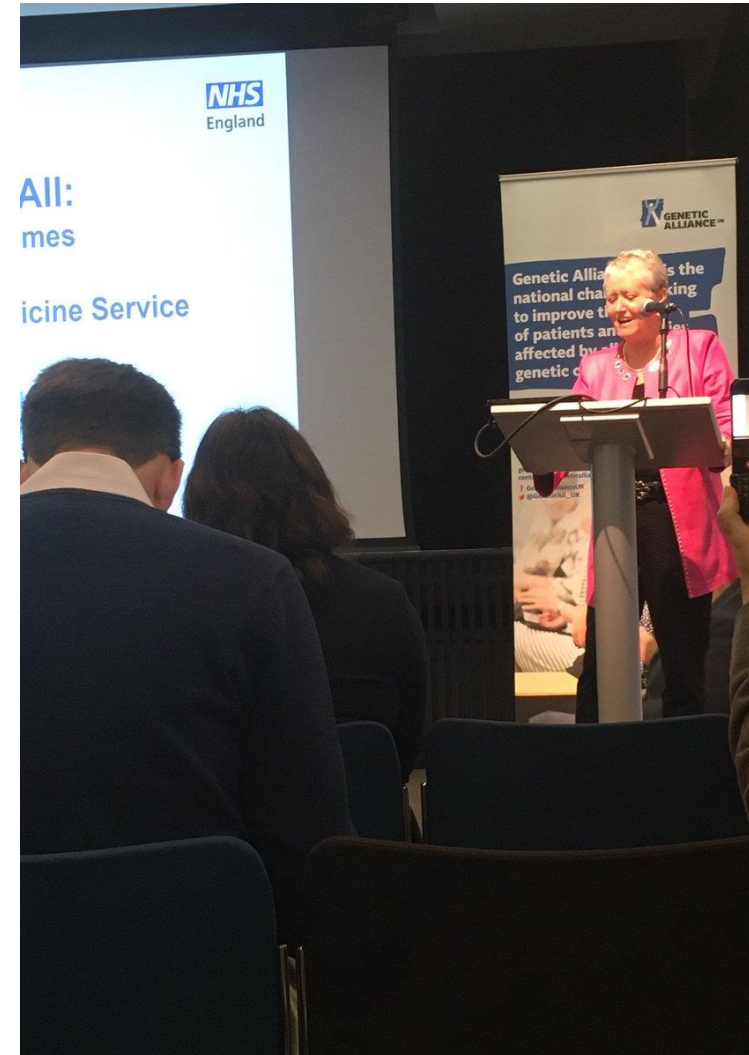
# Membership Data

- James and Keith are working on our contact database to:
  - Change from a household to individual system
  - Enable us to send people the data we hold on them so they can check it then confirm or change it as necessary
  - Collect permission to store and process personal to conform to the General Data Protection Regulation

# Liaison/Public Relations

We sent representatives to:

- Genetic Alliance UK Annual General Meeting
- London Vision Information Day





# Aniridia Day 2018 - UK

- Held a meet-up in London attended by 6 patients and 1 parent



# Aniridia Day 2018 - International

## James and Glen led the worldwide event:

- Hosted 12 hours of webinars in 4 languages, and speakers from Russian, Egypt, Spain, Germany and the UK
- Orchestrated #AniridiaSight social media campaign: 174 posts including:
  - 90 photos,
  - 11 videos,
  - 48 links,
  - 25 statuses

People gave  
4,300 reactions,  
shared 333 times and  
wrote 400 comments.






# Website


- 13,266 page views
- 7100 visitors
- 36 blog posts

Up 16% compared  
to previous year

Top blog post about  
Eve and Allyn



# Aniridia Network



[Home](#) [Blog](#) [Events](#) [About us](#) [Services](#) [Support us](#) [About Aniridia](#) [Links](#)


← Orbit absell fundraiser Goggles and aniridia →

## Inspired to study aniridia for a degree

Posted on November 23, 2018 by biolieve

In February this year I started the final module for my degree, a literature review of the latest research in my chosen topic. Suggested topics included stem cells and human senses (among others). I wanted to pick something that I could relate to on a personal level, knowing it would motivate me to do the best I could – so I chose aniridia.


