

Support groups

Finding out that someone in the family has a genetic condition can raise a lot of issues. Different people will deal with the situation in different ways.

Some people will want to learn as much as possible and will need as much information as possible, as soon as possible.

Some people may need emotional support to get through what can be, for some, a difficult time.

Some people may want practical help and advice – what does this mean for work, for insurance, for the future, for others in the family?

Some people may want to talk to others who are going through, or have been through, a similar experience.

All this help is available through support groups. There is usually a support group for all but the rarest genetic conditions. Even where there is no particular group for your condition, the peak agency in each state may be able to help by putting you in contact with another family in similar circumstances.

Support groups operate in a number of different ways. Some have regular meetings. Some offer telephone support. Some provide information in printed form and/or via websites. Some keep members up to date with research. Some provide one-to-one contact with someone who has been there. While they vary in how they operate, the common theme is that they offer support and information to individuals and families dealing with genetic conditions and their families.

There is also a coordinating agency in most states for all these support groups.

State/Territory	Coordinating Organisation
Australian Capital Territory	Self-Help Organisations United Together (SHOUT) PO Box 717, Mawson ACT 2607 Ph: (02) 6290 1984 Fax: (02) 6286 4475 Email: admin@shout.org.au Website: www.shout.org.au
New South Wales	The Association of Genetic Support of Australasia (AGSA) Inc. 66 Albion Street, Surry Hills NSW 2010 Ph: (02) 9211 1462 Fax: (02) 9211 8077 Email: info@agsa-geneticsupport.org.au Website: www.agsa-geneticsupport.org.au

New Zealand	<p>New Zealand Organisation for Rare Conditions (NZORD) PO Box 38-538, Petone. NZ 6008 Ph: (+64) (0)4 566 7707 Fax: (+64) (0)4 566 7717 Email: exec.director@nzord.org.nz Website: www.nzord.org.nz</p>
Queensland	<p>Self Help Queensland (SHQ) Inc. PO Box 353, Sunnybank QLD 4109 Ph/Fax: (07) 3344 6919 Email: selfhelp@gil.com.au Website: www.selfhelpqld.org.au</p>
Victoria	<p>Genetic Support Network Victoria (GSNV) 10th Floor, Royal Children's Hospital Flemington Road, Parkville VIC 3052 Ph: (03) 8341 6315 Fax: (03) 8341 6390 Email: info@gsnv.org.au Website: www.gsnv.org.au</p>
Western Australia	<p>Genetic Support Council WA (GSNWA) Level 1, Oasis Lotteries House 37 Hampden Road, Nedlands WA 6009 Ph: 08 9389 6722 Fax: 08 9389 9377 Email: info@geneticsupportcouncil.org.au Website: http://geneticsupportcouncil.org.au</p>

These coordinating organisations come together to form one group known as the Australasian Genetic Alliance, which you can find on the web (<http://www.australasiangeneticalliance.org.au>).

Note that there are no coordinating organisations for support groups in South Australia, Tasmania or the Northern Territory. In these regions, please contact the Australasian Genetic Alliance or your nearest genetics service, teaching hospital or health department for advice.

Contacts and further information

- For other related fact sheets, you can contact the Gene Technology Information Service on **free call Australia-wide 1800 631 276** or email gtis-australia@unimelb.edu.au or visit Biotechnology Australia's website at <http://www.biotechnology.gov.au>