



Aniridia Network

Annual Report 2024/2025

1 April - 31 March

Web: **aniridia.org.uk**

Email: **info@aniridia.org.uk**

  **@AniridiaNetUK**

 **AniridiaNetworkUK**

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

Key points

- After a year with none, 2 people did fundraising plus a legacy donation
- Several useful events: meetups, conference and leadership academy
- Moved from Twitter/X to Threads and BlueSky
- Membership numbers steady
- Very low amount of volunteering
- Appointed new Medical Advisors
- Developing safeguarding policy and practices

Contents

- Services & Information
- Conferences and Events
- Finance & Funding
- Communications & Membership
- Volunteering & Development
- Governance

Services & Information

Enquiries & Information

3 medical enquiries on a variety of topics including:

- Recommendation for an ophthalmologist in a specific city
- Asking if there are any known links between aniridia and another medical condition
- Cataract operation on toddler via Instagram

Befriending

- 4 members with a child offered a buddy
- 6 new adults offered buddy, or would like to be a buddy
- 6 buddy relationships set up in total.
- No requests relating to newborns

Education

8 education advice requests. Information sent included:

- Pupil Passport resource
 - Appendix 1 for completing EHCP
 - Link to RNIB Early Years resources
 - Auditory Processing Disorder
 - Early years Development Matters link
 - Links to local Parent Partnership/ SEND Information & Support Service
-
- 1 contact from school SENCO

Conferences & Events

Conference 2024

I had never met anyone else with aniridia. I wondered how I would feel. But someone said to me how pleased they were to meet me, as someone with aniridia! It was the opposite way round to what I thought would happen - a moment I will never forget.

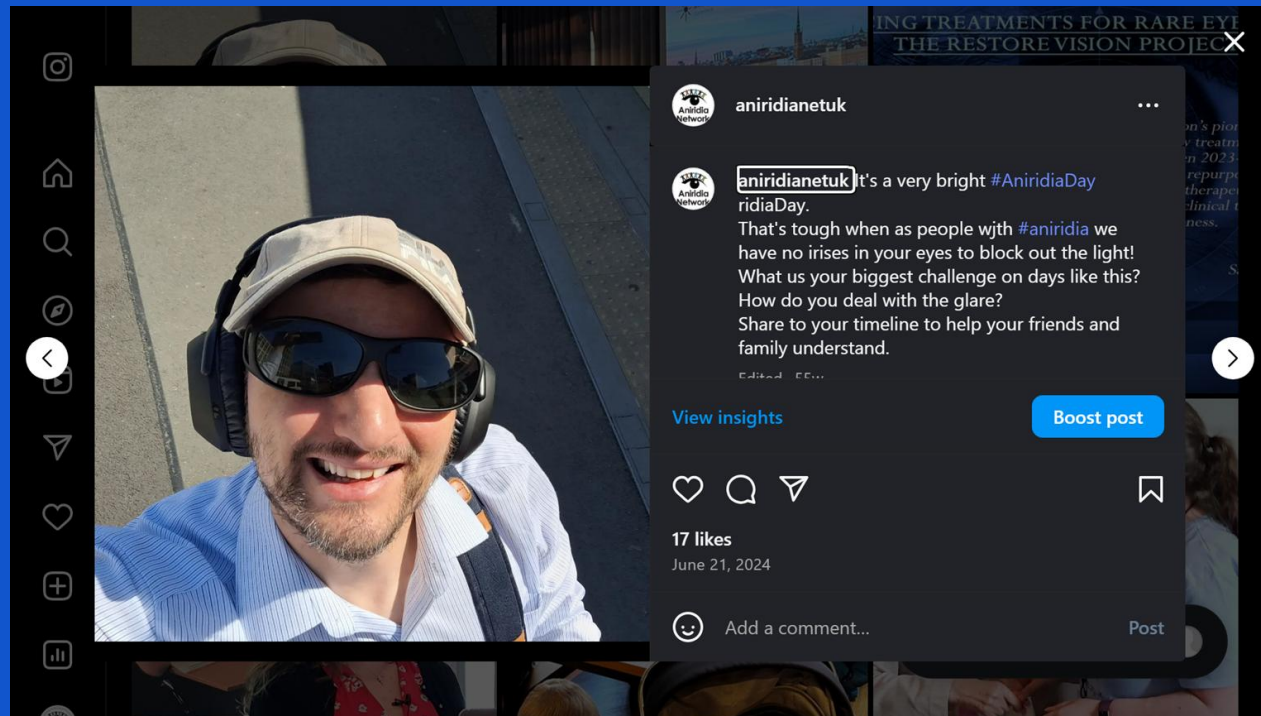
- Held online on 27 July
- Recordings published on YouTube and on our website with a transcript
- Thank you Tierney for wrangling speakers and hosting the event so well.
- Presentation subjects:
 - Supporting children with aniridia in education
 - Impact of sight loss between adults with sporadic and familial aniridia.
 - Developing eyedrops to treat aniridia-associated keratopathy
 - Retinal detachments in aniridia research at Moorfields
 - 3D corneal organoids for disease modelling and limbal stem cell deficiency cell therapy research

I felt included, informed and more hopeful for my daughter

Aniridia Day 2024



We made posts online and boosted posts by others



RARE DISEASE DAY 2024



8 members came to
4 meet ups:

