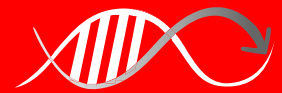


[www.geneticsupportcouncil.org.au](http://www.geneticsupportcouncil.org.au)



**Genetic Support Council of WA Inc**

2011  
Services  
Directory



*"We are more than the sum of our genes!"*



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# About the Genetic Support Council

The Genetic Support Council WA (GSCWA) is a not for profit organisation that acts as a peak body for genetic support groups in Western Australia.

Since its inception in 2002 the Genetic Support Council has worked to increase awareness of genetic conditions in the community, improve consumer participation in decisions pertaining to genetic service delivery, provide up-to-date information, resources and referral services and mentor genetic support groups.

The Council participated in the Australian Law Reform Commission Inquiries into genetic privacy and gene patenting. The Council's views were incorporated into the final report and have helped formulate the direction of the national Human Genetic Advisory Committee.

At a State level, the Council plays an important and valuable role in providing advice to government and non-government organisations on matters affecting its members. The combination of knowledge and experience, evident in the membership of the genetic support groups, is a powerful force in today's world of consumer engagement.

## Our vision

A world where genetics is an integral component of health and health care; where human genetic variation is celebrated and where all people benefit from advances in genetic science and technology.

## Our mission

To promote and develop awareness of genetic conditions and their impact on families and community, to foster research, encourage and support service delivery by genetic support groups and facilitate their development by linking and empowering individuals, families and communities.

## What we do

The Genetic Support Council WA Inc:

- Promotes awareness of genetic conditions in the community
- Assists in the greater participation of consumers in policy, planning, research and service delivery across the genetic services field
- Develops and contributes to policies of common concern to genetic support groups
- Provides genetic support information, resources and referral services to individuals and genetic support groups
- Encourages and supports effective and efficient management and service delivery practices within genetic support groups
- Promotes leadership and cooperation between non-government and community organisations within the genetic services field

## Membership

There are no fees payable to become a member of the Genetic Support Council WA.

GSCWA services are free to member groups and individuals. Please contact us for further information or to access any of the services outlined in this directory.

## What is a genetic condition?

Genetic conditions include many of the health, growth or developmental problems seen at birth. Others may not be noticed until childhood, adolescence or adulthood. There are over 6,000 known conditions which affect growth, development and health that are due to a change in just one of the 20,000 or so gene pairs in the human cell. There are over a hundred syndromes known to be due to a chromosomal change.

There is a growing number of genetic conditions identified due to an interaction between a genetic susceptibility (predisposition), environmental factors or other influences on the expression of the genes (epigenetics), many of which cause common health problems.

## Important points about genetics

- ⦿ Genetic conditions include many of the health or developmental problems seen at birth, in childhood, adolescence or adulthood
- ⦿ They include rare and common conditions and make a significant contribution to the problems in growth, development and health experienced by humans
- ⦿ Some conditions are directly due to a change in the genetic information in one or more genes. Others are due to an interaction between a change in the genetic information and other factors which can either affect the expression of a gene or cause changes to the information in other genes during the person's lifetime
- ⦿ Certain population groups are more at risk for developing particular genetic conditions than others
- ⦿ For some genetic conditions, when a family member is affected or at risk, genetic testing may be available and appropriate
- ⦿ It is currently not possible to cure a genetic condition
- ⦿ For some genetic conditions there is no treatment but more treatments are being developed each year
- ⦿ For other conditions it may be possible to implement preventive and early detection strategies to limit or stop the symptoms developing
- ⦿ Current information and support is available from a genetic consultation
- ⦿ Support groups provide information about the day to day living with a particular genetic condition and an understanding and empathic ear

## Genetic conditions in Australia

- About 50% of the Australian population will, during their lifetime, be adversely affected by a condition with a genetic basis
- In the first twenty five years of life about 5% of the Australasian population will be affected by an illness, impairment or disability either wholly or partly due to their inherited information
- About 30% of patients in paediatric hospitals have a genetic component to their illness
- At least 28% of all infant deaths result from genetic factors
- At least 50% of all miscarriages are caused by chromosomal abnormalities

## About genetic support groups

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

The last two decades have witnessed a marked growth in the number and diversity of self-help and support groups for families with persons with disabilities. In particular, there has been a striking emergence of support groups for genetic disorders. Genetics practitioners have come to routinely make a referral to a genetic support group in their care and management of a family.

