

ANIRIDIA NETWORK

England & Wales - Charity number 1176792

Details

Other names	ANIRIDIA NETWORK UK
Status	Registered
Legal form	CIO
Registered	2018-01-23
Register	View on the Charity Commission register

Contact

Address	22 Cornish House Adelaide Lane Sheffield South Yorkshire S3 8BJ
Phone	07792867949
Email	info@aniridia.org.uk
Website	https://aniridia.org.uk

Activities

Objects: THE OBJECTS OF THE CIO ARE, FOR THE PUBLIC BENEFIT, IN THE BRITISH ISLES AND ELSEWHERE: (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.(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.

Activities: We support people in the UK affected by aniridia: those who have it plus their family, carers, doctors, educators and others. We want 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.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- Ireland
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£11,090	£2,564	-	-
2024-03-31	£4,365	£7,635	-	-
2023-03-31	£3,183	£2,813	-	-
2022-03-31	£22,186	£19,535	-	-
2021-03-31	£5,394	£1,402	-	-

Trustees

Name	Role	Appointed
KATHERINE ATKINSON	Chair	2018-04-14
Andrew Baghurst		2021-09-01
JAMES BULLER		2018-04-14

ANIRIDIA NETWORK

England & Wales - Charity number 1176792

Accounts



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.

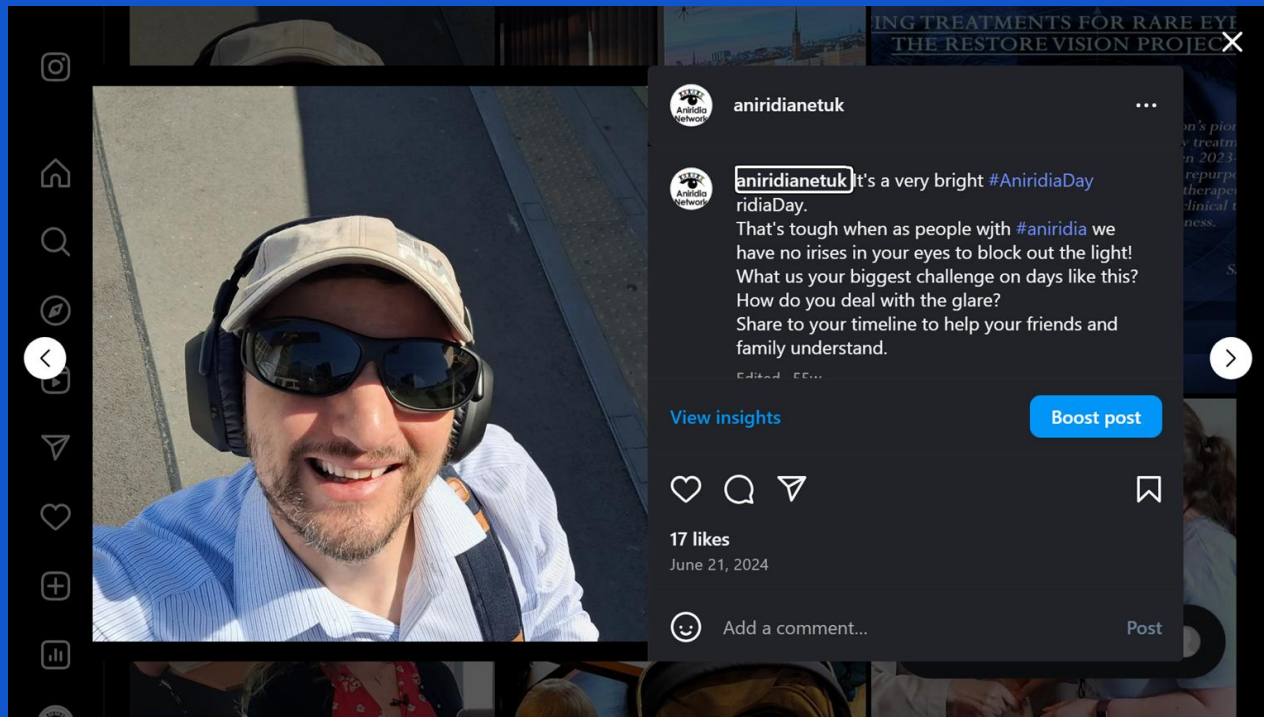
- Held online on 27 July
- Recordings published on YouTube and on our website with a transcript
- Thank you Tierney for wrangling speakers and hosting the event so well.
- Presentation subjects:
 - Supporting children with aniridia in education
 - Impact of sight loss between adults with sporadic and 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

