

NEED MORE INFORMATION?

Tear off this section and mail to:

Genetic Alliance Australia

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

I would like more information on:

The following genetic condition/syndrome/disease

How I can contact others with the following condition/syndrome/disease

How I can make a bequest to Genetic Alliance Australia

Other ways I can contribute to Genetic Alliance Australia

How did you hear about us?



GENETIC ALLIANCE AUSTRALIA AIMS TO:

- Provide peer support to families and individuals affected by a genetic condition.
- Provide a contact point for families who are affected by genetic conditions so rare that they do not have their own support group.
- Facilitate access to individual support groups for those families with particular genetic disorders.
- Provide a forum for the exchange of information between support groups regarding available community services.
- Educate the medical and allied health professionals and the community about genetic conditions.
- Consult with government bodies, both Federal and State, on important issues regarding genetic conditions and services.

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People who prefer a language other than English should contact us through the Telephone Interpreter Service (TIS) on **131 450**.

 www.facebook.com/GeneticAllianceAustralia
(or search for Genetic Alliance Australia)

 @GeneticAll_AU

www.geneticalliance.org.au



genetic alliance
australia

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

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Genetic Alliance Australia, a tax-deductible registered charity, was formed in 1988 to provide support and information for individuals and families affected by a genetic condition.

What is a genetic condition?

Genes are the instructions for the growth and development of our bodies. They determine our physical characteristics and make sure things inside our body work correctly as well.

There are an estimated total of 20,000-25,000 genes that serve as blueprints for building all of our proteins (DNA). Genes are packaged in the 23 pairs of chromosomes within the nucleus of all our cells.

Sometimes, a gene contains a variation – like a spelling mistake – that disrupts the gene’s coded message. Variations in the coding that make a gene not work properly (faulty) are called mutations and can directly or indirectly lead to a wide range of conditions. A variation can occur spontaneously (no known cause) or it can be inherited. Around 6,000 known genetic conditions are caused by an altered gene and may occur without a previous family history.



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How many families in Australasia are affected by a genetic condition?

Around half of all miscarriages are caused by an imbalance in genetic information in the developing baby.

¹International Human Genome Sequencing Consortium, 2004

Similarly, about half of the Australian population will be affected at some point in their life by an illness that is at least partly genetic in origin.



The four broad groups of genetic conditions are:

- **single gene conditions** (monogenic): scientists currently estimate that over 10,000 human diseases are known to be monogenic, that is, caused by a single error in a single gene in the human DNA. These include Thalassaemia, Sickle cell anaemia, Haemophilia, Cystic Fibrosis, Tay Sachs disease and Huntington's disease;
- **chromosome conditions**: over 1,000 known conditions are caused by chromosome abnormalities, meaning a change in either the structure or the number of chromosomes, and include conditions such as Down syndrome, Triple X syndrome, Turner syndrome and Fragile X syndrome;
- **mitochondrial conditions**: are caused by either inherited or spontaneous alteration in the mitochondrial DNA, which can lead to cardiac disease, liver disease, diabetes, respiratory complications, seizures, visual/hearing problems and other complications;
- **multifactorial conditions**: common medical problems such as heart disease, diabetes, and obesity do not have a single genetic cause – they are likely associated with the effects of multiple genes in combination with lifestyle and environmental factors. Although these conditions often affect more than one person in a family, they do not have a clear-cut pattern of genetic inheritance. This makes it difficult to determine a person’s risk of inheriting or passing on these conditions.

At present genetic testing is available in Australia for approximately 400 genetic conditions. Some tests are for genes involved in rare diseases of childhood, while others may test for conditions that develop in the adult years.

How can Genetic Alliance Australia help?

The diagnosis of a genetic condition in a family member, particularly a child, places enormous stress on a family. Families may feel the need for personal support offering specialised understanding of their particular condition.

Whilst there are support groups established for a number of genetic conditions within the Australasian region, Genetic Alliance Australia may be the only contact point for families affected by rare conditions. Genetic Alliance Australia will endeavour to facilitate contact with another family/individual affected by the same or similar condition and/or provide a fact sheet and information on national and international support groups.



Genetic Alliance Australia also provides:

- Information, peer support and facilitates ongoing support for individuals, families, health professionals and other interested groups.
- A database of over 1,300 predominantly rare genetic conditions
- Resources relating to education, fact sheets, medical services, allowances and other helpful organisations
- Information seminars
- Local and regional contacts
- Quarterly newsletters
- Annual Information Day for BRCA1/2 gene faults
- Annual Genetic Disorders Awareness Week
- Family consultations
- Social gatherings



MEMBERSHIP FORM

Genetic Alliance Australia is a community of people supporting each other for a common cause. Membership is not required to access information and support services. If you would like to support us and receive our quarterly newsletter, become a member today!

Membership type

- Individual Organisation Professional

Surname: _____

Given Name: _____

Organisation: _____

Address: _____

Suburb: _____ Postcode: _____

Telephone: _____

Mobile: _____

Email: _____

Fax: _____

If Individual, please indicate your disorder: _____

If Professional, please state profession: _____

Signature: _____

Name of Signatory: _____
(IN BLOCK LETTERS)

Membership

- Individual – A\$30 Organisation – A\$48

Donation: (tax deductible if over \$2) \$ _____

It is understood this information will be kept on a mailing list. Should you at any time wish to be removed from our database, simply contact us.

Please make cheques payable to / post to:

Genetic Alliance Australia
C/- Garvan Institute of Medical Research
Level 6, 384 Victoria Street
Darlinghurst NSW 2010 Australia



EFT BSB 032 131 Account Number: 117037
Name: Genetic Alliance Australia Limited
State payment details as follows: SURNAME, Initials,
Subscription and/or donations or both.