



Aniridia Network

Aniridia Network Annual Report 2019/2020 1 April - 31 March

Web: aniridia.org.uk

Email: info@aniridia.org.uk

Twitter: [@AniridiaNetUK](https://twitter.com/AniridiaNetUK)

Facebook: [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

Services & Information

Enquiries & Information

- 6 enquiries by email and others on social media asking about:
 - Personal Independence Payments
 - Speech with WAGR
 - Iris implants
 - Indoor lighting advice
- Promoted the Rare Reality campaign for Rare Disease Day



Consultation on artificial iris implants

NICE have been developing guidance for the use of artificial iris implants in patients with aniridia.

- June 2019: Aniridia Network invited to submit views on the procedure.
- October 2019: Volunteer Mary Cox attended first meeting of NICE medical advisory committee to observe the discussion.
- November 2019: Draft guidance published and public consultation opened. We wrote a blog post publicising public consultation.
- March 2020: Second meeting of medical advisory committee scheduled. It and publication of the finalised guidance was put on hold due to COVID19.

Education

- Requests for our aniridia pupil passports
 - 8 from members
 - 2 from teachers for the visually impaired
 - 1 from Romania

Other information sent out includes: links to websites, Early Years Support, and Department for Education documents

- 1 referral to Education Advisor Clive Matthews
- People who post on the Aniridic Family group on Facebook, are contacted by email, if appropriate, and offered further support

Befriending

- . 29 individuals/families made contact with the Befriending Scheme or were contacted when they became members. 10 more than last year.
- . All new members with children are sent our Parent Information
- . 12 did not respond to initial emails on becoming members.
- . 4 requested a buddy and were successfully linked to other families
- . Many families now make contact through the Aniridia Family group on Facebook, which may be why we have fewer requests for the Befriending Scheme.

Gene.Vision

A team at Moorfields is developing a website about rare genetic eye diseases.

We:

- Reviewed text about aniridia
- Advised on accessibility
- Took part in a user research session
- Edited a write-up submitted to a medical journal



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 two major projects during this year:

- ERASMUS+ Project Looking Out For A School For All: early educational inclusion for students with low vision
- COST ACTION: ANIRIDIA-NET: Aniridia networking to address an unmet medical, scientific and societal challenge



Conferences & Events

Conference 2019

- Held on 1 June in Birmingham in a new venue for us. BVSC was very accessible, but attendance was lower.
 - 55 attendees
 - Half went to the social evening for dinner at Radisson Blu
- 97% satisfaction rating
- Speakers included:
 - Dr Nagozi, GOSH
 - Simon Hayhoe, Bath University
 - members Miriam, Glen & Eleanor
- A great time was had by all.



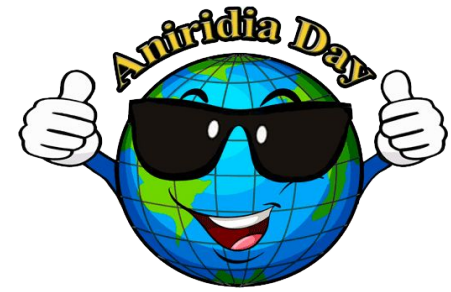


Meet Ups

34 people attended gatherings
arranged by:

- Eleanor
 - Dublin
 - Edinburgh
- James and Glen
 - London Victoria
 - London Kensington

Aniridia Day 2019

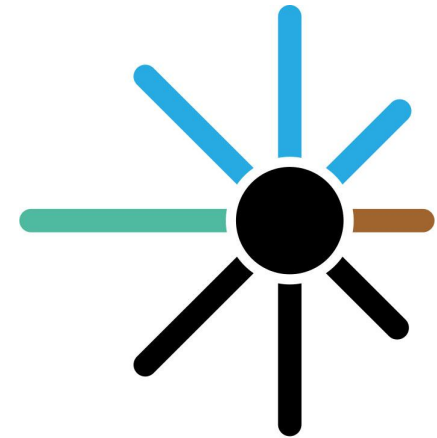


- Held meet-ups in London and Dublin
- Participated in #CanDoWithAniridia social media campaign
- Promoted logo addition to profile picture on Facebook and Twitter
- Launched international online shop



European Aniridia Conference hosting

- Planned to host the 5th of this biannual scientific event on 14-16 August 2020
- Efforts to secure sponsorship had not yet been successful
- All arrangements were made and ticket sales about to begin when COVID-19 lockdowns began
- Consulted with trustees, scientific committee and Aniridia Europe to decide to postpone, probably until Summer 2021
- Plan to hold webinars on Aniridia Day 21 June in the meantime.