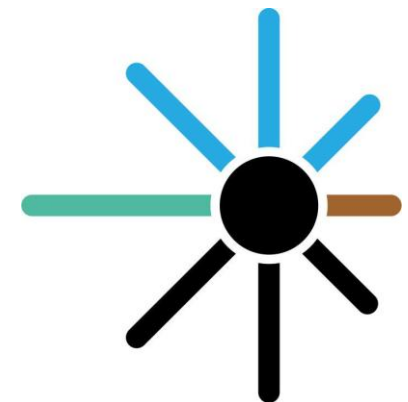
Big thanks to
the hosts,

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

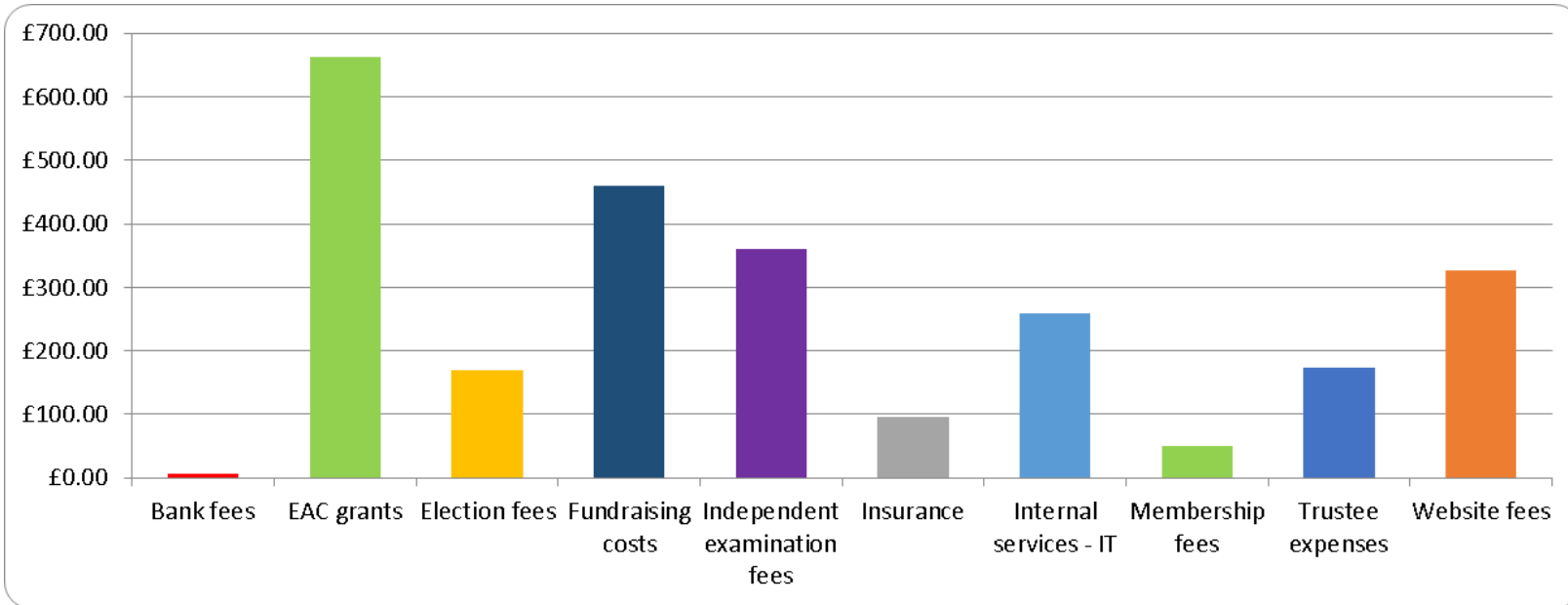
Funds end of year: £57,668

Expenditure: £ 2,564

Income: £11,090

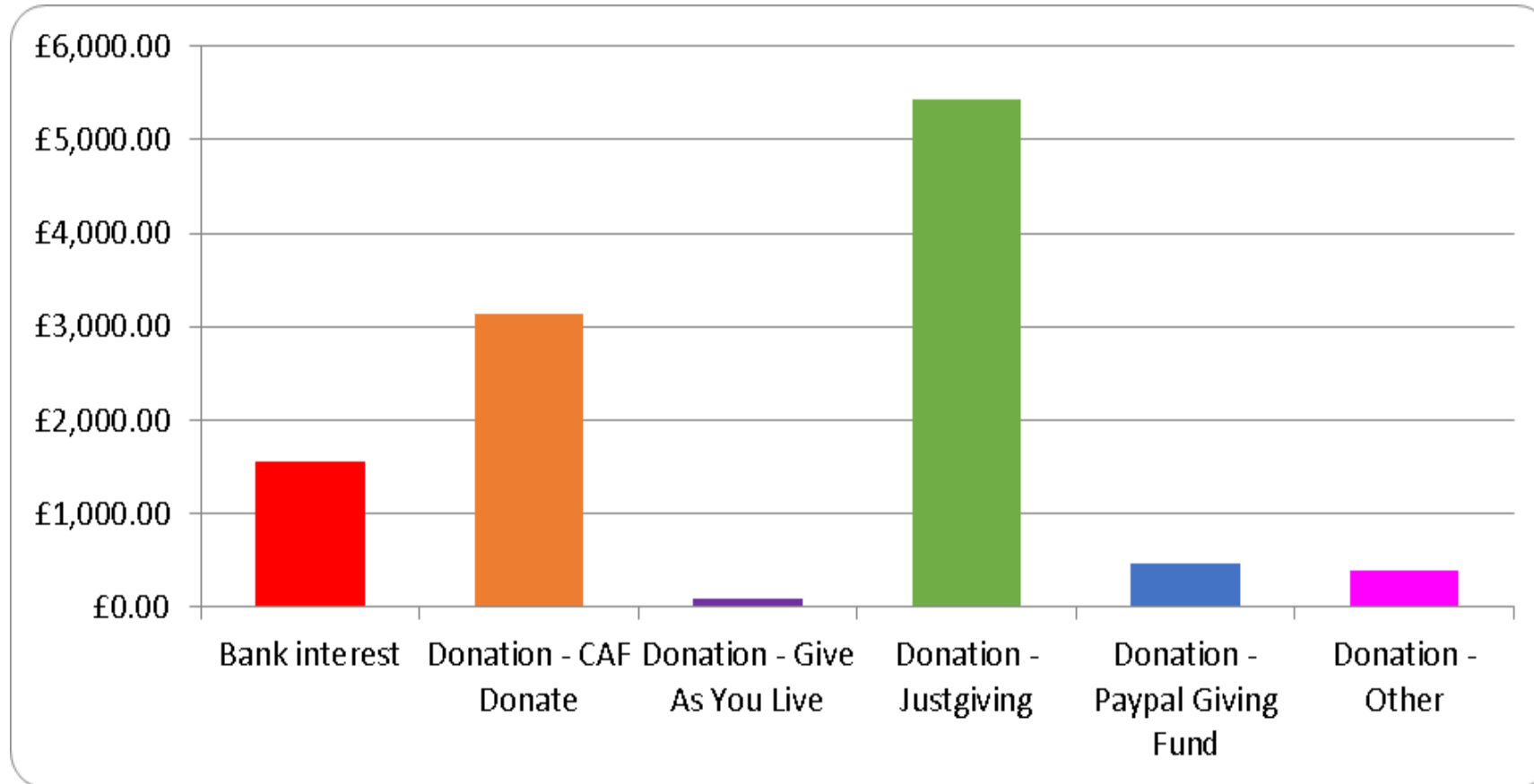
Compared to the previous year, we saw a significant uplift in donations with a reduction in costs primarily due to hosting the conference online.

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

[View in browser](#)



Aniridia Network

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 so you hear their stories and ask your questions on Zoom!

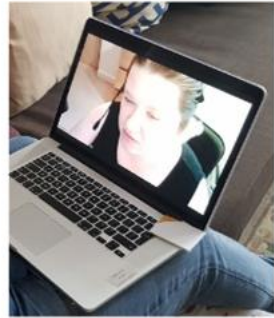

Afterwards you'll also get to chat with fellow patients and parents affected by aniridia, enabling you make important connections and improve your understanding of aniridia.

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

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

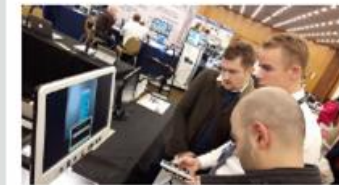
Members should also have received an email about voting in the annual election of an Aniridia Network trustee. Please follow its instructions to cast your vote by the end of Friday 26 July. The election result will be announced at the Annual General Meeting during conference.

Speakers in 2024



November after Sight Village

Tuesday 5 November to talk about all aspects of



food court very close to [High Street Kensington](#) by 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 who 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.

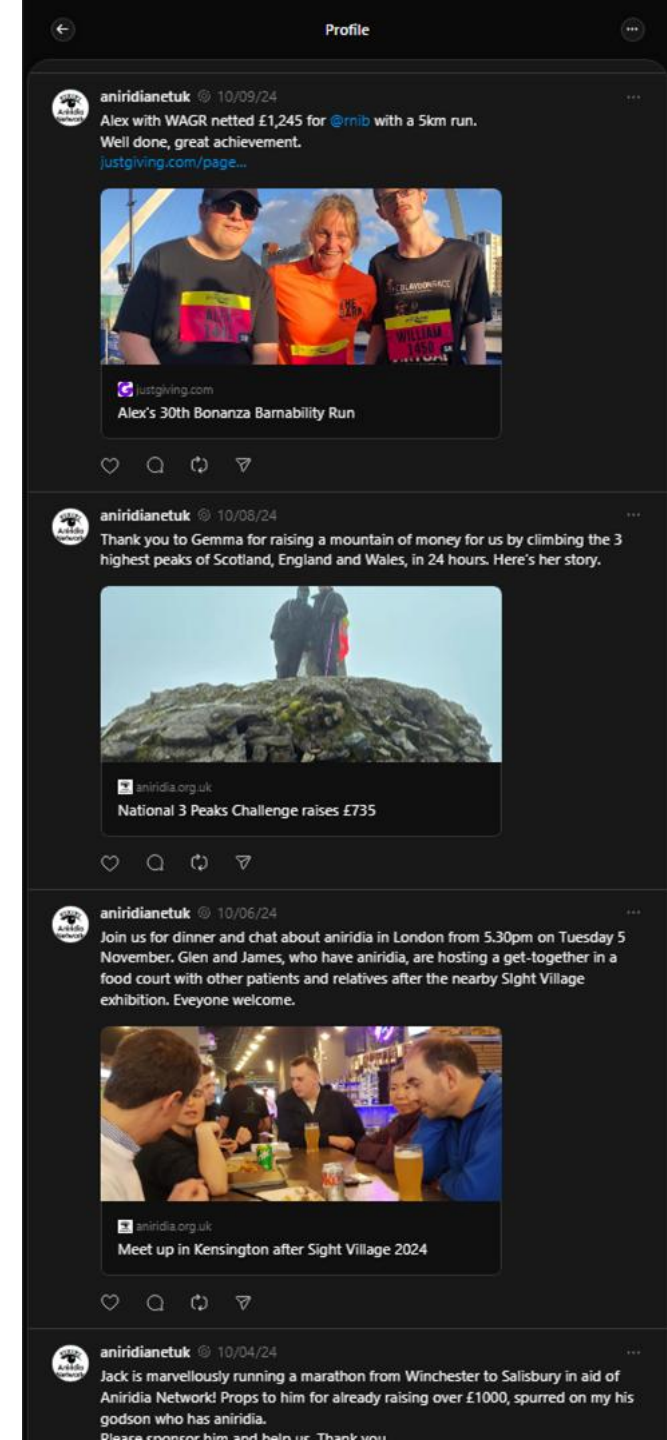
[Get more details and sign up for our meet up](#)



@ 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

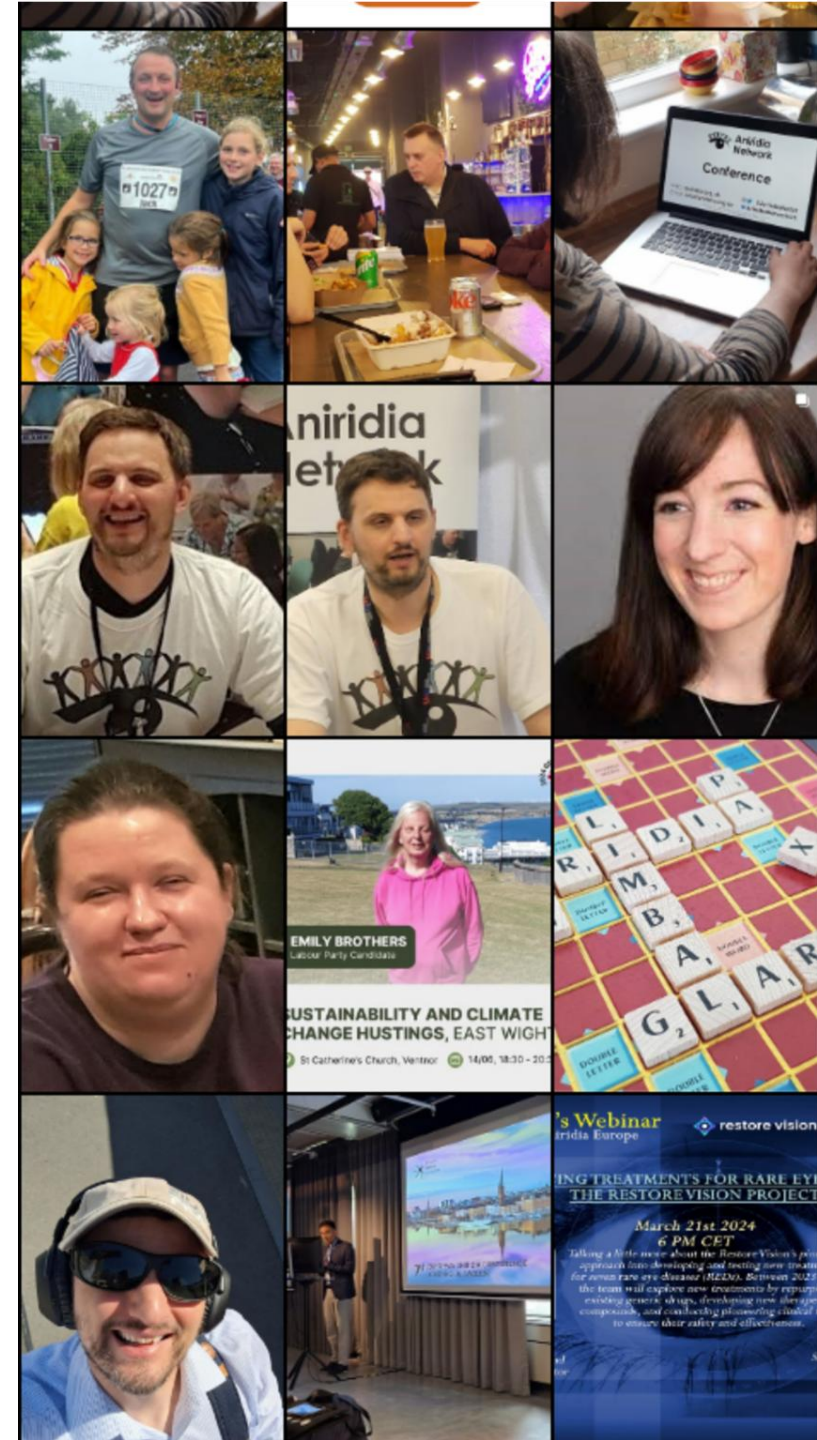
November 16, 2024 at 11:19 AM Everybody can reply

1 like



Instagram

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



Facebook

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 all owned by Meta we can use Buffer to post efficiently to them and schedule when useful too.