Support groups provide affected individuals and families with information about the condition and community resources, as well as an understanding and empathic ear. There are over 850 support groups/branches in Australasia.

Genetic support groups can be an invaluable resource for individuals and families living with a genetic condition. Sharing their knowledge, experience and support are one of the key services that these groups are able to provide – in short they can be experts in dealing with daily life.

# Services

The Genetic Support Council provides current and relevant genetics information to individuals and family members affected by genetic conditions. The Council also provides referrals to appropriate organisations to ensure that the wider community has information on the services provided by genetic support groups.

In Australasia, there are hundreds of such groups each focusing on a specific genetic condition. We can help put you in contact with these groups or provide the support and guidance to help you establish a new support group. The Council may also be able to provide information and support for conditions so rare that there is no specific local support group.

The GSCWA maintains an up-to-date website and publishes 'The Gene Advocate', a bi-monthly newsletter. The GSCWA's 'Directory of Genetic Support Groups and Community Service Organisations' is available online. A printed copy of the Directory is available from the office upon request.

## Resources and referral

The Genetic Support Council WA Inc provides information on the services provided by genetic support groups and can assist with enquiries and facilitate ongoing support for individuals, families, health professionals and other interested groups.

The GSCWA maintains a database of genetic support groups throughout Australia and with international links can provide up to date information on genetic conditions — including the latest information on research developments.

Information is also readily available on a range of associated topics including - online resources, living with a family member with a genetic condition, parenting, and educational needs in association with a genetic conditions.



### Link line service

The diagnosis of a genetic condition can be devastating. After patients are suddenly faced with medical decisions, they usually want to know how this condition will affect their future. Families can feel isolated and alone because they don't know anyone else facing the same problems. Link Line provides a supportive and confidential means of connecting individuals and families who've been through a similar experience and with whom they can share their experiences about coping with a mutual problem or concern.

## Educational programs

The Council conducts public information and awareness events to enable participants to network, increase their knowledge and skills and access up to date information about issues and resources for people affected by genetic conditions. Forums for members are held on topics of interest or concern to enable member's views to be represented to the wider community and State and Federal Governments.

## Services provided to genetic support groups

### Developing and maintaining an effective support group

If you are thinking about starting a support group but don't know where to start, or you are currently leading, or will be leading a genetic support group and would like to fine-tune your group facilitation skills, Council staff can assist you.

Council staff can provide support and guidance in:

- getting (and keeping) a group off the ground
- publicising your group
- recruiting new members
- getting members to volunteer
- structuring your group
- shared leadership
- developing an effective group format; and
- how to run effective meetings.

### Governance

Governance is about how your group or organisation is run – the structures and systems and understandings that enable the group to make the right decisions and set the right course.

The character of Boards varies widely - in size, in the sources of their membership, and in the role they perform within the organisation. Many groups report that great wisdom, experience and commitment are to be found among the Boards of their organisations, but there can be deficits.

Some Boards, or their members, don't understand what their roles and responsibilities are.

GSCWA member groups can access a number of resources relating to effective governance ranging from job descriptions for Board members, Board development and accountability practices as well as confidential one-on-one support and guidance for specific concerns or issues.

## **Promotion and advertising**

Council staff are available to assist members wishing to develop and design their own web sites and genetic support groups are able to register information about their group on the GSCWA website.