European **Aniridia**
Conference

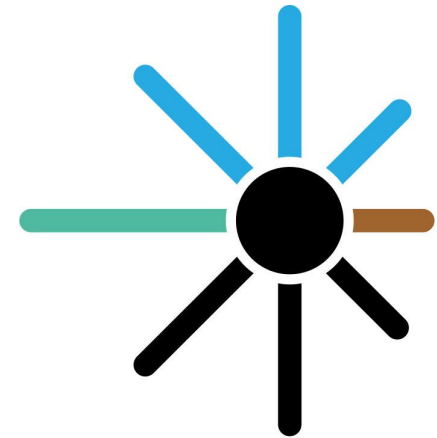
Funding for European Aniridia Conference



Applied for €30,000 from the Network Support Scheme of the European Joint Programme on Rare Diseases, to fund:

- event venue and catering
- travel and accommodation for delegates from underrepresented european countries

Aniridia Network (James, Veronica and Nikki) wrote the bid supported by 9 co-applicants, a mix of patient group leaders and researchers from across Europe.
Awaiting decision.



European **Aniridia**
Conference



Cornea Connect 2019

5 members attended an open day at UCL Institute of Ophthalmology for cornea researchers, doctors and patients. Included:

- Presentations from Sajjad Ahmad and Carla Sanchez Martinez
- Georgina spoke about life and a daughter with aniridia involving 23 operations
- Demonstrations what laboratory research is being done and how
- 'What should be researched?' focus group





2019 WAGR Weekend UK

James attended and presented at the International WAGR Syndrome Association meeting in Cambridge

Genetic Alliance UK Conference 2019

Katie and James
attended seminars
and represented us
at the Annual
General Meeting

Made a useful
contact at PTC
Therapeutics UK.



Communications & Membership

Membership statistics

Category	Members	Increase since 2019	
familial aniridia	184	13	7%
sporadic aniridia	174	12	7%
aniridia but origin unknown	87	-3	-3%
Total with aniridia	445	22	5%
Traumatic aniridia	2	0	0%
WAGR	45	5	11%
None/unknown	388	14	4%
Total	880	41	5%

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

Membership commentary

- We estimate about a quarter of people with aniridia in the UK have contacted Aniridia Network.
More may have accessed our information without us knowing.
- New members are usually families with newborn cases of aniridia.
- Growth rate has been roughly the same for the past 3 years
- James continues to manage membership but we need a dedicated volunteer to recruit and retain members.

Website

- 11800 page views
- 6222 visitors
- 24 blog posts

Down 11%

Top blog posts:

- Research into aniridia symptoms link to genetics
- Testing if drugs can improve cornea regeneration



Aniridia Network

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

[← Consultation on artificial iris implants guidance: have your say](#)

[Rare Disease Day 2020 Meetup →](#)

Testing if drugs can improve cornea regeneration

Posted on [January 6, 2020](#) by [docmartin2mc](#)

By researcher Martin Collinson

Aniridia, caused by mutation in the so-called eye 'master regulator gene', PAX6, can impact on vision in several ways. In addition to the absence or near-absence of the iris, people with aniridia are at high risk of cataract (cloudy lenses) and glaucoma.



One of the most intractable problems however is the deterioration of the front surface of the eye, the cornea, which can occur over time, leading to inflammation, opacity and irritation. Conventionally, this corneal deterioration ('aniridia-related keratopathy' or ARK) is treated as a failure of the stem cells that maintain the corneal epithelial surface, and transplant of stem cells can improve vision, at least for a while.