The image shows a vertical scroll of Facebook posts from the 'Aniridia Network' page. The top post is a promotional graphic for Rare Disease Day (28 Feb 2025) with the text 'THERE ARE 7,000+ IDENTIFIED RARE CONDITIONS'. It includes logos for Genetic Alliance and Rare Disease, and a link to 'geneticalliance.org.uk/rdd'. Below this is a post with 5 likes and 2 shares, featuring interaction buttons for Like, Comment, and Share. The bottom post is a text-based announcement about a research opportunity, published by Jetpack on 24 February, with a photo of a modern building and the text 'Be a part of cutting-edge brain and aniridia research'.

YouTube

- 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

The screenshot displays the YouTube channel page for the Aniridia Network. The channel name 'Aniridia Network' is visible in the top right corner of the page. The page features a grid of 12 video thumbnails, each with a title, speaker name, and view count. The videos are:

- Taking part in the European Aniridia Leadership Academy – Good things come to those who hustle** by Haya Hassan, Person with sporadic aniridia (22:15)
- “Mini corneas” - 3D corneal organoids for aniridia disease modelling and potential for cell therapy** by Dulce Lima Cunha, PhD (21:41)
- Taking part in the European Aniridia Leadership Academy** (23 views • 6 months ago)
- 3D corneal organoids for aniridia disease modelling and potential for cell therapy** (88 views • 7 months ago)
- Retinal detachments in Aniridia research at Moorfields** by Vivienne Kit, Ophthalmology Researcher, UCL Institute of Ophthalmology (23:59)
- Annual General Meeting** (12:32)
- Retinal detachments in Aniridia research at Moorfields** (37 views • 7 months ago)
- Annual General Meeting 2024 of Aniridia Network** (26 views • 8 months ago)
- Progress on developing eyedrops to treat aniridia-associated keratopathy** by Professor Martin Collinson, The Institute of Medical Sciences, University of Aberdeen (44:10)
- The impact of further sight loss in people with sporadic and familial aniridia** by Helen Campbell, 27 July 2024 (27:11)
- Progress on developing eyedrops to treat aniridia-associated keratopathy** (104 views • 8 months ago)
- The impact of sight loss between adults with sporadic and familial aniridia** (36 views • 8 months ago)
- Supporting Babies, Children and Young People with Aniridia in Education** (43:17)
- Four steps forward two steps back ...?** by Permit Bhachu, Information, Advice & Guidance Coordinator, Focus Birmingham (15:16)
- Supporting children with aniridia in education** (56 views • 9 months ago)
- Four steps forward, two steps back...?** (35 views • 9 months ago)

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 stirling 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

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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

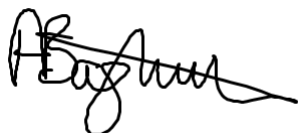
Conference – online conference held on 27 July 2024, with recordings published on Youtube and on the website with a transcript available. The conference covered various topics include supporting children with aniridia in education, the impact of sight loss between adults with sporadic and familial aniridia, 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)		-	-	-
<u>3183</u>	Total receipts		<u>11090</u>	<u>-</u>	<u>11090</u>
	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		-	-	-
<u>7635</u>	Total payments		<u>2564</u>	<u>-</u>	<u>2564</u>
(3270)	Net receipts/(payments)		8526	-	8526
52412	Cash funds at start of this period		49142	-	49142
<u>49142</u>	Cash funds at end of this period		<u>57668</u>	<u>-</u>	<u>57668</u>

**Aniridia Network
Statement of assets and liabilities
at 31 March 2025**

2024		2025
£		£
<u>49142</u>	Cash assets	
49142	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

Date

11/10/2025

Andrew Baghurst, Trustee

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.

ANIRIDIA NETWORK

England & Wales - Charity number 1176792

Accounts

Aniridia Network
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Independent examiner

John O'Brien, employee of Community Accounting Plus, Units 1 & 2 North West, 41 Talbot Street, Nottingham, NG1 5GL

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(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 – 10 medical enquiries on a variety of topics.

Befriending – 8 new members referred to service and offered a buddy, with 4 new adults being offered a buddy or offering to be a buddy. Parent information packs sent to all new members with children. 12 buddy relationships set up in total.

Education – 16 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 referral made to Aniridia Network's education adviser. 26 parents responded to our survey requesting information about support received from their local authority.

Aniridia Network

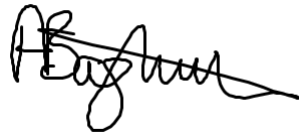
Conference – first in-person conference for 4 years, held in Birmingham on 2nd September 2023, with 59 delegates and 9 speakers. The conference covered various topics and included a talk from the Network’s patrons on their careers.

Events – various social events were arranged, including several national Rare Disease Day events and an event in London for Aniridia Day.

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

17/11/2024

Andrew Baghurst, Trustee

**Independent examiner's report to the trustees of
Aniridia Network
for the year ended 31 March 2024**

I report to the trustees on my examination of the accounts of Aniridia Network (the charity) for the year ended 31 March 2024.

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').

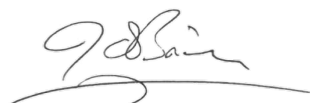
I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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 21/11/2024
John O'Brien MSc, FCCA, FCIE
Employee of Community Accounting Plus

Aniridia Network
Receipts & payments account
for the year ended 31 March 2024

2023			2024
Total		Unrestricted	Restricted
Funds		Funds	Funds
£	Note	£	£
			Total
			Funds
			£
	Receipts		
3180	Grants & donations	2	3247
-	Conference attendance		1013
-	Bank interest		105
3	Exchange rate gains		-
<u>3183</u>	Total receipts		<u>4365</u>
	Payments		
-	Conference		5245
664	European Aniridia Conference grants		-
251	Events		-
587	Internal services - IT		310
103	Membership fees		77
420	Independent examination fees		438
96	Insurance		96
175	Printing and postage		583
52	Trustee expenses		290
81	Election Fees		201
4	Bank Fees		52
320	Website Fees		326
60	Volunteer awards		17
<u>2813</u>	Total payments		<u>7635</u>
370	Net receipts/(payments)		(3270)
52042	Cash funds at start of this period		52412
<u>52412</u>	Cash funds at end of this period		<u>49142</u>

**Aniridia Network
Statement of assets and liabilities
at 31 March 2024**

2023		2024
£		£
<u>52412</u>	Cash assets	
<u>52412</u>	Bank accounts	<u>49142</u>
		<u>49142</u>
	Assets retained for the charity's own use	
414	General equipment	414
	Liabilities	
<u>(438)</u>	Creditors - Independent examination fee	<u>(360)</u>
<u>(438)</u>		<u>(360)</u>

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



Signed

Date

17/11/2024

Andrew Baghurst, Trustee

Aniridia Network
Notes to the accounts
for the year ended 31 March 2024

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	2307	-	2307
Cafess	20	-	20
Give As You Live	34	-	34
Justgiving	584	-	584
Paypal Giving Fund	162	-	162
Other	141	-	141
	<u>3247</u>	<u>-</u>	<u>3247</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.

ANIRIDIA NETWORK

England & Wales - Charity number 1176792

Accounts

Aniridia Network
(Registered charity, number 1176792)
Financial statements
for the year ended 31 March 2023

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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 2023**

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

John O'Brien, 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

Patron – secured a new distinguished patron in Professor Tony Moore MA FRCS FRCOphth FMedSci.

Advocacy – responded to a Department of Health and Social Care call for evidence on the Down Syndrome Act, on behalf of those with WAGR.

Enquiries – 9 medical enquiries on a variety of topics.

Befriending – 7 new members referred to service, 5 requested a buddy. Parent information packs sent to all. 2 existing members requested further buddies. 14 buddy relationships set up in total.

Aniridia Network

Education – 12 requests for education advice. Information sent out included: pupil passports, EHCP Appendix 1 resource, aniridia links to Development Matters and links to RNIB Early Years resources. Apart from parents, requests also came from 2 Qualified Teachers of Vision Impairment (QTVIs), an Educational Psychologist, a nursery provider and a teacher from Singapore, all of whom were supporting children with aniridia.

Conference – online conference held on 13 August 2022 which included a talk on the benefits of a low vision assessment for children and adults with aniridia, a medical presentation on the prevention of and current therapies for the failure of cornea stem cells, and an introduction to a qualitative study of attitudes to internet use in adults with aniridia.

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

10/08/2023

Andrew Baghurst, Trustee

**Independent examiner's report to the trustees of
Aniridia Network
for the year ended 31 March 2023**

I report to the trustees on my examination of the accounts of Aniridia Network (the charity) for the year ended 31 March 2023.

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').