I chose it because of my cousin, [Allyn](#), who recently wrote a blog post about his [aniridia and depression](#). Up until very recently, I didn't know what it was. I knew he had trouble with his eyes and had undergone many surgeries. I knew he'd had stem cell therapy and a corneal



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more, at a scientific level.

Growing up with Allyn, as part of a large family, I didn't think of him any differently to any other cousin – he was loud, energetic, loved pizza and was pretty annoying on times. In recent years, when I realised how progressively worse his eyesight had become I wished and prayed for him to regain his sight, so he could live his life to the fullest. As a family we sat and awaited the news of how his latest eye surgeries had gone – when I heard that it had improved his vision and he told his sister “You’re just as ugly as I remember” (that’s our family’s humour for you!) I both laughed and cried, feeling overjoyed for him and



Allyn

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- Donate once or regularly by card/direct debit/Paypal
- Create your own fundraising page on JustGiving or Everyclick
- Sell on eBay and donate a percentage

**for Charity**

- Earn donations from online shops



**Shop for us!**


Turn every pound you spend online into funds for us.

- Get Amazon to donate to us

**smile amazon.co.uk**

**We recommend**

JULBO Kids sunglasses with loop SP4



# Email broadcasts sent

- Summer 2018 news and Aniridia Day
- Winter 2019 news
- Spring 2019 news & Conference booking

# Email broadcasts received

- Statistics from 3 emails
  - 436 emails sent on average of these
  - 32-31% opened of these
  - 12-20% clicked on at least one link

447 emails were sent



187 emails were opened



38 contacts clicked



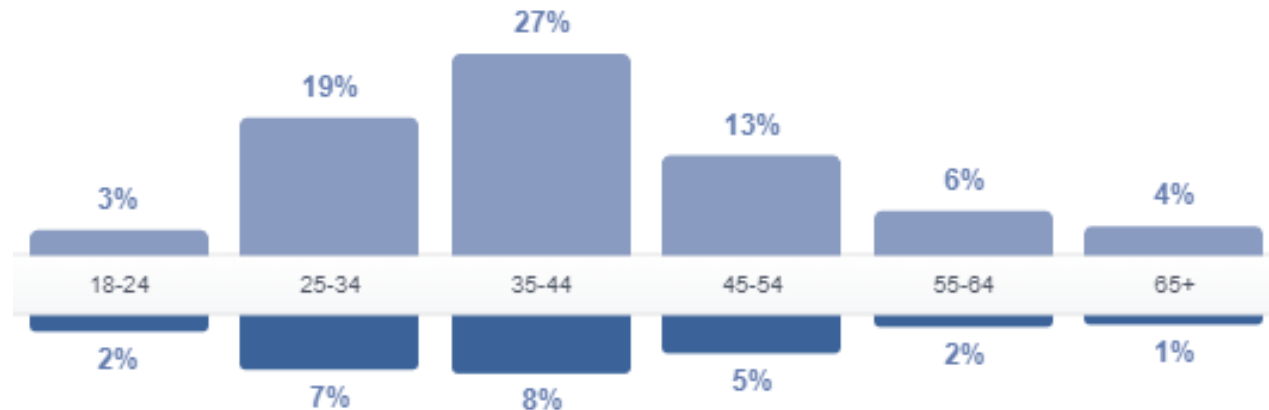
# Social media

- Monitored and promoted mentions of 'aniridia'
- Promoted and engaged in Aniridic Family Facebook group
- Regular reminder posts for setup about fundraising and volunteering
- Live posting from Conference 2018

# Facebook followers

951 followers

- up 11% on 2018
- 59% aged 25-54 (down 9%)
- 493 in UK
- 172 in USA
- 73% women  
25% men



