



genetic alliance
australia

An Overview

Jan Mumford

Filling the Void - Grafton

27 July 2018

Genetic Alliance: Who are we?

The 'go-to' organisation in Australia for individuals and their families who are living with one or more genetic conditions for which there is no other support available.



Genetic Alliance: Who are we?

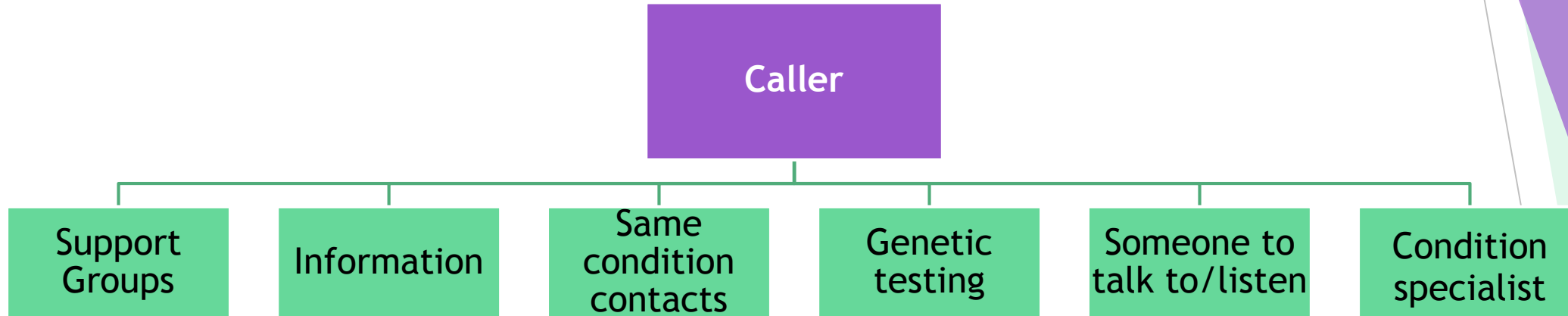
- ▶ Formed in 1988
- ▶ Contact Register is one of the largest in Australia, over 1500 rare genetic conditions represented
- ▶ Located at the Garvan Institute of Medical Research
- ▶ Funding: NSW Health
- ▶ Donations
- ▶ Master of Genetic Counselling Student placements



Enquiries

- ▶ **Field 1000 + calls** a year regarding a rare genetic condition
- ▶ 200+ emails/year
- ▶ A few requests over social media (FB and Twitter)
- ▶ **Who calls?** Mums (the majority of enquiries), Dads, siblings, grandparents, friends and partners about to marry who have a history of some genetic condition in the family paternity testing.
- ▶ Health professionals asking about services available.

How enquiries are directed



Most of our peer support is a combination of the above.

We also maintain an active social media presence and encourage our followers to comment and post regularly

Just to give you an idea...

Some of the recent enquiries that we have come across:

- ▶ Klinefelters syndrome
- ▶ Behcets syndrome
- ▶ Hypophosphatemic Rickets
- ▶ Emery-Dreiffus Muscular Dystrophy
- ▶ PPP2R5D & Schaaf Yang syndrome
- ▶ Duane syndrome
- ▶ Proteus syndrome
- ▶ Maple Syrup Urine disorder
- ▶ SAS/Glass syndrome
- ▶ Dercums disease
- ▶ Chromosome 16p 11.2 del

and many, many more

GA's Activities

- ▶ Individual consultations/counselling
- ▶ Resources relating to education, respite care, medical services and other helpful organisations
- ▶ Rural outreach program – Filling the Void
- ▶ Genetic Information Seminars
- ▶ Annual Genetic Awareness Week
- ▶ Quarterly Leadership meetings
- ▶ Updates via social media


GA's Activities continued

- ▶ Sibling workshops
- ▶ National Health Genomics Forum
- ▶ Human Genetics Society of Australia (HGSA) Meetings
- ▶ Rare Disease Day Activities
- ▶ Condition specific meetings
- ▶ Rare Disease Day activities
- ▶ Representation on research committees
- ▶ Support and networking for other organisations

Conditions List

<http://www.geneticalliance.org.au/conditions.php>

http://www.geneticalliance.org.au/chromosome_conditions.php



Home ▾ About Us ▾ Genetic Conditions & Support ▾ News & Events ▾ Contact

Please note the genetic conditions listed here represent people who have a child or have the condition themselves on our Contact Register. They have contacted GA seeking peer support and information, as well as contact with others who have a child with the same genetic condition.

We have over 3500 people on our Contact Register who are looking for other people affected by the same or similar condition. The link for each condition listed contains details of support groups (national and international), information about certain conditions, as well as contacts for useful services/information regarding that condition.

If we are unable to assist we can always point people who contact us with queries in the right direction plus provide the much needed support after the diagnosis of a genetic condition or are undiagnosed as the case may be.