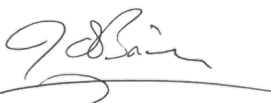
I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

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 10/8/23
John O'Brien MSc, FCCA, FCIE
Employee of Community Accounting Plus

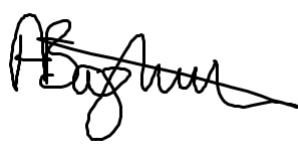
Aniridia Network
Receipts & payments account
for the year ended 31 March 2023

2022			2023
Total		Unrestricted	Restricted
Funds		Funds	Funds
£	Note	£	£
	Receipts		
22185	Grants & donations	2	3180
2	Exchange rate gains	3	-
<u>22187</u>	Total receipts	<u>3183</u>	<u>3183</u>
	Payments		
220	Training	-	-
10273	Conference	-	-
3485	Conference - transfer to Aniridia Spain	-	-
1933	Conference - returned to funders	-	-
-	European Aniridia Conference grants	664	664
-	Events	251	251
18	Internal services - Education	-	-
293	Internal services - IT	587	587
50	Membership fees	103	103
-	Independent examination fees	420	420
-	Insurance	96	96
178	Printing and postage	175	175
-	Trustee expenses	52	52
2487	Election Fees	81	81
272	Bank Fees	4	4
286	Website Fees	320	320
40	Volunteer awards	60	60
<u>19535</u>	Total payments	<u>2813</u>	<u>2813</u>
2651	Net receipts/(payments)	370	-
49391	Cash funds at start of this period	52042	52042
<u>52042</u>	Cash funds at end of this period	<u>52412</u>	<u>52412</u>

**Aniridia Network
Statement of assets and liabilities
at 31 March 2023**

2022		2023
£	Cash assets	£
52042	Bank accounts	52412
<u>52042</u>		<u>52412</u>
	Assets retained for the charity's own use	
414	General equipment.	414
	Liabilities	
(420)	Creditors - Independent examination fee	(438)
<u>(420)</u>		<u>(438)</u>

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

Signed 
Andrew Baghurst, Trustee

Date 10/08/2022

Aniridia Network
Notes to the accounts
for the year ended 31 March 2023

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	2437	-	2437
Give As You Live	108	-	108
Justgiving	14	-	14
Paypal Giving Fund	26	-	26
Other	594	-	594
	<u>3180</u>	<u>-</u>	<u>3180</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.

Restricted funds: These are funds given to the charity, subject to specific restrictions set by the donor, but still within the general objects of the charity.

ANIRIDIA NETWORK

England & Wales - Charity number 1176792

Accounts

Aniridia Network
(Registered charity, number 1176792)
Financial statements
for the year ended 31 March 2022

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6	Receipts & payments account
7	Statement of assets & liabilities
8 - 9	Notes to the accounts

**Aniridia Network
Trustees' annual report
for the year ended 31 March 2022**

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, from September 2021

Dave McKay, Trustee, April to September 2021

Eleanor Burke, Trustee, April to June 2021

Independent examiner

John O'Brien, 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

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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'.

Aniridia Network

Summary of the main achievements during the period

Enquiries – 8 medical enquiries on a variety of topics, 2 enquiries regarding Personal Independence Payment (PIP) and Disability Living Allowance (DLA).

Befriending – 20 individuals interacted with the befriending service, 9 parent information packs were sent out and 15 buddy relationships were set up.

Education – 5 pupil passports issued, 2 EHCP resources issued, 2 pupil passports and EHCP resources issued to teachers of the visually impaired, work progressing on new resource to support parents with babies with aniridia.

Conference – integrated in to the 5th European Aniridia Conference, a 2-day event with 45 speakers over 43 sessions, 353 attendees and 10 patients/parents benefited from 25-minute video clinics with Moorfields Eye Hospital consultants.

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

19/07/2022

Andrew Baghurst, Trustee

**Independent examiner's report to the trustees of
Aniridia Network
for the year ended 31 March 2022**

I report to the trustees on my examination of the accounts of Aniridia Network (the charity) for the year ended 31 March 2022.

Responsibilities and basis of report

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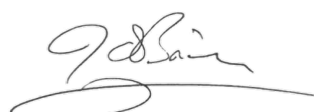
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Independent examiner's statement

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 19/07/2022
John O'Brien MSc, FCCA, FCIE
Employee of Community Accounting Plus

**Aniridia Network
Statement of assets and liabilities
at 31 March 2022**

<i>2021</i>		<i>2022</i>
£		£
	Cash assets	
49391	Bank accounts	52042
<u>49391</u>		<u>52042</u>
	Assets retained for the charity's own use	
414	General equipment.	414
	Liabilities	
-	Creditors - Independent examination fee	(420)
<u>-</u>		<u>(420)</u>

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

Signed  Date 19/07/2022

Andrew Baghurst, Trustee

Aniridia Network
Notes to the accounts
for the year ended 31 March 2022

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	3142	-	3142
CafePress	19	-	19
Everyclick	21	-	21
Justgiving	1053	-	1053
Paypal Giving Fund	10	-	10
Other	4512	-	4512
NSS grant and donations for EAC	-	13428	13428
	<u>8757</u>	<u>13428</u>	<u>22185</u>

3. Funds analysis

	Opening balance £	Receipts (Payments) £		Transfers £	Closing balance £
Restricted funds					
European Aniridia Conference	2810	13428	(15960)	(277)	-
	<u>2810</u>	<u>13428</u>	<u>(15960)</u>	<u>(277)</u>	<u>-</u>
Unrestricted funds					
General Fund	46581	8759	(3575)	277	52042
	<u>46581</u>	<u>8759</u>	<u>(3575)</u>	<u>277</u>	<u>52042</u>

The transfer from the European Aniridia Conference fund to the General fund reflects the release of restrictions on the use of a portion of a donation.

4. Premises & staff

The Aniridia Network has no staff employed and no premises.

5. Trustees' remuneration

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

6. Related party transactions

There were no related party transactions in this period.

Aniridia Network

7. Glossary of terms

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

Restricted funds: These are funds given to the charity, subject to specific restrictions set by the donor, but still within the general objects of the charity.

ANIRIDIA NETWORK

England & Wales - Charity number 1176792

Accounts



Aniridia Network

Aniridia Network Annual Report 2020/2021

1 April - 31 March

Web: aniridia.org.uk

Email: info@aniridia.org.uk



[@AniridiaNetUK](https://www.instagram.com/AniridiaNetUK)



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

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

Contents

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

Impact of COVID-19 pandemic

On people affected by aniridia

- Not aware of any health effects relating specifically to aniridia
- Visually impaired people experienced challenges such as with being guided and social distancing

On Aniridia Network

- Online instead of physical events
- Less activity to communicate
- No fundraising feats so lower income
- Lower expenditure on events and travel
- Deferment of retirement by rotation of trustees

Services & Information

Enquiries & Information

7 medical enquiries on a variety of topics including:

- Glaucoma medication
- Genetic testing
- Cataract surgery
- General treatment options for aniridia

2 enquiries asking for advice on Personal Independence Payments (PIP)

Befriending

- 27 individuals/families made contact or were contacted when they became members.
- 22 members with children were sent our Parent Information pack and offered buddy support.
- 6 did not respond to initial emails on becoming members.
- 7 requested a buddy and were successfully linked to other families, resulting in 18 buddy relationships.
- Many make contact with each through Aniridic Family group on Facebook.

Education

- 16 requests for our aniridia Pupil Passports, 3 from teachers for the visually impaired.
- 2 referrals to Education Advisor Clive Matthews about Education Health Care Plans (EHCP) and local authority input.
- People posting on Aniridic Family, are contacted if appropriate and offered further support
- Information sent includes links to websites Early Years Support, and Department for Education documents.

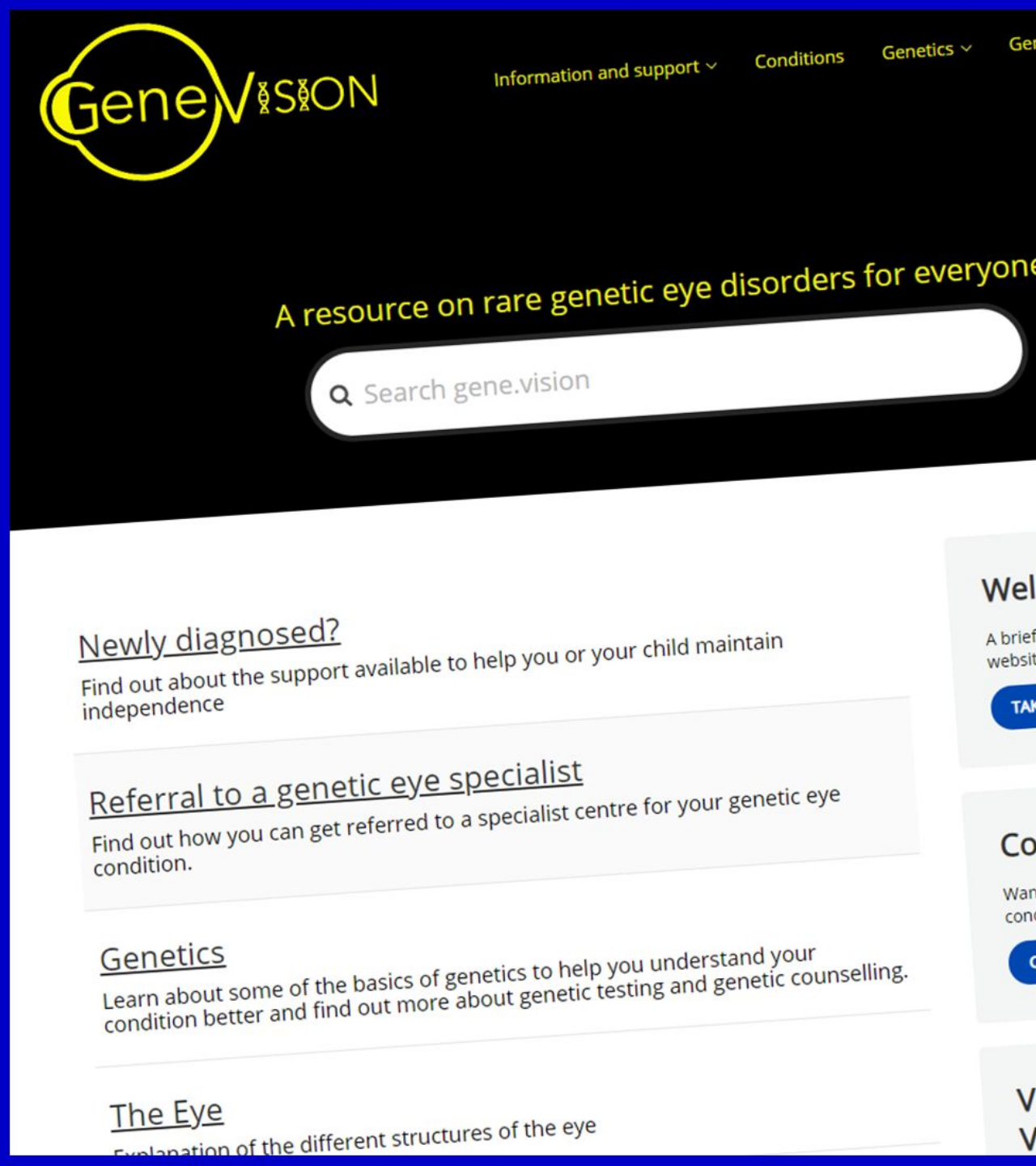
- Developing resource for parents to complete Appendix 1 in the assessment for Education Health Care Plans with examples from members who have previously gone through this process.