# Facebook posts

## Engagement

- 6016 reactions
- 1388 shares
- 1366 comments

## Post types

- 196 photos
- 91 videos
- 997 links
- 649 statuses

The screenshot displays the Facebook profile of the Aniridia Network (@AniridiaNetworkUK). The page features a cover photo of a young girl and a profile picture with the organization's logo. The left sidebar contains navigation links: Home, Posts, About, Reviews, Photos, CAF Donate, Videos, Flickr, Poll, Events, Community, Fundraisers, and Info and ads. The main content area shows three posts. The top post is a link post titled 'Read Kieron's story' about fundraising for Fight for Sight, with 2 comments and 3 shares. The middle post is a text post about the 'Aniridia Network Conference 2019 - Powered by Eventzilla', dated 31 March at 16:34, with 6 shares. The bottom post is a text post titled 'Nataasha and Violet: fundraising and media stars', dated 31 March at 12:58, with 2 comments and 3 shares. The right sidebar includes a 'Sign Up' button, a 'Send Message' button, a 'Community' section with a 'Join Friends' button, an 'About' section with contact information, a 'Page Transparency' section, and a 'Pages liked by this Page' section.



# Twitter

758 followers  
up 5% on 2018



**Aniridia Network** @AniridiaNetUK · Feb 6

Light stimulation centre wows child with aniridia ani

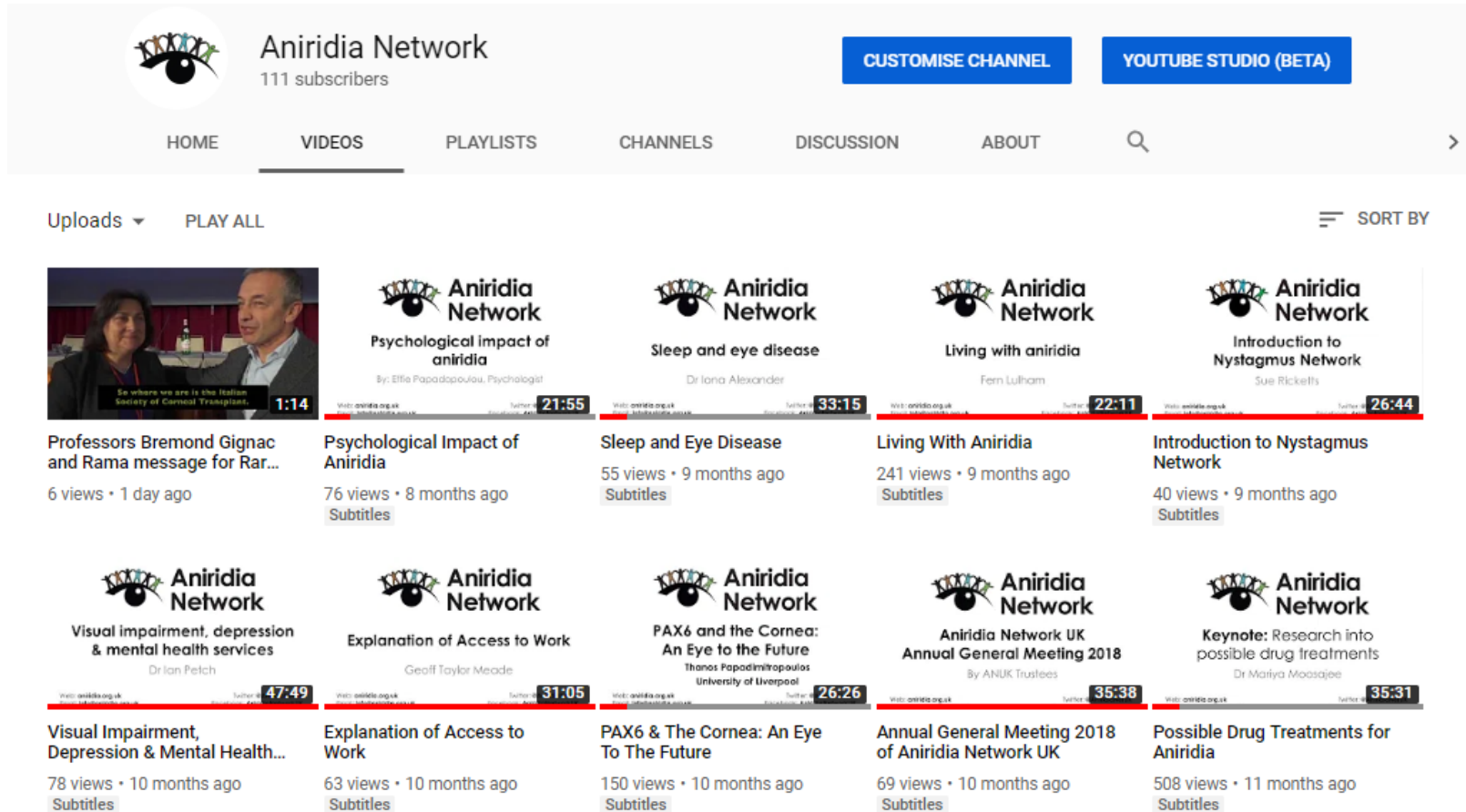


Site	2015/16	2017/18	2018/19	Year on year increase							
				2015-16		2016-17		2017-18		2018-2019	
Facebook	705	850	951	98	16%	74	10%	71	9%	101	11%
Twitter	597	718	758	80	15%	82	14%	39	6%	40	5%



# YouTube

- Published 9 videos of sessions at Conference 2018
- 111 subscribers (up 41)