- Birmingham
- Cambridge
- London
- Reading

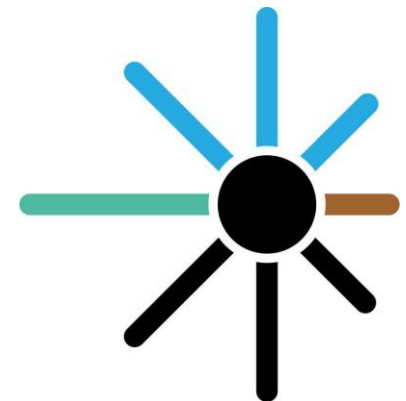
Big thanks to
the hosts,

I can't explain in words
how valuable I have
found speaking with
other families with
aniridia so thank you
both for making this
possible for us.
Helen

It was lovely meeting up,
can't wait do it again.
Annie

7th European Aniridia Conference

- Trustees James and Katie went to the 2 day event in Stockholm.
- They grew their knowledge and made new contacts with peers and professionals
- We covered their expenses



European Aniridia Leadership Academy

This initiative aimed to boost young people's' confidence and create future leaders of aniridia associations.

- We advertised the opportunity to take part
- We sponsored member Haya to attend
- Katie and James both delivered sessions
- Haya spoke about her experience at our 2024 Conference
- We advocate for the academy to run again



