

# NOTICE OF ANNUAL GENERAL MEETING



NOTICE IS HEREBY GIVEN to members that the Annual General Meeting (AGM) of Genetic Alliance UK for 2018 will be held as follows:

**Venue:** Amnesty International UK, 25 New Inn Yard, London EC2A 3EA

**Date:** 25 September 2018

**Time:** 13:00 - 14:00

The AGM will be held during the lunch break on the day of Genetic Alliance UK's Annual Conference. Members can book their free tickets via Eventbrite:

[eventbrite.co.uk/e/genetic-alliance-uk-conference-2018-tickets-46608444111](http://eventbrite.co.uk/e/genetic-alliance-uk-conference-2018-tickets-46608444111)

Each member organisation is entitled to a single vote on each resolution and voting cards will be issued on the day. Voting on all resolutions will be by 'show of hands'. Lapsed members will not be eligible to vote.

## Agenda

1. Welcome and introductions
2. Apologies for absence
3. Chair's opening remarks
4. Minutes of the AGM held on 26 September 2017.
5. Summary of Trustee Report 2017/18 (Chair)
6. Financial Report 2017/18 (Treasurer)
7. Resolution 1: To consider and, if thought fit, adopt the Accounts of Genetic Alliance UK for the period ended 31 March 2018 and the Reports of the Board of Trustees and Auditors.
8. Resolution 2: To appoint Nyman Libson Paul [Regina House, 124, Finchley Road, London NW3 5JS] as Auditors to hold office until the conclusion of the next General Meeting of Genetic Alliance UK before which Accounts are laid.
9. Resolution 3: To authorise the Trustees to determine the remuneration of the Auditors.
10. Resolution 4: Retiring board members: to endorse a vote of thanks to Mr Christopher Goard, who has completed his term of office as Chair and is not seeking re-election.
11. Resolution 5: To re-elect, if thought fit, the following as a Trustee:
  - a) Rafael Yanez
12. Resolution 7: To elect, if thought fit, the following as Trustees:

Genetic Alliance UK

[contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)

[www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

- a) David Ramsden (Cystic Fibrosis Trust)
  - b) Nic Bungay (Muscular Dystrophy UK)
  - c) Sarah Lewell (Unique)
  - d) Julie Wootton (Max Appeal)
13. Retirement and succession of Chair
  14. Presenting our new strategy (CEO)
  15. **Special Resolution:** To adopt, if thought fit, amendment of Memorandum and Articles of Association (amendments emboldened)

Article 3: The Charity's objects (the objects) for benefit are:

- a) to relieve persons affected by genetic, **and/or rare and/or undiagnosed conditions**;
- b) to advance the education of the public concerning genetic **and/or rare and/or undiagnosed conditions** in such ways as the Trustees of the Charity think fit.

Article 4.1

[the charity has the power to]

4.1 act as an umbrella group to voluntary organisations which are concerned with genetic **and/or rare** conditions.

Article 3 Members

3.3 Membership is open to individuals and patient organisations and not-for profit groups, whether corporate or unincorporated, associated with genetic and/or rare conditions and interested in furthering the work of the Charity who.-

3.3.1 apply to the Charity in the form required by the Trustees; and

3.3.2 are approved by the Trustees.

**Supporting Statement:** We have learned from our membership survey that the strength gained from being part of our wider community is the main reason organisations choose to join Genetic Alliance UK. There are over 6,000 known rare conditions. Research has shown that the majority of rare diseases have an underlying genetic cause or component (current estimates area around 80%). The cause of the remainder is a subject of research, and, in some cases, clear genetic links are being identified. Almost all single gene disorders are rare, and 99% of our members support people with and/or research into rare conditions. This close relationship between rare and genetic conditions is reflected at the level of policy development. It is vitally important that we continue to include those affected by undiagnosed genetic conditions in our work and our community pending diagnosis through clinical services or research. It makes sense that we ensure our work is transparently inclusive of all concerned with genetic, rare and undiagnosed conditions by reflecting the interconnectedness of the work we do in our governing document.

16. Any other business
17. Chair's closing remarks.

By order of the Trustees

A handwritten signature in black ink, appearing to read 'Goard', is written over a light blue horizontal line. The signature is stylized and cursive.

Christopher Goard, Chair of the Trustee Board

**Notes**

- (i) Biographical details of the proposed new Trustees can be downloaded [here](#).
- (ii) The audited accounts of Genetic Alliance UK for the period ended 31 March 2018 can be downloaded [here](#).