However, there is a lot more going on: the corneal surface of people with aniridia is typically more fragile than found in the general population. Not only is it more likely to suffer small recurrent abrasions, it is also slower at repairing wounds, and metabolically slightly less able to respond to environmental stress. Corneas have fantastic powers of regeneration, but this 'triple-whammy' means that over time, the corneas of people with aniridia do tend to deteriorate, and there is no cure.

Email broadcasts

- Provider CharityeMail shut down
- We migrated to Charity Digital Mail
- 4 mailings sent
- Statistics for latest:

496 emails were sent



180 emails were opened



41 contacts clicked



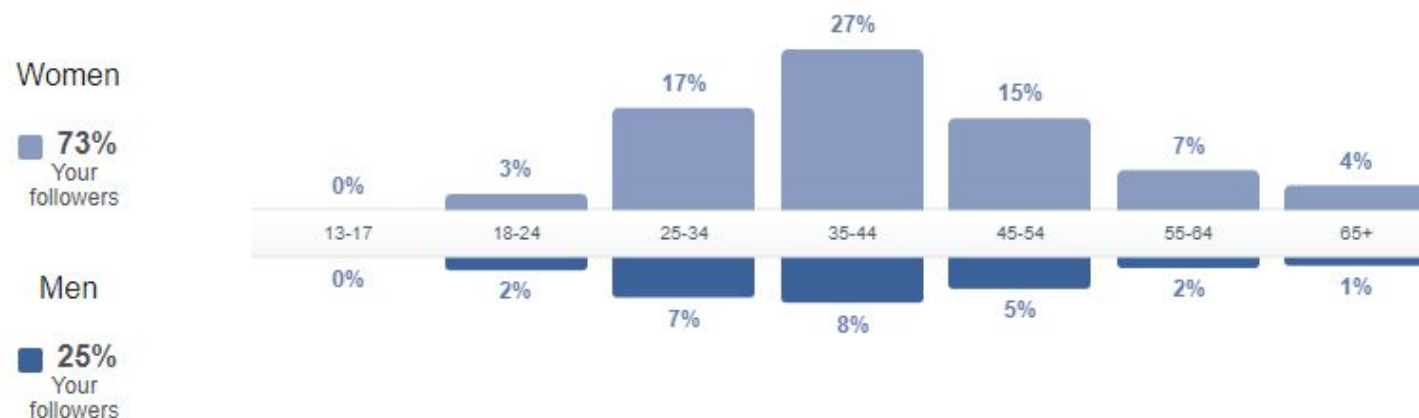
Social media

- Monitored and promoted mentions of 'aniridia'
- Promoted and engaged in Aniridic Family Facebook group
- Regular reminder posts for setup about fundraising and volunteering
- Live posting from Conference 2019

Facebook followers

1023 followers

- +72 since 2019 [+7%]
- 59% aged 25-54 [unchanged]
- 520 (51%) in UK [+1%]
- 192 (19%) in USA [+1%]
- 73% women
25% men



Facebook posts

Engagement

- 1324 reactions
- 481 shares
- 134 comments

Post types

- 60 photos
- 20 videos
- 62 links
- 128 statuses

The screenshot displays the Facebook profile of the Aniridia Network. The profile picture features a logo with stylized figures holding hands above the text 'Aniridia Network'. The page name is 'Aniridia Network' with the handle '@AniridiaNetworkUK'. A sidebar on the left lists navigation options: Home, Posts, About, Reviews, Photos, Videos, Flickr, Poll, Events, Community, Fundraisers, and Groups. A green 'Create a Page' button is visible below the sidebar.

The main feed shows two posts from the Aniridia Network page:

- Post 1:** Dated 15 April at 12:05. The text reads: 'Two things taught Fern about insecurity - being blind due to aniridia and online dating. Watch her amazing TEDx talk. <http://aniridia.org.uk/2020/04/15/insecurity-and-aniridia/>'. The post includes a video thumbnail of a woman on stage. Engagement shows 'Andrew Edwards and 1 other' liked it. Interaction buttons for Like, Comment, Share, and Buffer are present, along with a comment input field.
- Post 2:** Dated 14 April at 11:33. The text reads: 'Take part in a sleep and visual impairment health study to help #CircadianTherapeutics learn more about the effects of aniridia. <http://aniridia.org.uk/.../sleep-and-visual-impairment-health.../>'. The post includes a photo of a city skyline at sunset. Engagement shows 'Haya Hassan and 6 others' liked it, with '1 comment' and '7 shares'. Interaction buttons for Like, Comment, Share, and Buffer are present.