Finance & Funding

Finances 2024/25

Funds start of year: £49,142

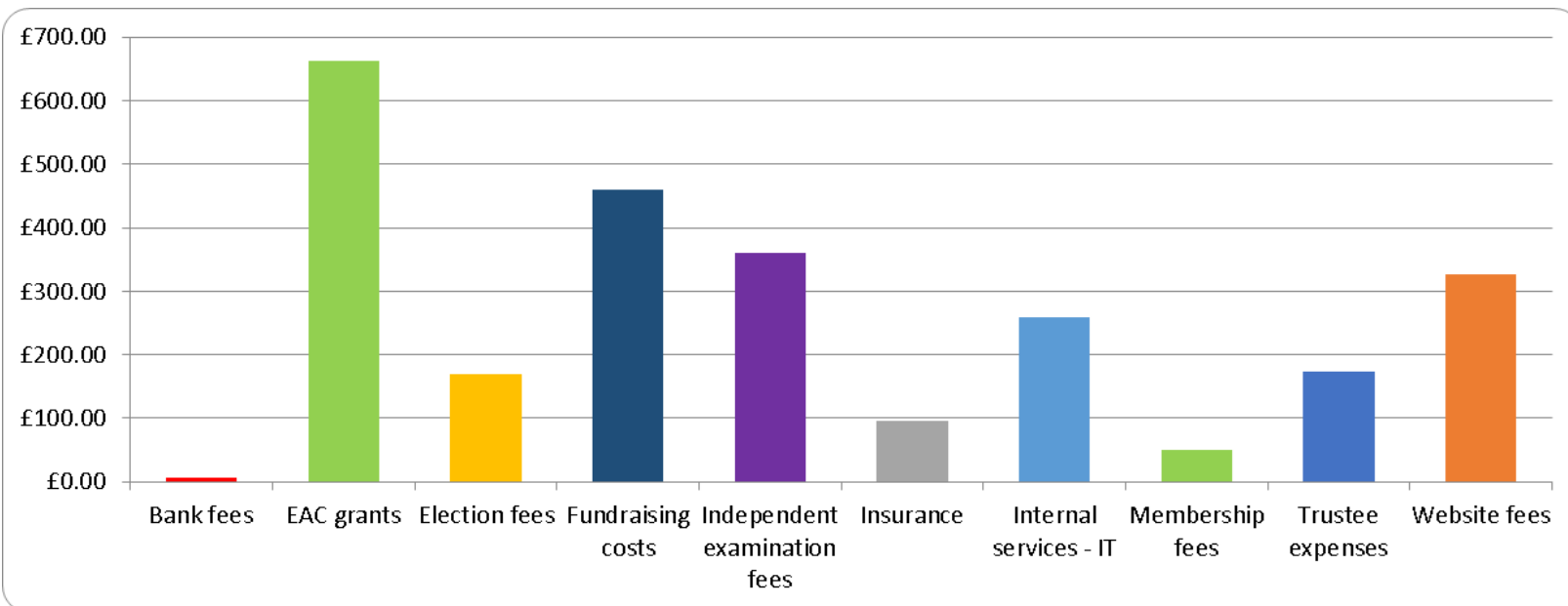
Funds end of year: £57,668

Expenditure: £ 2,564

Income: £11,090

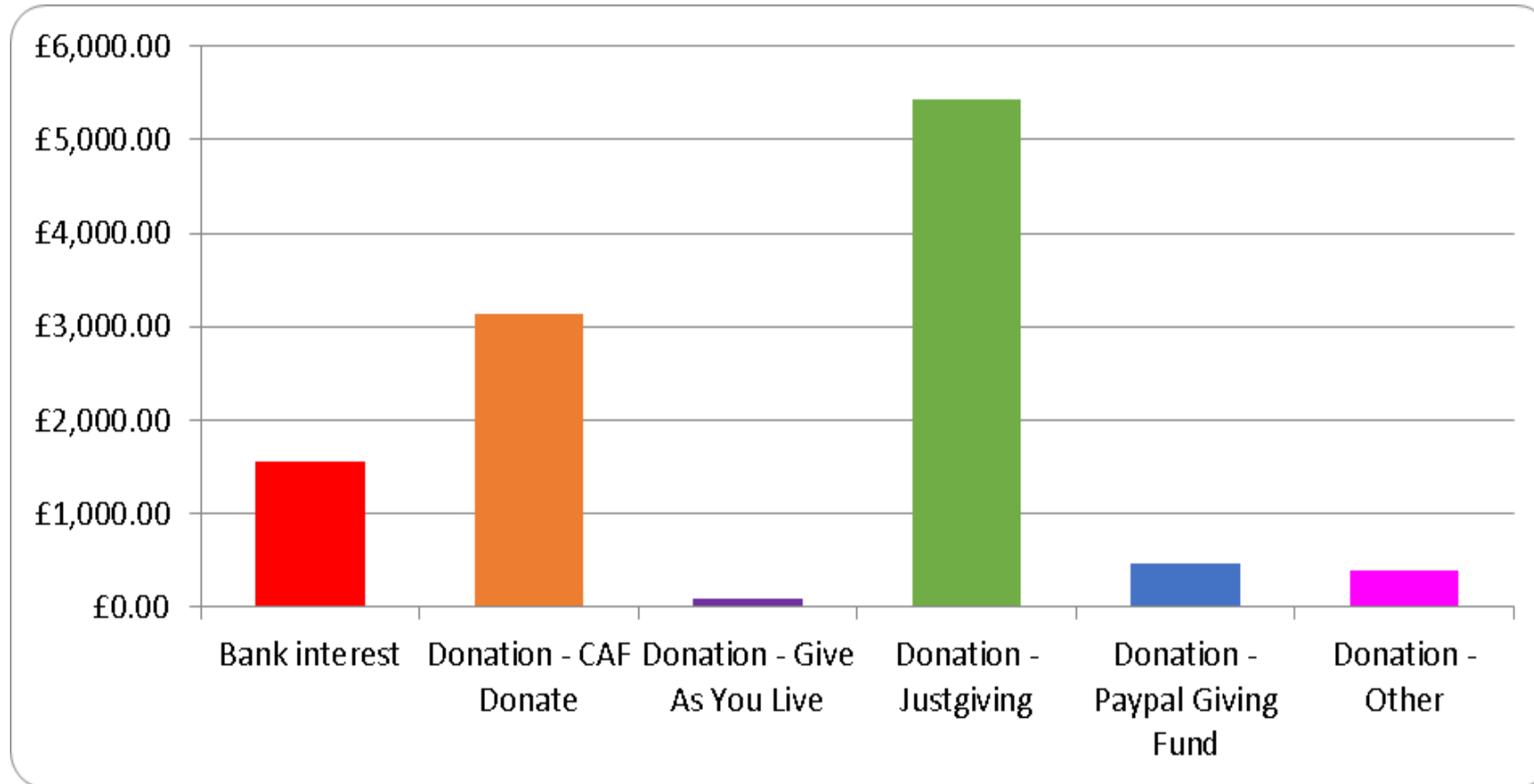
Compared to the previous year, we saw a significant uplift in donations with a reduction in costs primarily due to hosting the conference online.

Expenditure 2024/25



Bank fees	£6.24
EAC grants	£663.48
Election fees	£169.20
Fundraising costs	£460.00
Independent examination fees	£360.00
Insurance	£96.00
Internal services - IT	£258.29
Membership fees	£50.00
Trustee expenses	£173.18
Website fees	£326.97

Income 2024/25



Bank interest	£1,561.92
CAF Donate	£3,133.07
Give As You Live	£92.35
Justgiving	£5,440.69
Paypal Giving Fund	£466.01
Donation - Other	£396.09

Accounts 2024/25

Income was generated from direct debits and other donations - thank you!

Savings account interest: more than £1,500.

Communications & Membership

Members and Supporters

17 adults and 3 children joined or renewed as members.
Our contacts breakdown into 3 categories:

- 161 Junior Members
- 502 Members
- 238 Supporters

Recruited a member from Gibraltar

We are losing members as children become adults but do not join in their own right.

We are considering establishing a Youth Member category to ease this transition

Contact's aniridia statistics

Category	People	Increase since 2024	
Familial aniridia	200	1	0.5%
Sporadic aniridia	196	2	1.0%
Aniridia but origin unknown	79	-1	-1.3%
Total with aniridia	475	2	0.4%
Traumatic aniridia	3	0	0%
WAGR	45	1	2.3%
None/unknown	440	0	0%
Total	963	3	0.2%

Website

- 8148 page views (up 16%)
 - 4920 visitors (up 10%)
 - 19 blog posts (down 14%)
- A post for each session of Conference 2024 with video and transcript



Email newsletter

3 campaigns with
re-mails to non-openers

- Autumn newsletter
- Conference promotion
- Invitations to meets ups

3,225 emails sent

2,858 opened

163 clicks

A 27% fall in engagement



Aniridia
Network

[View in browser](#)

Last call for Conference and AGM 2024 online

Online presentations

On Saturday 27 July 2024, at 2pm to 6.30pm is our Conference and Annual General Meeting (AGM) for 2024.