Gene.Vision

We contributed to the content of this new website by Moorfields Eye Hospital for both patients and doctors

It contains in-depth, but easy to read, details about aniridia.

Alongside is scientific content aimed at clinicians and other professionals who are diagnosing patients or learning about the condition.



Gene.Vision

Trustee James was a digital consultant for the project. He advised on development methods and checked the code for accessibility issues.

He later took part in the trials.

This led to helping to edit a [peer-reviewed paper published in the Journal of Medical Internet Research.](#)




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Published on 20.1.2021 in Vol 23, No 1 (2021): January
Preprints (earlier versions) of this paper are available at <https://preprints.jmir.org/preprint/19151>, first published April 06, 2020.



A Newly Developed Web-Based Resource on Genetic Eye Disorders for Users With Visual Impairment (Gene.Vision): Usability Study

Jian Lee Yeong ¹ ; Peter Thomas ² ; James Buller ³ ; Mariya Moosajee ^{1, 2, 4}

[Article](#) [Authors](#) [Cited by](#) [Tweattions \(17\)](#) [Metrics](#)

Abstract

This is a corrected version. See correction statement in: <http://www.jmir.org/2021/1/e27330/>

Related Article

Citation
Please cite as:
Yeong JL, Thomas P, Buller J, Moosajee M
A Newly Developed Web-Based Resource on Genetic Eye Disorders for Users With Visual Impairment (Gene.Vision): Usability Study
J Med Internet Res 2021;23(1):e19151
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PMCID: 7857953

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RIS for: RefMan, Procite, Endnote, RefWorks

- [Abstract](#)
- [Introduction](#)
- [Methods](#)
- [Results](#)

Aniridia Europe

Aniridia Network is a founding member of Aniridia Europe and Katie sits on its Board of Directors.

Aniridia Europe has been participating in three major projects during this year:

- ERASMUS+ Project Looking Out For A School For All: early educational inclusion for students with low vision. This project was due for completion in 2020 but the final stage, disseminating the outcomes has been postponed to summer 2021.
- COST ACTION: ANIRIDIA-NET: Aniridia networking to address an unmet medical, scientific and societal challenge
- AAK-INSIGHT: 'Aniridia – novel therapeutic tools to treat or prevent progressive corneal opacification'

It launched a series of webinars in 2021 to better connect with the wider aniridia community.

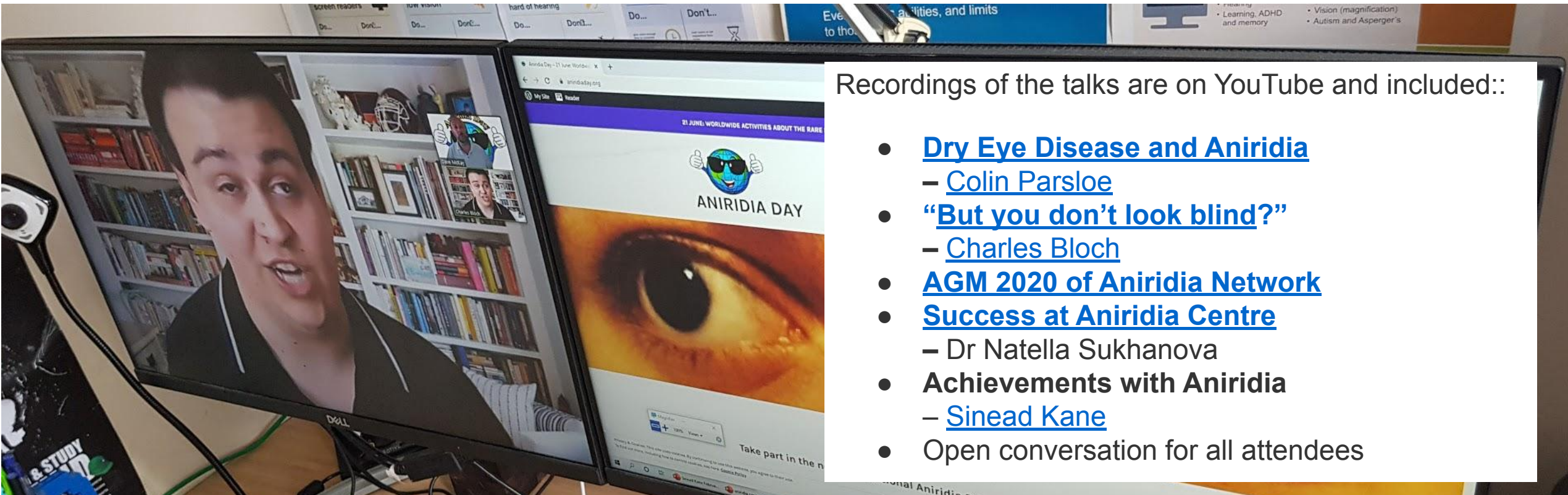
Conferences & Events

Conference 2020

An online event for connecting with and supporting each other, in spite of pandemic restrictions .

An afternoon of free, informative presentations and discussions

Around 70 attended including people from all over the world as part of Aniridia Day.

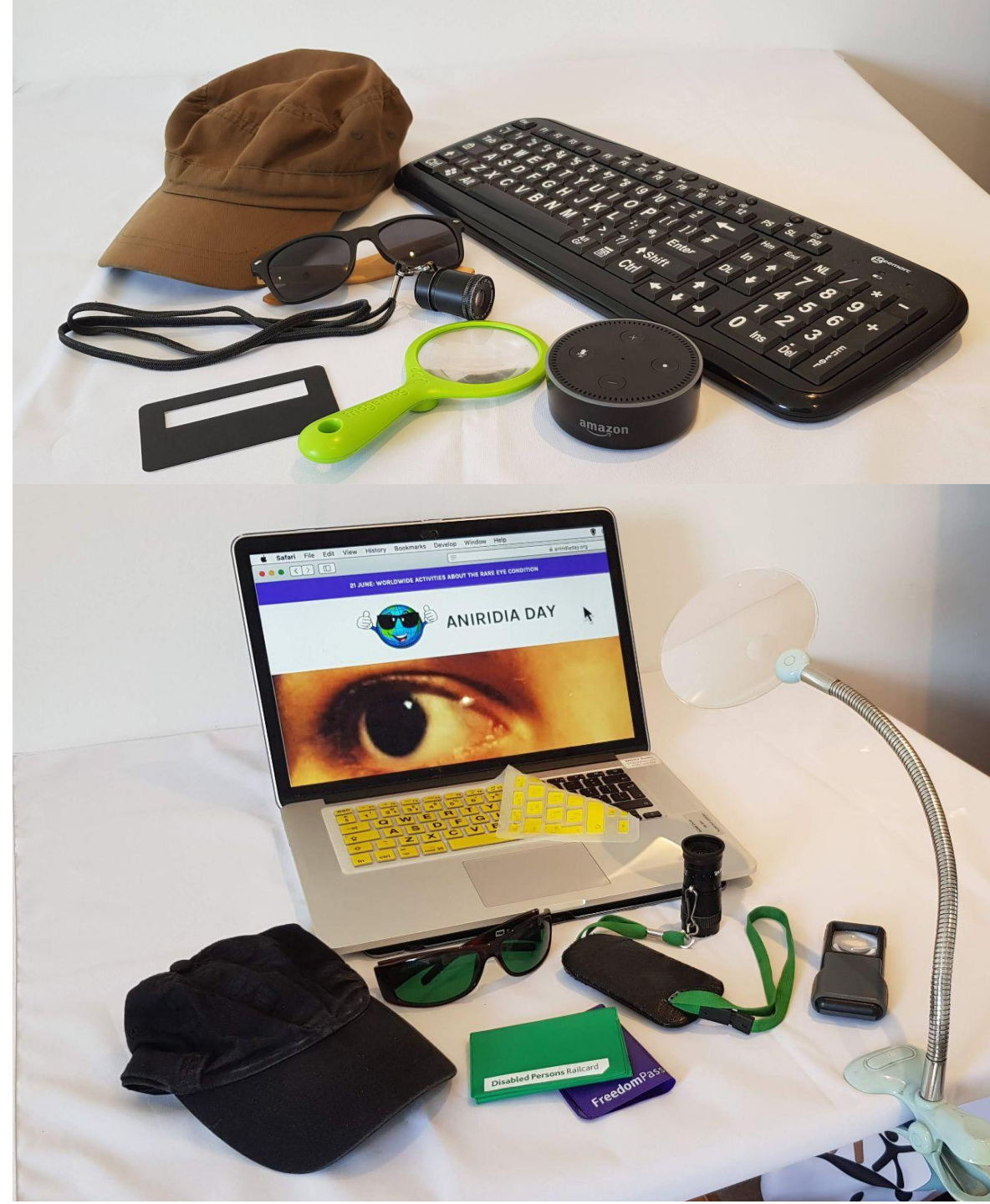


Recordings of the talks are on YouTube and included::

- [**Dry Eye Disease and Aniridia**](#)
 - [**Colin Parsloe**](#)
- [**“But you don’t look blind?”**](#)
 - [**Charles Bloch**](#)
- [**AGM 2020 of Aniridia Network**](#)
- [**Success at Aniridia Centre**](#)
 - Dr Natella Sukhanova
- [**Achievements with Aniridia**](#)
 - [**Sinead Kane**](#)
- Open conversation for all attendees

Aniridia Day 2020 Campaign

We promoted sharing the #AniridiaAids we use.



Aniridia Day 2020 Competition

We promoted international art & video competitions.