The GSCWA is able to promote individual groups at; information seminars, public displays, conferences and community expos. We are able to assist member groups and individuals with the development of promotional resources such as information packages, brochures and event flyers from design through to printing.

Members can also publish articles, advertise events and promote their support group's activities on the GSCWA website and in our bi-monthly newsletter the "Gene Advocate".

Council staff can also provide information and assistance relating to media and publicity for groups as required.

## **Current issues and resources**

The Resource area in the GSCWA Office has been developed to keep members up to date in areas of interest and provide opportunities for them to participate or comment on matters of concern. Staff are able to assist groups and individuals in researching information regarding particular genetic conditions or predispositions upon request. Information available includes relevant newsletters, support group brochures, journals, videos, training manuals and other information to assist in group development.

Genetic support groups and service providers are invited to display their information in the resource area.

## **Meeting facilities**

GSCWA member groups are able to access an air-conditioned meeting room at Oasis Lotteries House in Nedlands suitable for board meetings, training seminars or group meetings. The room accommodates up to 25 people and includes a whiteboard and audio visual facilities, kitchen facilities, a chill-out space or play area for children with a TV/DVD/Video. All the furniture in the rooms can be moved and all rooms have good wheelchair access and facilities.

Bookings are essential and subject to availability.

## **IT support and computer access**

The GSCWA actively facilitates the development of genetic support groups by providing expertise, information and technology including office facilities that can be accessed by members to further enable and support their activities.

# Publications



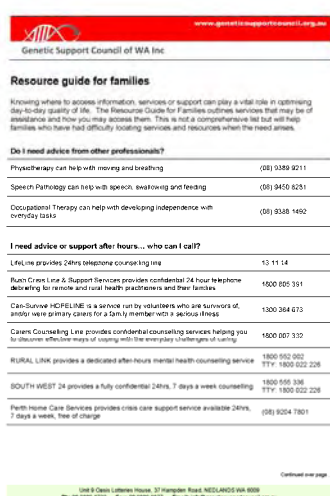
## Directory of Genetic Support Groups and Community Support Organisations

The purpose of the Directory is to provide health professionals and community members with a ready reference to assist in the appropriate referral for individuals and families with either a known or newly diagnosed genetic condition, to these genetic support groups.

The groups listed in this Directory range from small groups of individuals with very rare genetic conditions to larger community groups with more common genetic conditions. These groups offer a very important service to many Western Australians, effectively offering support from isolation by allowing the opportunity to share information and experiences, and by providing support through group activities and available services.

One of the important aspects of these genetic support groups is to provide information and resource materials about the specific genetic condition to affected individuals and families. The Groups also endeavour to provide health professionals and the community with information about their group and the genetic condition they represent.

The Community Support Organisations listed in the back of this Directory provide services that may be of additional support or assistance to individuals and families with either a known or newly diagnosed genetic condition or predisposition.



## Resource Guide for Families

Knowing where to access information, services or support can play a vital role in optimising day-to-day quality of life.

The Resource Guide for Families outlines services that may be of assistance and how you may access them. This is not a comprehensive list but will help families who have had difficulty locating services and resources when the need arises.



## Gene Advocate Newsletter

The 'Gene Advocate' is published bi-monthly and features a range of relevant information for health professionals, service providers, community organisations, resource centers and other support groups.

The newsletter is an important resource providing information on the development and delivery of genetic services including genetic tests and technologies, treatments and services. Each edition also profiles a specific support group and detailed information on coming events and funding sources.

Member support groups are able to publicise their events and activities in the Gene Advocate or insert an information flyer into the mail out.

The newsletter aims to keep our members informed of issues of interest or concern and we welcome any feedback or contributions from our readers.

The 'Gene Advocate' can be downloaded from our website or copies may be posted upon requested.

## Contact GSCWA

Genetic Support Council WA Inc. (GSCWA)

Phone: (08) 9485 8999

Email: [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au)

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