The line of up speakers is amazing. A summary of what they will be presenting is below and by following the booking link.

Don't miss out. Sign up to get the meeting links o you hear their stories and ask your questions on Zoom!

Afterwards you'll also get to chat with fellow patients and parents affected by aniridia, enabling you make important connections and improve your understanding of aniridia.


[Contact us](#) if you have any questions.

[Find out more & book a place now](#)

Members should also have received an email about voting in the annual election of an Aniridia Network trustee. Please follow its instructions to cast your vote by the end of Friday 26 July.


The election result will be announced at the Annual General Meeting during conference.

Speakers in 2024



November after Sight Village

Tuesday 5 November to talk about all aspects of




food court very close to [High Street Kensington](#) y aniridia at this ever popular and positive event.

an event that was, in essence, a collection of common. But I really loved hearing about other's y got there."

The venue is [Medz Corner](#) which has a choice of pizzas, sushi, Thai and middle eastern eateries. Buy your own food and drink then take a seat at our table.

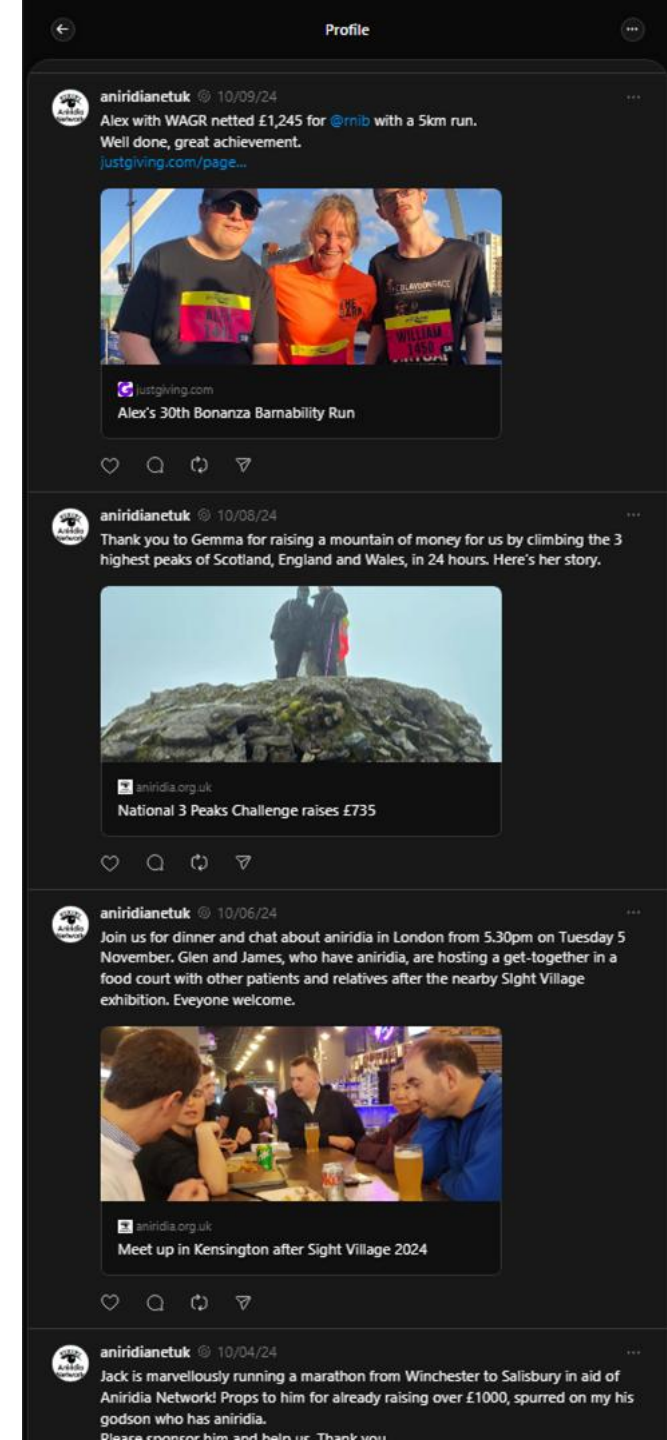
[Get more details and sign up for our meet up](#)



@ Threads

- Posted all our news and events here instead of X/Twitter
- 86 followers (+16)
- Posts are also available to the metaverse for wider reach

Full analytics unavailable until we have 100+ followers





We set up an account
on this other Twitter
alternative.