Twitter

820 followers
up 8% on 2019



Aniridia Network @AniridiaNetUK · Feb 29

Mariya and her team are doing fantastic scientific research into aniridia. Find out more at aniridia.org.uk/tag/research/ Thank you all #RareDiseaseDay



Mariya Moosajee @MariyaMoosajee · Feb 28

#Aniridia affects the whole eye with an underdeveloped iris & retina, nystagmus, glaucoma, cataracts & corneal scarring. Caused by mutations in the #PAX6 gene. Dulce Cunha & Vivienne Kit are studying disease history and testing new drugs @AniridiaNetUK #RareDisease @EyeCharity



1

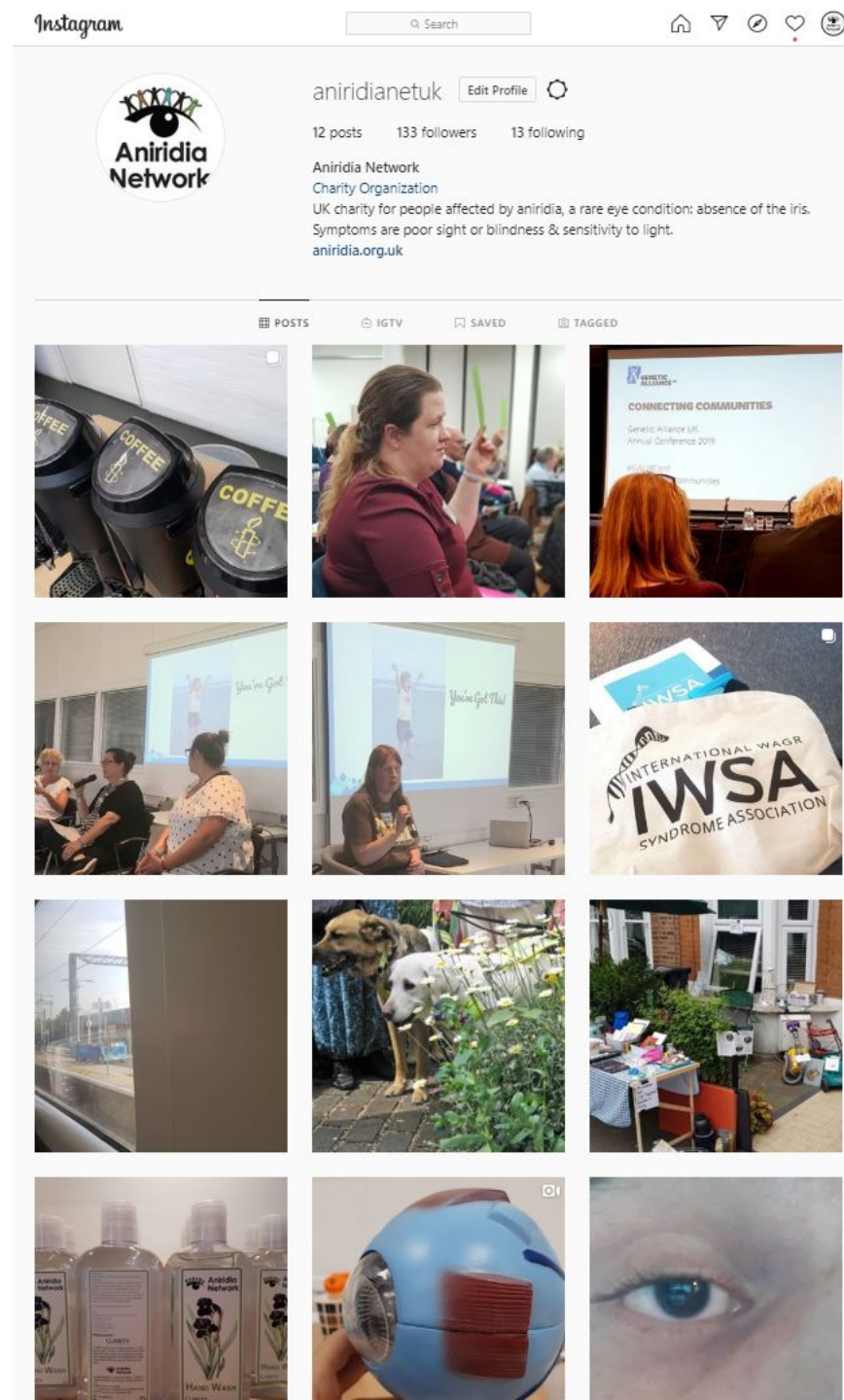
5



Site	2015/16	2017/18	2018/19	2019/20	Year on year increase									
					2015-16		2016-17		2017-18		2018-2019		2019-20	
Facebook	705	850	951	1023	98	16%	74	10%	71	9%	101	11%	72	7%
Twitter	597	718	758	820	80	15%	82	14%	39	6%	40	5%	62	8%







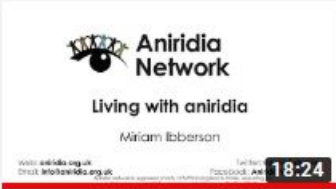
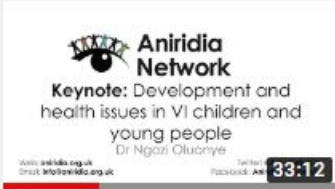




Instagram

- Started a profile
- 133 followers
- 12 posts
- Following 13 other organisations



YouTube

- Published 12 videos with captions
- 156 subscribers (up 45)

 <p>Codwr arian Nofio Sianel Traws Saesneg ar gyfer pob...</p> <p>5 views • 5 months ago</p> <p>Subtitles</p>	 <p>Cross Channel Swim fundraiser for people aniriid...</p> <p>11 views • 5 months ago</p> <p>Subtitles</p>	 <p>Aniridia Network My baby hasn't opened her eyes Eleanor Burke</p> <p>130 views • 6 months ago</p> <p>Subtitles</p>	 <p>Aniridia Network Inclusive technologies to help VI people Dr Simon Hayhoe</p> <p>61 