UK children were among the winners



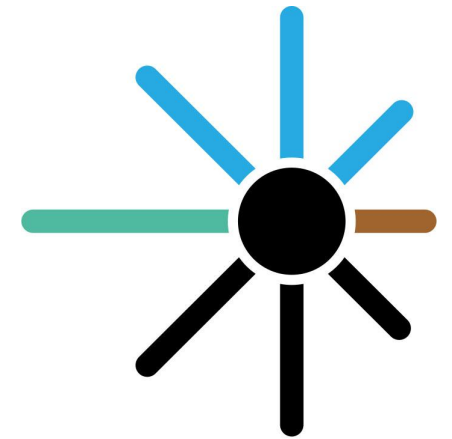
European Aniridia Conference

- Granted €30,000 by Network Support Scheme



Pandemic effects:

- Postponed until summer 2021
- Sponsorship seeking unsuccessful
- Uncertain social distancing and travel restrictions mean it will be online meaning budget agenda and interactions will be revised.



European **Aniridia**
Conference

Finance & Funding

Finances 2020/21

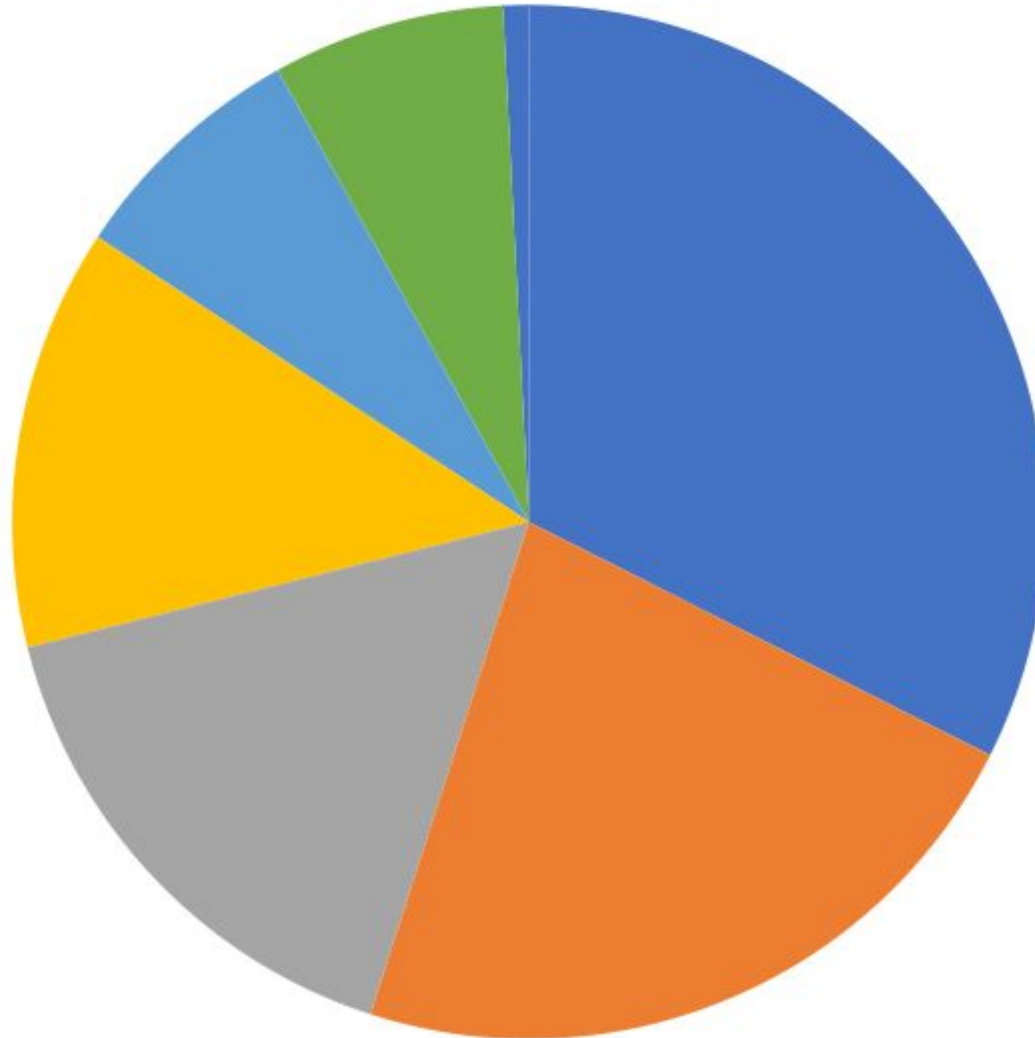
Start of year: £45,400.20

End of year: £49,391.40

Expenditure: £1,402.44

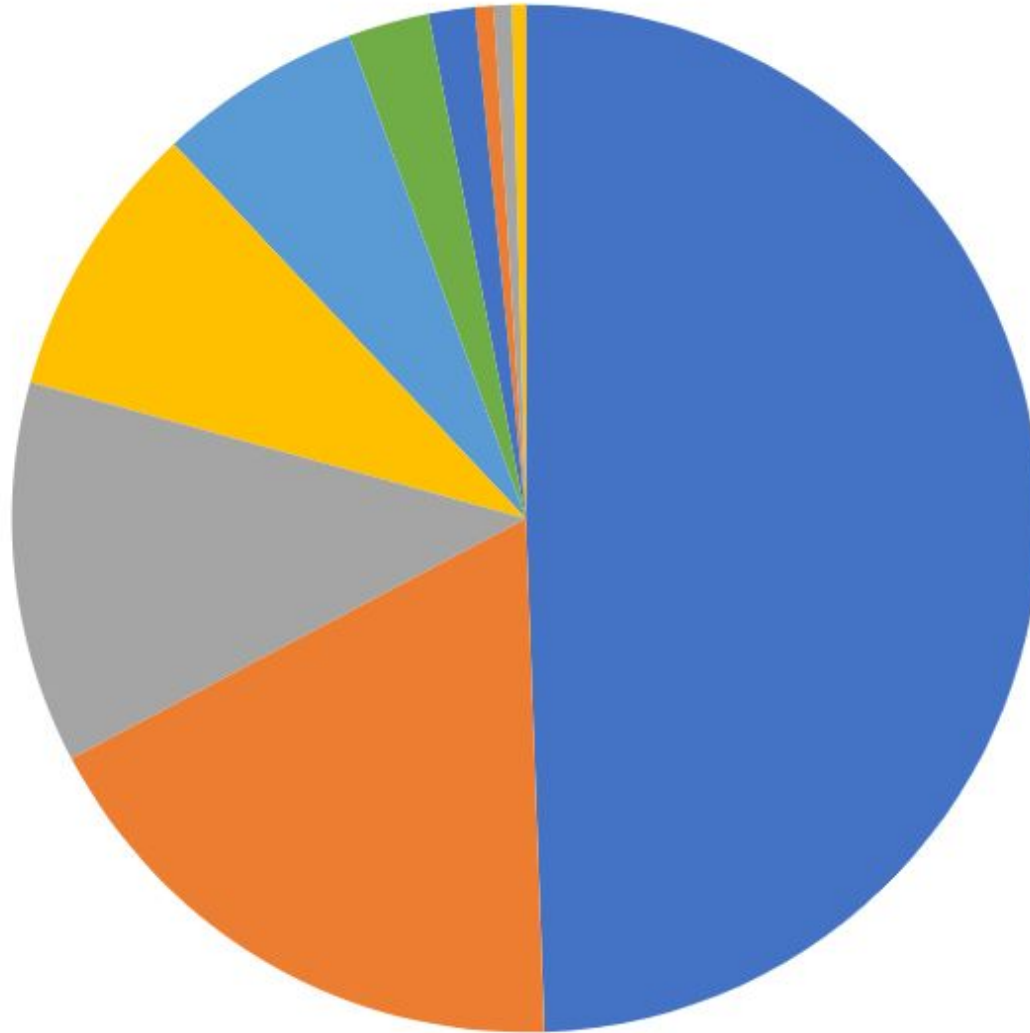
Income: £5,393.64

Expenditure



Category	Amount
Internal Services - IT	£455.03
Website fees	£315.78
Marketing	£226.26
Insurance	£185.00
Membership fees	£107.10
EAC 2020	£102.00
Bank fees	£11.27
Total	£1,402.44

Income



Category	Amount
Donation - CAF Donate	£2,665.84
Donation - Facebook	£962.13
Donations - PPGF	647.82
Donation - Other	£470.00
Donation - Justgiving	£347.18
Donation - Amazon	£136.75
Donation - Everyclick	£78.13
Donations - DSMAC	31.6
Donations - CafePress	30.68
Donation - DONR	£23.50
Total	£5,393.63

Notes

Income still generated from direct debits, donations, royalties and commissions.

Overall costs remained low due to COVID-19 pandemic

Independent examination

Passed



CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's
report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
Aniridia Network

On accounts for the year
ended

31st March 2021

Charity no
(if any)

1176792

Set out on pages

1-4

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31 / 03 / 2021**.

Responsibilities and
basis of report

As the charity trustees of the Trust, 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 Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed 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 material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

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

Signed:

Date:

26/07/2021

Name:

Paul Haggan

Address:

Sittingbourne

Kent

Communications & Membership

Membership/Supporter statistics

Category	People	Increase since 2020	
Familial aniridia	192	8	4.2%
Sporadic aniridia	181	7	3.9%
Aniridia but origin unknown	84	-3	-3.6%
Total with aniridia	457	12	2.6%
Traumatic aniridia	2	0	0%
WAGR	45	0	2.8%
None/unknown	399	11	2.8%
Total	903	23	2.5%

- Rate of increase has slowed
- New registrations are usually families with newborn cases of aniridia.
- There are an estimated 1400 people with aniridia in the UK. So we know about a third of them

Website

- 11103 page views (down 6%)
- 5626 visitors (down 10%)
- 11 blog posts

Top blog posts:

- Gene.Vision website launch
- Rhiannon's Story



The screenshot shows the Aniridia Network website. At the top right is the logo with the text "Aniridia Network". Below it is a navigation menu with links: Home, Blog, Events, About us, Services, Support us, About Aniridia, Links. The main content area features a header for "European Aniridia Conference 2020" dated "July/August 2021 in London". A link "Visit the European Aniridia Conference website" is provided. The text describes the conference as a forum for discussing the medical aspects of aniridia. A quote from a Consultant Ophthalmologist is included: "There are a number of exciting possibilities for the treatment of aniridia now arising from research. The conference will examine the possibilities and how the research in areas such as stem cell therapy and drugs might move from the lab to the clinic." Below the quote, it states "Growing understanding of aniridia is challenging, due to the limited and distributed patient population, its highly variable impact on people and the complications of linked conditions." At the bottom, it says "So every 2 years, in a different city." On the right side, there is a search bar, a "Join us" button with a group of people icon, a "Subscribe" section with an email input field and a "Send me notifications" button, and a "Support us" section with a list of options: "Donate once or regularly by card/direct debit/Paypal", "Create your own fundraising page on JustGiving or Everyclick", and "Sell on eBay and donate a percentage". The eBay logo is visible at the bottom right.