In 6 months:

- 15 followers
- 4 following
- 28 posts



Aniridia Network

@aniridianetuk.bsky.social

People with [#aniridia](#) are very sensitive to light, including sunshine.
So we don't typically like bright blue sky!
Overcast is a poor Xperience too though; being glarey in all directions and in terms of shade.
Let's see how we get on here!
Learn more & join our UK community aniridia.org.uk



Aniridia Network

Supporting people with aniridia and their families

aniridia.org.uk

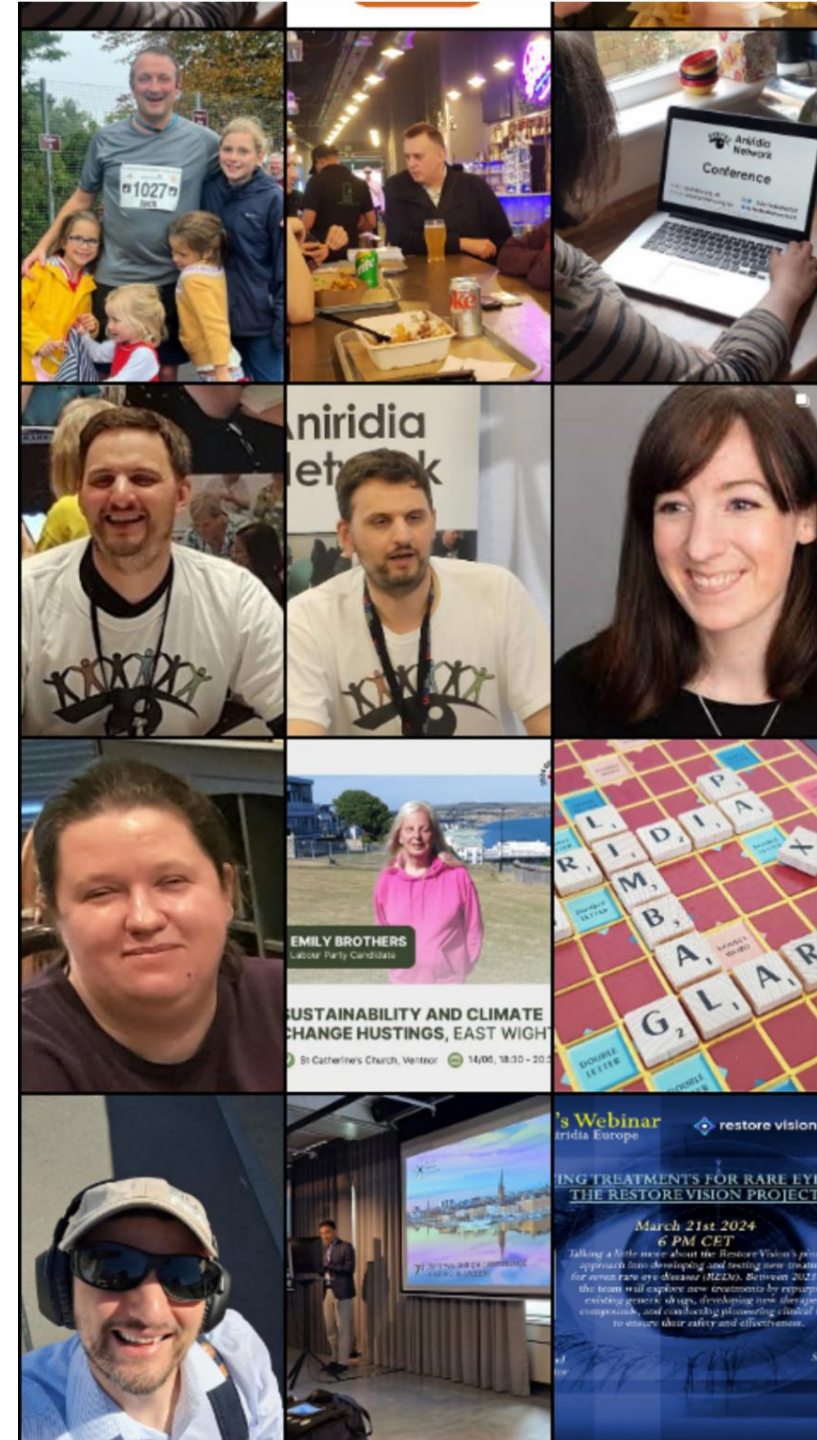
November 16, 2024 at 11:19 AM [Everybody can reply](#)

1 like



Instagram

- 523 followers (up 26 5.2%)
- 15 posts (-20) mainly about
 - events
 - elections
 - Aniridia Day
- Following 36 organisations & individuals