views • 6 months ago</p> <p>Subtitles</p>	 <p>Aniridia Network Meeting the unmet need Special educational needs of VI children Clive Matthews</p> <p>57 views • 6 months ago</p> <p>Subtitles</p>	 <p>Aniridia Network Growing in confidence with aniridia Glen Turner</p> <p>62 views • 7 months ago</p> <p>Subtitles</p>
 <p>Aniridia Network Living with aniridia Miriam Ibberson</p> <p>38 views • 7 months ago</p> <p>Subtitles</p>	 <p>Aniridia Network Keynote: Development and health issues in VI children and young people Dr Ngazi Oluonye</p> <p>78 views • 8 months ago</p> <p>Subtitles</p>	 <p>Aniridia Network Aniridia Network Annual General Meeting 2019 By the Trustee Board</p> <p>50 views • 10 months ago</p> <p>Subtitles</p>	 <p>Living With Aniridia - Georgina Clements - Cornea...</p> <p>93 views • 10 months ago</p> <p>Subtitles</p>	 <p>Stem Cell Research & Aniridia - Sajjad Ahmed - Cornea...</p> <p>160 views • 10 months ago</p> <p>Subtitles</p>	 <p>Aniridia Network Conferences</p> <p>140 views • 1 year ago</p> <p>Subtitles</p>

Volunteering & Development

Volunteers

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

Volunteers

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

- Clive Matthews
- Glen Turner
- Gavin Fox
- Liz & Robin Atkinson
- Lyn & Peter Buller
- Emily Nash
- Keith Spink
- Robert Meikle
- Veda Petre
- Zoe Kilb
- Mary Cox

Volunteers gift

Following a stock donation from Clarity, and labels design by Gavin Fox, we thanked volunteers with a present of 'Iris' hand wash.