Email newsletter

- 4 mails sent
- Improved accessibility
- Statistics for New Year 2021 newsletter:

492 emails were sent



152 emails were opened



29 contacts clicked



Social media

- Monitored and promoted mentions of ‘aniridia’
- Promoted and engaged in Aniridic Family group on Facebook
- Regular reminders about membership, fundraising and volunteering
- Young Aniridics ‘takeover’ for Rare Disease Day 2021



Twitter

865 followers
up 5% on 2020



Aniridia Network @AniridiaNetUK · Feb 2

Want to present or run a session online at this year's international aniridia conference?

Get in touch!

Scientific and people focused topics all welcome.

Please RT

2020.aniridiaconference.eu/call-for-paper...

#RareDisease #VI #Genetics #PAX6 #EuroAniridiaConf



1



1

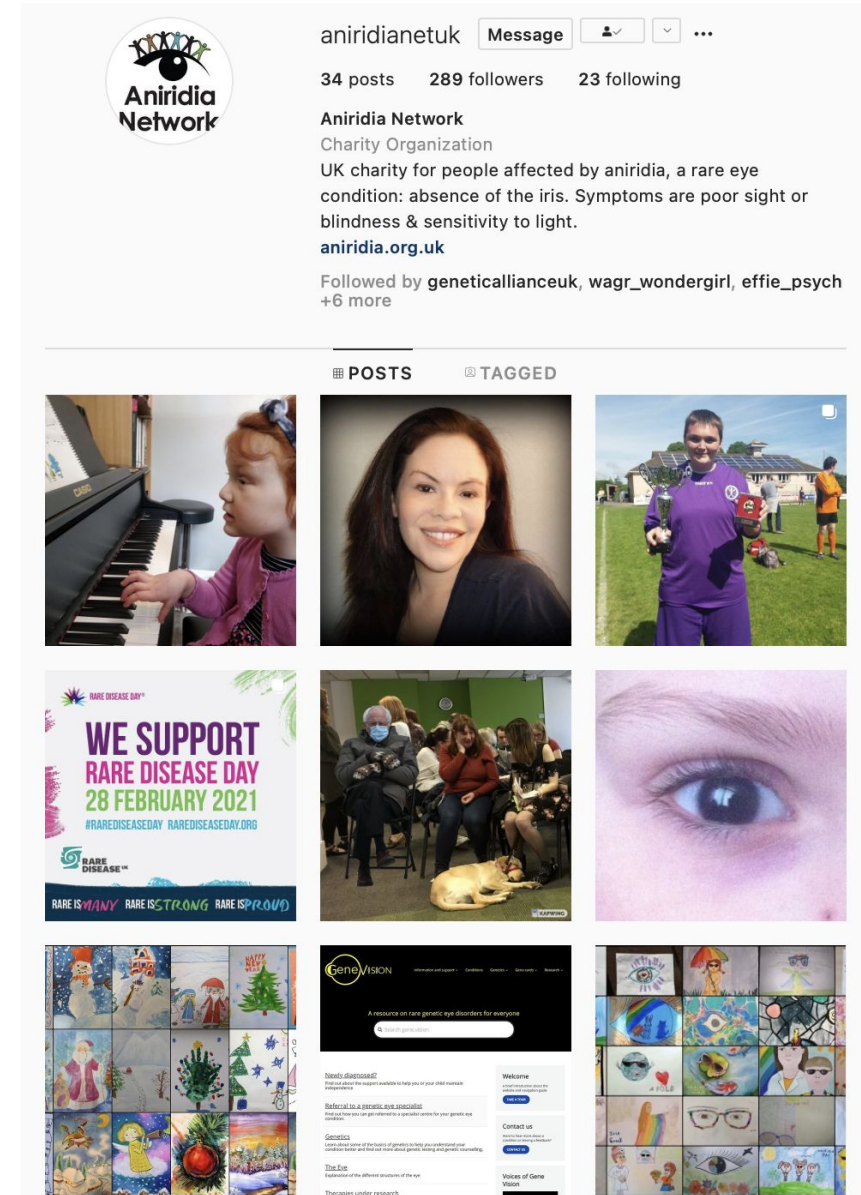


Site	2016-17	2017-18	2018-19	2019-20	2020-21	Year on year increase									
						2016-17		2017-18		2018-19		2019-20		2020-21	
Facebook	779	850	951	1023	1063	74	10%	71	9%	101	11%	72	7%	40	4%
Twitter	679	718	758	820	865	82	14%	39	6%	40	5%	62	8%	45	5%

Instagram

- 289 followers (up 117%)
- 34 posts
- Following 23 organisations & individuals

Focus of the Young Aniridics takeover for #RareReality campaign for #RareDiseaseDay

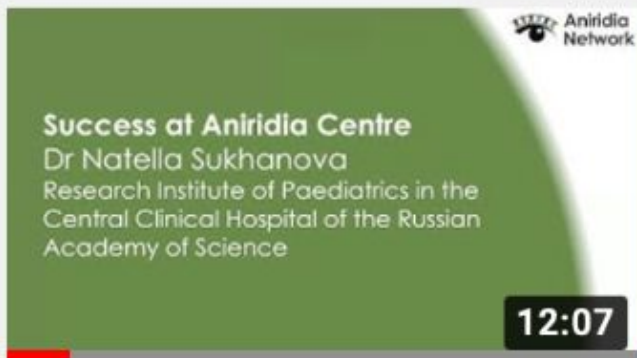


The screenshot shows the Instagram profile for Aniridia Network. The profile picture is the organization's logo. The bio identifies it as a UK charity for people with aniridia, providing the website aniridia.org.uk. It lists 34 posts, 289 followers, and 23 organizations followed. The main content area displays a grid of posts, including a young girl playing piano, a woman's portrait, a man in a purple shirt, a 'Rare Disease Day' poster, a group of people with a dog, a close-up of an eye, a holiday-themed collage, a 'GeneVISION' website snippet, and another collage of eye-related illustrations.



Youtube

- Published 4 videos with captions
- 187 subscribers (up 31)



Success At Russian Aniridia Centre

41 views • 8 months ago

Subtitles



"But You Don't Look Blind?" - Growing Up With An Invisibl...

57 views • 9 months ago

Subtitles



Dry Eye Disease & Aniridia

101 views • 9 months ago

Subtitles



Annual General Meeting 2020 of Aniridia Network

48 views • 10 months ago

Subtitles

Facebook

1063 followers

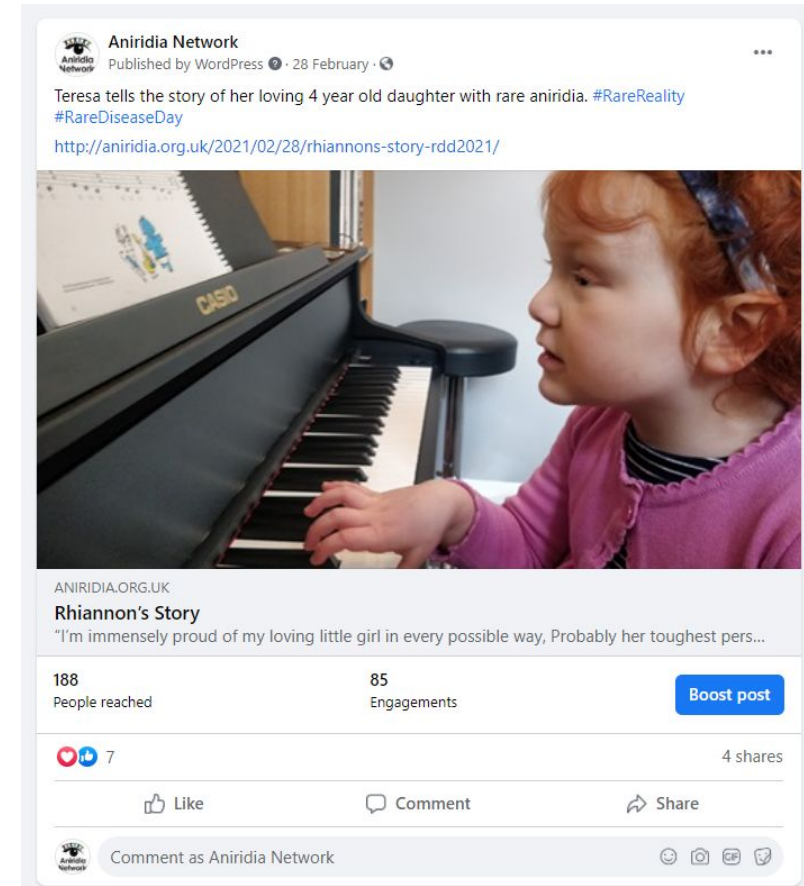
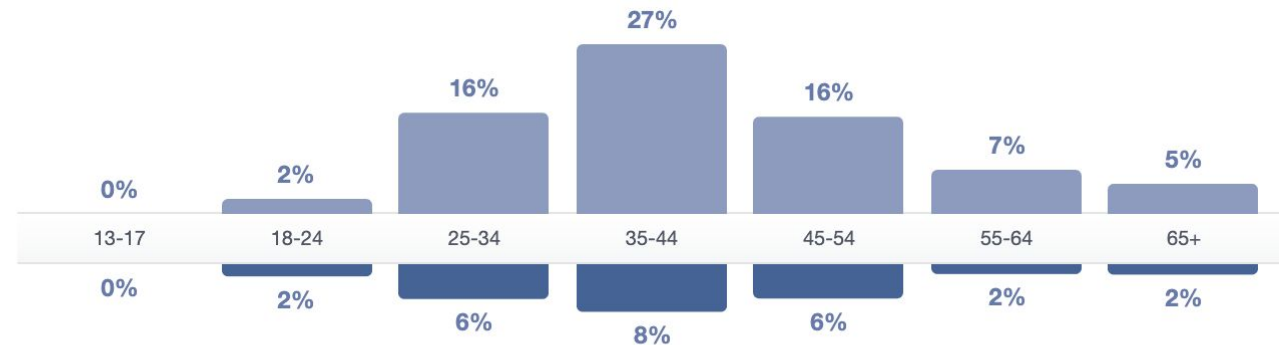
- +40 since 2020 [+ 4%]
- 79% aged 25-54 [+20%]
- 521 (49%) in UK [- 1%]
- 213 (20%) in USA [+ 1%]
- 74% women
24% men