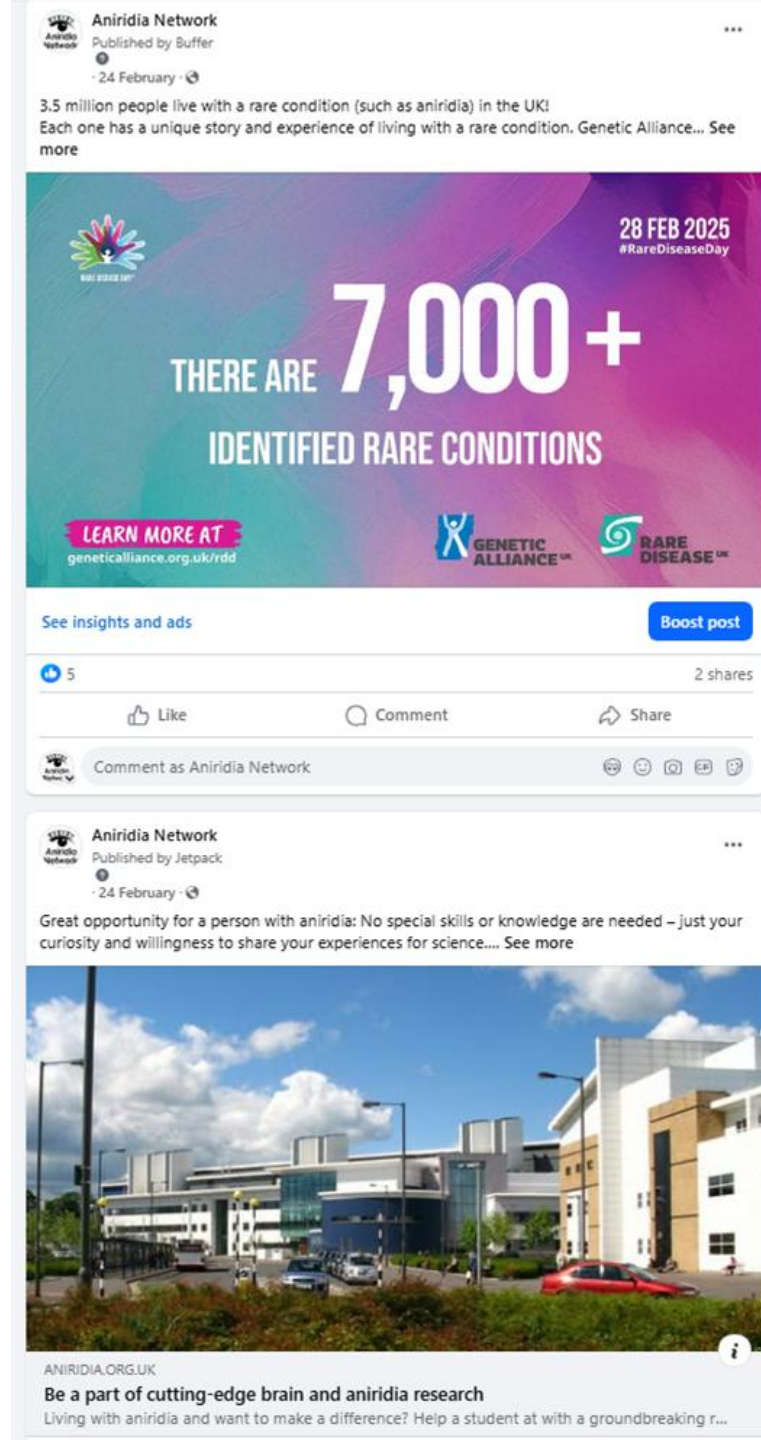


1276 followers

- +26 2.1% since 2024

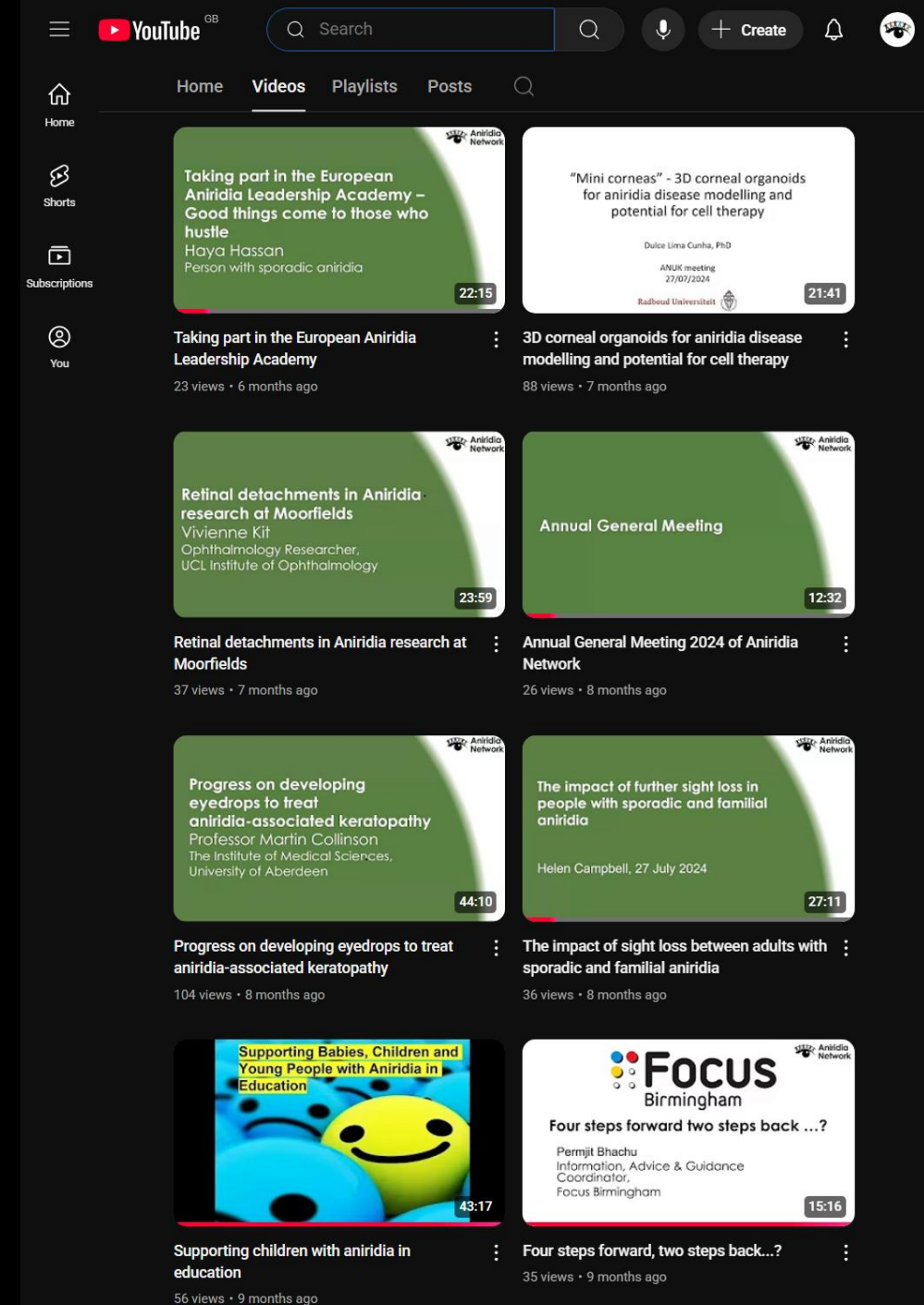
We post on our own page and engage with the Aniridic Family group.