If you cannot find your condition here, or you would like to add a support group to the list, please contact us directly by phone or email. If you know of a change of contact details for a support group listed here, please contact us so that we can update the website.

Please [click here](#) to view the list of Chromosomal Conditions.

ABCDEFGHIJKLMNOPQRSTUVWXYZ4

A

Aarskog syndrome

Achondroplasia

Acid Maltase Deficiency

Acoustic Neuroma

Acrocallosal Syndrome


Acrodysostosis with Multiple Endocrine Resistance

Acute Necrotizing Encephalopathy (ANE1 or IIAE3)


Adams Oliver syndrome

LATEST TWEETS


Tweets by @GeneticAll_AU

**Genetic Alliance AU**
@GeneticAll_AU

Children with suspected disabilities waiting up to year for diagnosis in parts of Sydney, parents at "breaking point"
abc.net.au/news/2017-02-0...


**Children in 'diag..**
Children with su...
abc.net.au

07 Feb

**Genetic Alliance AU**
@GeneticAll_AU

Last night @60Mins aired a segment on Matthew & Ashleigh Knox who's family carries the BRCA2 gene. Watch here - 9now.com.au/60-minutes/201...

05 Feb

**Genetic Alliance AU**
@GeneticAll_AU

Embed

View on Twitter

OUR MISSION STATEMENT

"To facilitate support for those affected directly or indirectly by genetic conditions throughout Australasia."



Newsletters

- ▶ Quarterly newsletter - posted or emailed
- ▶ Editorials, news, contact corner, events, profile genetic condition, personal stories



Filling the Void

Reducing the Gap by providing support and information to families living in isolation.

- Networking events for patients and health professionals in genetics
- Tele-counselling groups
- Support group leadership meetings
- Workshops for siblings and carers



Genetic Disorders Awareness Week

- ▶ Event has been running for 24 years and is held annually in September
- ▶ The aim of Genetic Disorders Awareness Week is to educate the public about the impact of genetic conditions on individuals and families by providing an insight into what is happening in this area.
- ▶ Speakers include clinicians, specialists, researchers, genetic counsellors, and most importantly a family story.

GA Events

- ▶ Filling the Void outreach program
- ▶ BRCA1/2 Information Day partnering with Pink Hope
- ▶ Participation in NAIDOC Week
- ▶ Rural outreach seminars in Albury, Tamworth and the Central Coast
- ▶ Participation in Multicultural Health Week

GA events continued

- ▶ Cohen syndrome seminar
- ▶ 25th Annual Genetic Disorders Awareness Week Launch
- ▶ Lynch Syndrome Seminar
- ▶ Thalassemia Society of NSW Seminar
- ▶ Immune Deficiency Foundation Australia
- ▶ Triple X

How do we do what we do?

Genetic Alliance Board

- ▶ Kate Dunlop – Director, Centre for Genetics Education
- ▶ Ann Mulder – Parent, Rural Outreach member
- ▶ Brenda Phillis – Parent
- ▶ Wendy Bruce – Executive Director, Fragile X Association
- ▶ Jane Fleming – Masters of Genetic Counselling
- ▶ Carolyn Shalhoub – Senior Genetic Counsellor, SCH
- ▶ Lizzy Harnett – Executive Director, Association for the Wellbeing of Children in Healthcare

Professional Advisory Committee

- ▶ Assoc/Professor K. Barlow-Stewart PhD, BSc, FHGSA (Genetic Counselling) (Chairperson)
- ▶ Dr Mimi Berman BM BS, FRACP, BSc Hons, PhD Medicine, Clinical Geneticist (HGSA)
- ▶ Prof. David Sillence AM, MB BS, MD (Melb), FRACP, FAFRM, FRCPA, FFSci (RCPA), FAFPHM
- ▶ Prof. Ron Trent PhD, BSc (Med); MB BS (Syd), DPhil (Oxon), FRACP, FRCPA.
- ▶ Prof Bridget Wilcken MB ChB, MD (Syd) FRACP, FRCPA

Consumer representation

Genetic Alliance is a consumer representative on:-

- ▶ Genetics Network Executive Committee
- ▶ NSW Newborn Screening Advisory Committee
- ▶ Consumer Health Forum - Voting Member
- ▶ Stepping Stones Triple P (SSTP) National reference Group

International membership





“Making the right connections since 1988”



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Email: info@geneticalliance.org.au

www.geneticalliance.org.au

Twitter: @geneticall_au

Facebook: <https://www.facebook.com/GeneticAllianceAustralia>

Membership

- ▶ 325 financial members
- ▶ \$30 for individuals/families, \$48 for organisations
- ▶ Yearly subscription (financial year calendar)
- ▶ Newsletter emailed or posted

Going Forward

- ▶ Genetic Alliance welcomes the opportunity to continue working with you, sharing your experiences and ultimately supporting as many families affected by a genetic condition as possible.