Women

■ 74%
Your followers

Men

■ 24%
Your followers



Collateral

We have printed:

- business cards, some with braille
- stall tablecloth
- pop-up banners



Volunteering & Development

Donations and commissions

We raise funds online and through regular donations.

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

- Commissions include:
 - Give as You Live (£78)
 - Amazon Smile (£136)
 - Humble Bundle
 - Christmas Cards
 - Online shop
- Several people generously continue to make regular donations and lump sums came from Veronica and Lyn & Peter
- Due to the pandemic there were no feasts and so no income from sponsorships

Volunteer induction

Aaron devised an online booklet to aid the onboarding of new volunteers



Volunteer Induction Pack



www.aniridia.org.uk
info@aniridia.org.uk

Volunteers thanks

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

- Aaron Lee
- Clive Matthews
- Emily Nash
- Gavin Fox
- Glen Turner
- Keith Spink
- Nikki Hall
- Lyn Buller

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

Deferment of trustee retirement

As there were no resolutions or new trustee nominations for the AGM 2020, the only other agenda item was to be a vote to reappoint Katie Atkinson as a trustee. It was her turn to 'retire' under a rotation system, despite serving only 2 years of a normal 3-year term.

An in-person meeting was not possible due to the government restrictions to control the COVID-19.

The trustees looked at the practicalities of holding an election by post and email. They concluded that a postal vote would be difficult to run efficiently, cheaply and fairly. They also considered the Charity Commission guidance on cancelling AGMs and the context of the currently 4 out of 5 filled trustee posts.

As a compromise, the board decided to hold the meeting online but waive the requirement for Katie to retire this year. This avoids a vote but still puts the team up for scrutiny.

We hope members will understand this choice, which was not made lightly. We welcome questions or comments about it.

Members & Supporters

We are taking steps to clarify the status of our contacts as supporters or voting members and enabling them to vote remotely in our next annual general meeting.

Trustee board

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

- Katie Atkinson
- James Buller
- Eleanor Burke
- Dave McKay

Additional people would be very welcome.

Management roles

- Head of Communications & Membership
James Buller
- Head of Services & Information
Katie Atkinson
- Head of Conferences & Fundraising
Dave McKay



Charity Name Aniridia Network	No (if any) 2
---	------------------

Receipts and payments accounts

For the period from	1/4/2020	To	31/3/2021
---------------------	----------	----	-----------

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 £
A1 Receipts				
Donation - Amazon	137	-	-	137
Donation - CAF Donate	2,666	-	-	2,666
Donation - Justgiving	347	-	-	347
Donation - DD	-	-	-	-
Donation - GAYL and EC	78	-	-	78
Donation - DONR	24	-	-	24
Donations - PPGF/CafePress/DSMAC	710	-	-	710
Donation - Other	470	-	-	470
Donation - Facebook	962	-	-	962
HMRC Gift aid claim	-	-	-	-
EAC 2020	-	-	-	-
Jun 19 Conf	-	-	-	-
Sub total (Gross income for AR)	5,394	-	-	5,394
A2 Asset and investment sales, (see table).				
	-	-	-	-
	-	-	-	-
Sub total	-	-	-	-
Total receipts	5,394	-	-	5,394

A3 Payments

Running costs	1,063	-	-	1,063
Marketing	226	-	-	226
Bank fees	11	-	-	11
June 2019 Conf		-	-	-
Trustee expenses		-	-	-
EAC 2020	102	-	-	102
		-	-	-
		-	-	-
Sub total	1,402	-	-	1,402

A4 Asset and investment purchases, (see table)

		-	-	-
	-	-	-	-
Sub total	-	-	-	-

Total payments	1,402	-	-	1,402
-----------------------	--------------	----------	----------	--------------

Net of receipts/(payments)	3,991	-	-	3,991
A5 Transfers between funds	-	-	-	-
A6 Cash funds last year end	45,400	-	-	45,400
Cash funds this year end	49,391	-	-	49,391

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

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £
B1 Cash funds	Lloyds Bank account	49,179	-
	Paypal	182	-
	PayPal (held as \$ value in £)	31	-

Total cash funds	49,391	-
-------------------------	---------------	----------

(agree balances with receipts and payments account(s))

OK

OK

Unrestricted funds
to nearest £

Restricted funds
to nearest £

B2 Other monetary assets

Details

Details	Unrestricted funds to nearest £	Restricted funds to nearest £
	-	-
	-	-
	-	-
	-	-
	-	-
	-	-

B3 Investment assets

Details

Details	Fund to which asset belongs	Cost (optional)
		-
		-
		-
		-
		-

B4 Assets retained for the charity's own use

Details

Details	Fund to which asset belongs	Cost (optional)
Fundraising equipment	100	-
Comms equipment	800	-
		-
		-
		-
		-

		-
		-
		-

B5 Liabilities

Details	Fund to which liability relates	Amount due (optional)
		-
		-
		-
		-
		-

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name
	James Buller

CC16a



Last year

to the nearest £

111
2,292
2,973
1,464
149
1,461
2,703
1,214
2,134
873
15,375

-
-

15,375

892
2,937
89
536
-
-
4,453

-

4,453

10,921
-
34,479
45,400



**Endowment funds
to nearest £**

-
-
-

0

-

OK

Endowment funds

to nearest £

-
-
-
-
-
-

Current value (optional)

-
-
-
-
-

Current value (optional)

-
-
-
-
-
-

-
-
-

**When due
(optional)**

**Date of
approval**

12/9/2021



Charity Name Aniridia Network	No (if any) 2
---	------------------

Receipts and payments accounts

For the period from	1/4/2020	To	31/3/2021
---------------------	----------	----	-----------

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 £
A1 Receipts				
Donation - Amazon	137	-	-	137
Donation - CAF Donate	2,666	-	-	2,666
Donation - Justgiving	296	-	-	296
Donation - DD	-	-	-	-
Donation - GAYL and EC	78	-	-	78
Donation - DONR	24	-	-	24
Donation - Other	3,367	-	-	3,367
Donation - Facebook	962	-	-	962
HMRC Gift aid claim	-	-	-	-
EAC 2020	-	-	-	-
Jun 19 Conf	-	-	-	-
Sub total (Gross income for AR)	7,528	-	-	7,528
A2 Asset and investment sales, (see table).				
	-	-	-	-
	-	-	-	-
Sub total	-	-	-	-
Total receipts	7,528	-	-	7,528

A3 Payments

Running costs	748	-	-	748
IT costs	336	-	-	336
Website subscriptions	307	-	-	307
June 2019 Conf		-	-	-
Trustee expenses		-	-	-
Bank fees	11	-	-	11
EAC 2020		-	-	-
	-	-	-	-
	-	-	-	-
Sub total	1,402	-	-	1,402

A4 Asset and investment purchases, (see table)		-	-	-
	-	-	-	-
Sub total	-	-	-	-

Total payments	1,402	-	-	1,402
-----------------------	--------------	----------	----------	--------------

Net of receipts/(payments)	6,126	-	-	6,126
A5 Transfers between funds	-	-	-	-
A6 Cash funds last year end	45,400	-	-	45,400
Cash funds this year end	51,526	-	-	51,526

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

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £
B1 Cash funds	Lloyds Bank account	49,179	-
	Paypal	182	-
		-	-
	Total cash funds	49,361	-

(agree balances with receipts and payments account(s))

Agreement Error
Unrestricted funds
to nearest £

OK
Restricted funds
to nearest £

B2 Other monetary assets

Details

Details	Unrestricted funds to nearest £	Restricted funds to nearest £
	-	-
	-	-
	-	-
	-	-
	-	-
	-	-

B3 Investment assets

Details

Details	Fund to which asset belongs	Cost (optional)
		-
		-
		-
		-
		-

B4 Assets retained for the charity's own use

Details

Details	Fund to which asset belongs	Cost (optional)
Fundraising equipment	100	-
Comms equipment	800	-
		-
		-
		-
		-
		-

		-
		-

B5 Liabilities

Details	Fund to which liability relates	Amount due (optional)
		-
		-
		-
		-
		-

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name
	Emily Nash

CC16a



Last year

to the nearest £

111
2,292
2,973
1,464
149
1,461
2,703
1,214
2,134
873
15,375

-
-

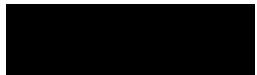
15,375

892
2,937
89
536
-
-
4,453

-

4,453

10,921
-
34,479
45,400



Endowment funds

to nearest £

-
-
-
-

- 2,166

OK

Endowment funds

to nearest £

-
-
-
-
-
-

Current value (optional)

-
-
-
-
-

Current value (optional)

-
-
-
-
-
-
-

-
-

**When due
(optional)**

**Date of
approval**

19/5/2020