With our 3 main channels now all owned by Meta we can use Buffer to post efficiently to them and schedule when useful too.





- Published 9 recordings with captions of our Conference sessions
- 348 subscribers (up 35 11%)
- 3,162 views
- 166 hours watched
- Top videos
 - Auditory processing disorder
 - Aniridia therapy and surgery



Volunteering & Development

Donations

We raise funds online and through regular donations.

Thank you very much to everyone who has given in any way.

- One-off donations
- Facebook fundraisers for special events
- Several generous regular donors
- A legacy from Miriam Ibberson of £150



Fundraisers

People have done great feats in aid of our charity.

- Gemma's National 3 Peaks Challenge raised £735
- Jack's Clarendon Marathon run raised £3,080

Thank you very much to all of them and everyone who sponsored them.



Volunteers thanks

Thank you to all our volunteers for their stirring efforts this year:

- Tierney McGuire
- Rachel Campling
- Simon Iskander
- Glen Turner
- Lyn Buller
- Clive Matthews

Several of our past helpers have not been able to resume volunteering for various reasons.

Volunteer of the year



Tierney McGuire for
wrangling speakers and
hosting our conference in
2024.



Medical Advisers

We appointed new experts to respond to medical enquiries from members:

- [Mr John Brookes](#)
- [Professor Mariya Moosajee](#)

Both are consultant ophthalmic surgeons at Moorfields Eye Hospital



Volunteers needed

More volunteers are badly needed especially people with skills in:

- finance
- fundraising
- volunteer management
- human resources and policy
- business development
- membership administration
- communications

Governance

Safeguarding

We have been working with a consultant to develop a safeguarding policy and code of conduct.

This will make being part of Aniridia Network safer for everyone, especially children and vulnerable adults.

Trustee board

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

- Katie Atkinson
- James Buller
- Andy Baghurst

We are trying to make arrangements to recruit new trustees, including external adverts and an information pack.

Management roles

- Head of Communications & Membership
James Buller
- Head of Services & Information
Katie Atkinson
- Head of Finances & Fundraising
Andy Baghurst

2024 AGM Voting

The vote was held online using
Choice Voting,

Participation was again sadly
very low, despite promotion

James Buller	28
Re-open nominations	1
Turnout:	~6.75%



Aniridia Network
(Registered charity, number 1176792)
Financial statements
for the year ended 31 March 2025

Page	Contents
2 - 4	Trustees' annual report
5	Independent examiner's report
6	Receipts & payments account
7	Statement of assets & liabilities
8	Notes to the accounts

**Aniridia Network
Trustees' annual report
for the year ended 31 March 2025**

Full name Aniridia Network

Organisation type Charitable incorporated organisation

Registered charity number 1176792

Principal address 22 Cornish House, Adelaide Lane, Sheffield, S3 8BJ

Trustees (held office throughout year unless noted otherwise)

Katie Atkinson, Chair
James Buller, Trustee
Andrew Baghurst, Trustee

Independent examiner

Eva Stevens, employee of Community Accounting Plus, Units 1 & 2 North West, 41 Talbot Street, Nottingham, NG1 5GL

Governance and management

The charity is operated under the rules of its governing document adopted 23/01/2018.

Trustees are recruited via adverts on the Aniridia Network's communications channels to members and followers. Trustees are appointed by members at Annual General Meetings or, on an interim basis, co-opted by the existing trustees (in accordance with the charity's governing document).

Objectives and activities

The objects of the CIO are, for the public benefit, in the British Isles:

(1) the protection and advancement of health, of people with aniridia, in particular but not exclusively by:

(a) promoting and facilitating research into the causes, effects and treatments of aniridia

(b) providing information to educate people with aniridia, their family members and relevant professionals about the causes, effects, treatments and management of aniridia.

Aniridia Network

(2) the relief of people suffering from aniridia and their families, in particular but not exclusively by:

- (a) providing a network of families, individuals and professionals in order to share: ideas, knowledge and experiences plus give practical and emotional support
- (b) providing information and services to people with aniridia, their family members and relevant professionals regarding education, health, employment and social security plus life skills relevant to having aniridia.

