



Minutes of Aniridia Network Annual General Meeting 2019

1 June 2019 – 138 Digbeth, Birmingham, B5 6DR, 11,20am.

Welcome and review of the 2018/19 year

James Buller opened the meeting, outlined the agenda for the meeting and welcomed those attending.

Minutes of previous meeting

The minutes of the 2018 AGM were agreed as an accurate record by the members present.

Matters arising.

There were no matters arising from the agreed minutes.

Reports & Accounts

James Buller, Emily Nash, Katie Atkinson and Lyn Buller presented a summary of the full annual report on behalf of the Trustees:

Services and information:

1. Advised RNIB on revisions to their aniridia factsheet,
2. 7 enquiries received in 2018/19,
3. Successfully appealed a refusal of disability benefits,
4. Thanked those who had made these services possible.

Web: aniridia.org.uk

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

Email: info@aniridia.org.uk

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

Aniridia Network is registered charity (CIO) 1176792 in England & Wales,
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Education

1. Produced an information pack for new parents of people with aniridia. Details of how to receive a copy were given. Copies were available for viewing at the event.
2. 7 information requests received.
3. Clive Matthews joined as Special Educational Needs Adviser and Advocate on the Education team.

Befriending

1. There had been a drop in number of requests.
2. 2 connections made.
3. Helped make a decision about an adoption application/request of a child with aniridia.

Events

1. Conference 2018
 - a) 125 delegates (111 adults, 14 children),
 - b) Positive feedback – survey said 93% satisfaction,
 - c) Goalball introduction session, pizza social evening,
 - d) Thanks to the team involved,
 - e) Suggestions from 2018 implemented for 2019 conference.

Finances

1. The accounts for 2018/19 were presented.
2. Over £12,000 income from fundraising activities, plus Give as You Live, Everyclick, Amazon Smile and regular donations. Thanks to everyone.
3. Expenditure included £7,500 research grant to UCL Institute of Ophthalmology/Moorfields Eye Hospital matched funding with Fight for Sight,
4. The bank account is migrating from CAF to Lloyds Bank.

Communication and membership

1. Aniridia Day 2018:
 - Hosted 12 hours of webinars in 4 languages,
 - Orchestrated #AniridiaSight social media campaign,
 - Meet ups in London and Cardiff,
2. Videos of all Conference 2018 speakers are on YouTube,
3. 839 members – increase of 4%.
423 with aniridia,
40 with WAGR,
4. Sponsored feats ranging from abseiling to cycling raised between £352 and £9,600. Thanks to all fundraisers,

Volunteering

1. Thank you to all our volunteers, Bottles of 'Aniridia Soap' were given out. They were donated by a social enterprise and the labels designed by Gavin Fox.
2. 2 new volunteers recruited.

Governance

1. Migration to new charity form 'Charitable Incorporated Organisation' completed,
2. Policies being created and published on our website – some have been uploaded (equal opportunities, anti-bullying, communications, complaints/grievance) and some are being worked on,

Questions to trustees

Members were invited to ask the Trustees about the year under review. No questions were raised.

Appointment of trustees

1. 2 spaces exist on the board, as two trustees are stepping down:
 - 1.1. Emily Nash – Treasurer,
 - 1.2. Martin Fleming – Head of volunteering.
2. 2 nominations have been received for the 2 available trustee roles:
 - 2.1. Dave McKay.
 - 2.2. Sarah Matthews.
3. The meeting voted to appoint Dave McKay and Sarah Matthews as trustees.

Resolution: Membership and governance of Aniridia Network

Dave McKay invited the meeting to debate and vote on which of the two options below the trustee board should pursue as preference.

Both options would require the trustees to propose a resolution at a future AGM, to amend the charity constitution. To be successful, that resolution would require members to vote in favour by a 75% majority.

- a) Transform into a trust
- b) Define membership

In addition to pros and cons set out in the resolution James and Katie set out the case for each option:

1. Katie (Define membership) by remaining as a membership the organisation's stakeholders have voting rights, and hence are more involved in running of the charity. This keeps us true to our original aim,
2. James (Transform to a trust)
We have scarce volunteer resources and membership is

complicated and takes a lot of time to administrate. Avoiding this would allow more time to deliver services to members, no need for an AGM would mean more flexibility on the events and better use of resources,

Question:

1. Q: [Eleanor] A household with 4 members vs a person living on their own seems disproportionate when it comes to voting. How can we make it fair?

A: [Katie] We have thus far operated 1 vote per household but we now need to be clearer who has a vote and who is just a subscribed support. If vote is to keep membership the trustees will consult and work out a way to allocate voting rights

2. Q: [Keith] In previous year most votes seem to be carried unanimously, so what are the benefits to continue membership when the votes are symbolic?

A: [Katie] A clearer membership scheme would hopefully encourage everyone to consider more carefully what happens at AGM and encourage more debate and more considered voting. If members want more say and to scrutinise trustees issue in more depth and come to their own decision rather than going with the majority.

3. Q: How would people influence trustees decisions and have their say and hold to account?

A: [James] Through private/public channels for example email or on social media such as asking questions. Under either model the trustees would still be reporting to Charity Commission with an annual return and accounts etc. Complaints could be sent there. This would be on top of our communications to keep you engaged as volunteers and gain new members. We'd still need to have a pathway to become volunteers including trustees.

4. Q: [John] We currently all meet annually to make decisions. A trust would be just a small group making decisions. How will this affect these meetings?

[James] Trustees already meet monthly and make daily and routine decisions. That would continue. These stakeholder meetings could happen in different way. In these meetings we'd probably still give a presentation report but we wouldn't have a vote on appointing trustees or debating constitutional issues. That would be taken care of internally We would inform you and get your input but not formally with votes.

Vote:

1. 8 for Define membership
2. 21 for Transform into a trust

Any other business

No other items of business were raised.

The meeting closed at 12.00.