



C/- Garvan Institute of Medical Research
Level 6, Room 6.39
384 Victoria Street
Darlinghurst NSW 2010

Phone: **+61 2 9295 8359**
Fax: **+61 2 9295 8181**

Email: info@geneticalliance.org.au

Professional Advisory Committee, Genetic Alliance Australia

Terms of Reference 2019

Background

Genetic Alliance Australia is a peak umbrella group for rare genetic conditions/diseases, so rare they do not have their own support group.

Genetic Alliance Australia (GA) endeavours to facilitate contact between families/individuals affected by the same, or similar condition, and/or provide information about relevant support groups both nationally and internationally. GA also deals with enquiries about services and facilitates ongoing support for individuals, families, health professionals and other interested groups. GA has an extensive rare disease database representing 1400 conditions and over 3500 individuals and families affected by genetic conditions.

Professional Advisory Committee Membership

1. The Professional Advisory Committee members will be members of GA.
2. Committee members will have expertise relevant to the Committee's roles and responsibilities. As a minimum, the Committee membership will include at least one clinical geneticist (medical specialist) and one genetic counsellor.
3. The Committee will have no more than 6 members. Additional members may be co-opted for a finite time to assist in addressing specific issues.

Term of Membership:

Flexible (for example: 1 year, 2 years or more)

Chair:

Elected by Professional Advisory Committee and endorsed by the Board.

Appointment:

By call for nominations taking into account minimum membership requirements or by invitation from the Executive Director and Board (and must be endorsed by the Board).

Role

- The role of the professional advisory committee is to provide an independent source of information and advice to the Executive Director and/or the Board related to clinical genetic conditions and services, strategic issues or risks facing Genetic Alliance
- The advisory committee is not a decision-making forum but may provide nonbinding strategic advice
- The committee is informal and meetings are organised as needed.

Responsibilities

- To act as a resource on professional and patient issues for Genetic Alliance including in clinical genetic services and trends in genetic and genomic health
- To provide “wise counsel” on issues raised by the Executive Director or the Board including exploration of new ideas
- To provide the Executive Director or the Board with insights and ideas and provide a ‘safe’ place to discuss issues of significance
- To encourage continued growth, whilst not stifling the spirit or vision of the original intent of the founding members
- To attend the AGM where possible

Please note:

The names and bios of the committee members will be included on the GA website, annual report and relevant GA publications.