The screenshot shows the YouTube channel page for the Aniridia Network, which has 111 subscribers. The channel features a navigation bar with links to HOME, VIDEOS, PLAYLISTS, CHANNELS, DISCUSSION, and ABOUT. Below the navigation bar, there are two buttons: "CUSTOMISE CHANNEL" and "YOUTUBE STUDIO (BETA)". The main content area displays a grid of 9 videos, all of which are uploads from the channel. Each video thumbnail includes the Aniridia Network logo, the video title, the presenter's name, the duration, and the view count and upload date. The videos are as follows:

Video Title	Presenter	Duration	Views	Upload Date
Professors Bremond Gignac and Rama message for Rar...	Dr. Eftis Papadapoulou, Psychologist	1:14	6 views	1 day ago
Psychological Impact of Aniridia	Dr. Eftis Papadapoulou, Psychologist	21:55	76 views	8 months ago
Sleep and Eye Disease	Dr. Iana Alexander	33:15	55 views	9 months ago
Living With Aniridia	Fern Lulham	22:11	241 views	9 months ago
Introduction to Nystagmus Network	Sue Ricketts	26:44	40 views	9 months ago
Visual Impairment, depression & mental health services	Dr. Ian Petch	47:49	78 views	10 months ago
Explanation of Access to Work	Geoff Taylor Meade	31:05	63 views	10 months ago
PAX6 & The Cornea: An Eye To The Future	Thamos Papadimitropoulos, University of Liverpool	26:26	150 views	10 months ago
Annual General Meeting 2018 of Aniridia Network UK	By ANUK Trustees	35:38	69 views	10 months ago
Possible Drug Treatments for Aniridia	Dr. Mariya Moosajee	35:31	508 views	11 months ago

# **Volunteering & Development**

# Volunteers

- The board wishes to recognise and thoroughly thank everyone who has volunteered in one way or another during the past year, no matter whether a large or small contribution.
- We have many regular volunteers supporting us in a variety of areas:
  - Advice
  - Communication/PR/web and social media
  - informative articles via the blog, Twitter/FB etc.
  - Technical and multimedia
  - Conference committee.
  - Trustee board.