Fundraising

£14,500 income this year.

Thanks to everyone who gave so generously including via birthday celebrations on Facebook.

Boosted by a claim for Gift Aid due on donations made in the years before 2018.

Some funds allocated to running the European Aniridia Conference.

Sponsored feats

£2,629 Nicola's English Channel swim

£1,065 Teresa et al cycling

£732 Edwards half marathon



Kieron's 100km Thames Path run raised £900 for aniridia research via Fight For Sight

Christmas Cards

- Raised £90 for European Aniridia Conference by selling e-cards on DontSendMeACard.com.
- Designs by children with aniridia across Europe
- Investigated potential to sell paper cards



Donations and commissions

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

- £1,464 Regular giving through Direct Debits
- Lump sums from Veronica and Lyn & Peter
- Commissions
 - Give as You Live (£148)
 - Amazon Smile (£111)
 - Humble Bundle

Online shop

Launched an print-on-demand online shop

- Gets merchandise featuring our logo into supporters hands with zero effort
- Earns a little revenue

Men's Shirts

(back to top)



[Aniridia Network logo & URL T-Shirt](#)
\$15.70



MORE COLORS AVAILABLE
[Aniridia Network logo & URL Long Sleeve T-Shirt](#)
\$20.99



MORE COLORS AVAILABLE
[Aniridia Network logo & URL T-Shirt](#)
\$16.79



MORE COLORS AVAILABLE
[Aniridia Network logo & URL Baseball Jersey](#)
\$24.10



[Aniridia Network logo & URL Golf Shirt](#)
\$19.89



MORE COLORS AVAILABLE
[Aniridia Network logo & URL T-Shirt](#)
\$18.89



MORE COLORS AVAILABLE
[Aniridia Network logo & URL T-Shirt](#)
\$16.79



MORE COLORS AVAILABLE
[Aniridia Network logo & URL T-Shirt](#)
\$21.99



Governance

Trustee Board

- Dave and Sarah were elected to at the 2019 AGM
- However Sarah later left the Board
- We would like to thank our trustees for their work over the year:
 - Katie Atkinson (Chair)
 - Dave McKay (Treasurer)
 - James Buller
 - Eleanor Burke

Management Roles

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



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
Aniridia Network

No (if any)
2

CC16a

Receipts and payments accounts

For the period
from

1/4/2019

To

31/3/2020

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Apr 18 Conf	-	-	-	-	2,305
Jun 19 Conf	873	-	-	873	-
Donation - Justgiving	2,973	-	-	2,973	12,306
Donation - DD	1,464	-	-	1,464	1,590
Donation - GAYL and EC	149	-	-	149	859
Donation - CAF Donate	2,292	-	-	2,292	1,309
Donation - Other	1,461	-	-	1,461	668
Donation - Facebook	2,703	-	-	2,703	-
Donation - Amazon	111	-	-	111	-
EAC 2020	2,134	-	-	2,134	-
HMRC Gift aid claim	1,214	-	-	1,214	-
Sub total (Gross income for AR)	15,375	-	-	15,375	19,037
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	15,375	-	-	15,375	19,037
A3 Payments					
Running costs	892	-	-	892	621
Research	-	-	-	-	7,500
Apr 2018 Conf	-	-	-	-	4,444
June 2019 Conf	2,937	-	-	2,937	475
Trustee expenses	89	-	-	89	569
Joint fundraising	-	-	-	-	660
EAC 2020	536	-	-	536	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	4,453	-	-	4,453	14,269
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	4,453	-	-	4,453	14,269
Net of receipts/(payments)	10,921	-	-	10,921	4,768
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	34,479	-	-	34,479	30,583
Cash funds this year end	45,400	-	-	45,400	35,350

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

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Lloyds Bank account	43,053	-	-
	Paypal	2,348	-	-
		-	-	-
	Total cash funds	45,400	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
	Fundriasing equipment	100	-	-
	Comms equipment	800	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Dave McKay	19/5/2020	