(3) the education of the public, in all areas relating to aniridia by:

- (a) publicising the needs, stories and achievements of people affected by and working with aniridia

For the purpose of this clause 'aniridia' means the genetic conditions causing iris defects (such as aniridia and iris hypoplasia) usually causing visual impairment. Where they occur in people with aniridia it also encompasses related conditions such as: dry eye, keratopathy, nystagmus, cataracts, glaucoma, auditory processing disorder and WAGR.

Summary of the main activities undertaken for the public benefit

Aniridia Network supports people in the UK affected by aniridia: those who have it plus their family, carers, doctors, educators and others. The charity wants all these people to be hopeful, confident, supported and well informed regarding aniridia. For them we: organise conferences, meetups and befriending, provide access to professionals and distribute or signpost to useful information.

Public benefit statement

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit, 'Charities and Public Benefit'.

Summary of the main achievements during the period

Enquiries – 3 medical enquiries on a variety of topics.

Befriending – 4 new members referred to service and offered a buddy, with 8 new adults being offered a buddy or offering to be a buddy. Parent information packs sent to all new members with children. 6 buddy relationships set up in total.

Education – 8 requests for education advice. Information sent out included: pupil passports, EHCP Appendix 1 resource, and links to RNIB Early Years resources and support for parents. 1 contact from a school SENCO.

Aniridia Network

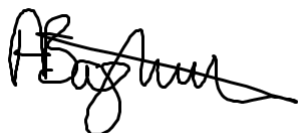
Conference – online conference held on 27 July 2024, with recordings published on Youtube and on the website with a transcript available. The conference covered various topics include supporting children with aniridia in education, the impact of sight loss between adults with sporadic and familial aniridia, developing eyedrops to treat aniridia-associated keratopathy and retinal detachments in aniridia research at Moorfields Eye Hospital.

Events – various social events were arranged, including several national Rare Disease Day events. Two Trustees represented the Network at the 7th European Aniridia Conference, and one member was supported financially to attend the European Aniridia Leadership Academy.

The charity's policy on reserves

The charity has no specific policy with regard to the level of reserves.

Signed on behalf of the charity's trustees:



Signed

Date

11/10/2025

Andrew Baghurst, Trustee

**Independent examiner's report to the trustees of
Aniridia Network
for the year ended 31 March 2025**

I report to the trustees on my examination of the accounts of Aniridia Network (the charity) for the year ended 31 March 2025.

Responsibilities and basis of report

As the trustees of the charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').


I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed  _____ Date 03/11/2025
Eva Stevens BSc, CPFA
Employee of Community Accounting Plus

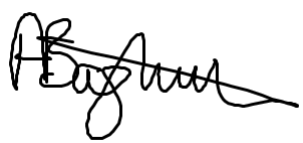
Aniridia Network
Receipts & payments account
for the year ended 31 March 2025

2024			Unrestricted	Restricted	2025
Total		Note	Funds	Funds	Total
Funds			£	£	Funds
£					£
	Receipts				
3247	Grants & donations	2	9528	-	9528
1013	Conference attendance		-	-	-
105	Bank interest		1562	-	1562
-	Exchange rate gain/(loss)		-	-	-
3183	Total receipts		11090	-	11090
	Payments				
5245	Events/Conference		-	-	-
-	European Aniridia Conference grants		664	-	664
-	Fundraising costs		460	-	460
310	Internal services - IT		258	-	258
77	Membership fees		50	-	50
438	Independent examination fees		360	-	360
96	Insurance		96	-	96
583	Printing and postage		-	-	-
290	Trustee expenses		173	-	173
201	Election Fees		169	-	169
52	Bank Fees		6	-	6
326	Website Fees		327	-	327
17	Volunteer awards		-	-	-
7635	Total payments		2564	-	2564
(3270)	Net receipts/(payments)		8526	-	8526
52412	Cash funds at start of this period		49142	-	49142
49142	Cash funds at end of this period		57668	-	57668

Aniridia Network
Statement of assets and liabilities
at 31 March 2025

2024		2025
£		£
49142	Cash assets	
<u>49142</u>	Bank accounts	<u>57668</u>
		<u>57668</u>
	Assets retained for the charity's own use	
414	General equipment	414
	Liabilities	
<u>(360)</u>	Creditors - Independent examination fee	<u>(372)</u>
<u>(360)</u>		<u>(372)</u>

These financial statements are accepted on behalf of the charity by:

Signed  _____
 Andrew Baghurst, Trustee

Date 11/10/2025

Aniridia Network

Notes to the accounts

for the year ended 31 March 2025

1. Receipts & payments accounts

Receipts and payments accounts contain a summary of money received and money spent during the period and a list of assets and liabilities at the end of the period. Usually, cash received and cash spent will include transactions through bank accounts and cash in hand.

2. Grants & donations

	Unrestricted	Restricted	Total
	£	£	£
CAF Donate	3133	-	3133
Cafess	-	-	-
Give As You Live	92	-	92
Justgiving	5441	-	5441
Paypal Giving Fund	466	-	466
Other	396	-	396
	<u>9528</u>	<u>-</u>	<u>9528</u>

3. Premises & staff

The Aniridia Network has no staff employed and no premises.

4. Trustees' remuneration

Trustees received no expenses, remuneration or benefits in this period.

5. Related party transactions

There were no related party transactions in this period.

6. Glossary of terms

Creditors: These are amounts owed by the charity, but not paid during the accounting period.