# Volunteers thank you

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

- Clive Matthews
- Eve Harris
- Glen Turner
- Gavin Fox
- Liz & Robin Atkinson
- Lyn & Peter Buller
- Dave McKay
- Keith Spink
- Valarie Jackson
- Veda Petre
- Zoe Kilb

# Sponsored feats

- £9,600 - Matt's cycling
- £1,200 - Rachel & Scarlett's walk
- £600 - Laura's 100 days walk
- £838 - Katja's half marathon
- £362 - James's abseil (+£660 for research)

Thank you to everyone who has given so generously

# Donations and commissions

We also raise funds online and through regular donations. Thank you to everyone who has given in this way.

- £1590 Regular giving through Direct Debits
- £1527 Commissions
  - Give as You Live
  - Amazon Smile (£52)
  - Humble Bundle

Visit our website to find out about ways to give regularly.

# SMS Giving

JustGiving's SMS donation service has closed  
We have moved to Donr instead.

- 'Iris5' will donate £5
- 'Irises5' will donate £5 each month
- 'EAC5' will donate £5 to EAC 2020
- 'EACs5' will donate £5 to EAC 2020 each month

Higher numbers can also be used to give more.



# Governance

# Trustee Board 2018-19

- Eleanor was elected at the 2018 AGM
- Martin and Emily are stepping down at the 2019 AGM
- We would like to thank our trustees for their work over the year:
  - Katie Atkinson (Chair)
  - Emily Nash (Treasurer)
  - James Buller
  - Martin Fleming
  - Eleanor Burke



# Management Roles

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

# Policies & procedures

We have been developing the policies below based on good practices examples from NCVO and elsewhere:

- Equal opportunities
- Privacy and data protection
- Whistleblowing
- Grievance
- Anti-harassment and bullying
- Event code of conduct
- Disciplinary
- Acceptable information technology use

Other policies are in development



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name	1
Aniridia Network	

## Receipts and payments accounts

CC16a

For the period from	23/01/2018	To	31/03/2019
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### Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
<b>A1 Receipts</b>					
Apr 18 Conf	2,794	-	-	2,794	-
Donation - Justgiving	12,318	-	-	12,318	-
Donation - DD	1,905	-	-	1,905	-
Donation - GAYL and EC	871	-	-	871	-
Donation - CAF Donate	1,336	-	-	1,336	-
Donation - Other	1,587	-	-	1,587	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>20,812</b>	<b>-</b>	<b>-</b>	<b>20,812</b>	<b>-</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>20,812</b>	<b>-</b>	<b>-</b>	<b>20,812</b>	<b>-</b>
<b>A3 Payments</b>					
Running costs	778	-	-	778	-
Research	7,500	-	-	7,500	-
Apr 2018 Conf	5,747	-	-	5,747	-
June 2019 Conf	475	-	-	475	-
Trustee expenses	728	-	-	728	-
Joint fundraising	660	-	-	660	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>15,888</b>	<b>-</b>	<b>-</b>	<b>15,888</b>	<b>-</b>
<b>A4 Asset and investment purchases, (see table)</b>					
<b>Comms equipment</b>	<b>871</b>	<b>-</b>	<b>-</b>	<b>871</b>	<b>-</b>
	-	-	-	-	-
<b>Sub total</b>	<b>871</b>	<b>-</b>	<b>-</b>	<b>871</b>	<b>-</b>
<b>Total payments</b>	<b>16,759</b>	<b>-</b>	<b>-</b>	<b>16,759</b>	<b>-</b>
<b>Net of receipts/(payments)</b>	<b>4,053</b>	<b>-</b>	<b>-</b>	<b>4,053</b>	<b>-</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>30,427</b>	<b>-</b>	<b>-</b>	<b>30,427</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>34,479</b>	<b>-</b>	<b>-</b>	<b>34,479</b>	<b>-</b>

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>	CAF Bank Account	27,569	-	-
	Lloyds Bank account	6,910	-	-
		-	-	-
	<b>Total cash funds</b>	<b>34,479</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
	Fundriasing equipment	100	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Emily Nash	28/09/2019	