



Genetic Support Council of WA Inc

Genetic & Community Support Group Links Page

Please find listed here links to all GSCWA related organisations.
See also our

[Other Interesting Links](#)
[Online Resources For Support Groups](#)

Web Link Disclaimer

This website provides various links to other websites on the Internet which are maintained by third parties - 'linked sites'. The Genetic Support Council of WA (Inc) takes no responsibility for the accuracy of the information contained on any of the sites listed on this page. Information accessed through the World Wide Web is of varying levels of quality and accuracy and should be discussed with your health care provider NOT used as a substitute for professional health care.

Genetic Support Groups

Acoustic Neuroma Association of Australasia, WA Branch

Provide information and support for individuals who have, or have had, acoustic neuromas or other tumours affecting the cranial nerves (nerves coming from the brain) and on individual rehabilitation to physicians and health care personnel interested in the treatment of benign tumours.

Website: <http://www.anaa.org.au>

Addisons Disease Association Inc., Australian

Supply up to date information to people with Addison's disease and a caring network to give support for people living with Addison's disease.

Website: <http://www.addisons.org.au>

Alzheimer's Australia WA Ltd

Represent and support individuals with dementia and provide carers with an opportunity for giving and receiving support, sharing experiences, and gaining knowledge and information in a small, informal group setting.

Website: <http://www.alzheimers.asn.au>

Androgen Insensitivity Syndrome Support Group

To provide support, information, education and advocacy services for people affected by AIS and other intersex conditions.

Website: <http://vicnet.net.au/~aissg>

Angelman Syndrome Association

Provide support and information to families and carers of individuals with AS and provide information to students, para-medicals, carers and allied health professionals.

Website: <http://www.angelmansyndrome.org>



Genetic Support Council of WA Inc

Arthrogyrosis Support Group

Offer support to each other and new and relevant information on Arthrogyrosis Multiplex Congenita. Support Group may appeal to you, if your child suffers from Hip Dislocation, Club Feet as well as those with Arthrogyrosis.

Website: <http://www.taag.org.au> **Additional Website:** <http://www.amcsupport.org>

Australasian Genetic Alliance (AGA)

Network of peak organisations that represent genetic support groups, individuals and their families in the Australasian region who are affected by a genetic condition or a genetic predisposition.

Website: <http://australasiangeneticalliance.org.au>

Autism Association of WA

The association aims to advance the personal development, equality of opportunity and community participation of people with Autism.

Website: <http://www.autism.org.au>

Autism Spectrum: Focus On Children Within The Autism Spectrum Inc. (FOCAS)

Objectives are to create educational and social opportunities for our children and their families in WA and to provide information and resources to families of children within the Autism Spectrum

Website: <http://www.focas.iinet.net.au>

Batten Disease Support and Research Association, Australian Chapter

The organisation support families affected by Batten disease, create awareness and provide information, fund research into Batten disease.

Website: <http://www.battens.org.au>

Blepharophimosis, BPEI Family Network.

Also known as **BPES** it stands for: Blepharophimosis Ptosis Epicanthus Inversus Syndrome. A Yahoo group called Blepharophimosis is available: the members of the group are parents with children who have BPES, some children or youngsters, and several adults. We get in touch via the bulletin board or directly with each other. The Yahoo group has more than 500 members. They have a lot of members in *Australia* and *New Zealand*.

Website: <http://freespace.virgin.net/andy.bowles>

Cancer Council Helpline

The cancer Council WA Cancer Council Helpline provides information about cancer related issues and support services for individuals, families and communities affected by cancer. Not only are we supported by health care professionals in updating our information, but we also support them in caring for cancer patients, their families and communities.

Website: <http://www.cancerwa.asn.au>

Cardio Facio-Cutaneous Syndrome Support - WA Group

Provides information and support to parents of children with Cardio Facio-Cutaneous, Noonans or Costello Syndrome.

Website: <http://www.cfcsyndrome.org>



Genetic Support Council of WA Inc

Charcot-Marie-Tooth Association Australia Inc

Aims are to: Distribute information related to the welfare of people with CMT; Promote contact with others who have CMT; Advocate for the development of facilities and services for people with CMT; Support CMT research.

Website: <http://www.e-bility.com/cmtaa>

CHARGE Syndrome Association (WA Branch), Australasian

Provide support to families via networking with others affected.

Website: <http://www.austcharge.com.au>

Chromosome 18 Registry & Research Society (Aust) Inc

A lay advocacy organisation composed primarily of the parents of individuals with one of the chromosome 18 abnormalities.

Website: <http://www.chromosome18.org>

Cleft Palate and Lip Society WA (Cleftpals)

A voluntary group of parents, relatives and professionals interested in the welfare of children born with cleft related conditions.

Website: <http://www.cleftpals.org.au>

Coeliac Society of WA Inc

Aim to create awareness of coeliac disease within the community and amongst health professionals and provide education on the gluten free diet and support for individuals with coeliac disease, dermatitis herpetiformis and others who medically require a gluten free diet.

Website: <http://www.wa.coeliac.org.au>

Cornelia De Lange Syndrome Australasia Support Group

The group support the families of children with Cornelia de Lange and support research to identify the genetic cause of Cornelia de Lange. They aim to assist understanding between groups with similar issues and encourage further development of other national organisations around the world.

Website: <http://www.cdlsaus.org>

Congenital Adrenal Hyperplasia Support Group Australia Inc

The purpose of the C.A.H. Support Group Australia Inc. is to provide support and information to families and those affected by Congenital Adrenal Hyperplasia.

Website: <http://home.vicnet.au/~cahsga>

Congenital Diaphragmatic Hernia (CDH) CHERUBS Australia

The group consists of families expecting children with CDH, families who have surviving CDH children and families who have lost their babies to CDH.

Website: <http://au.geocities.com/ozcherubs>

Costello Syndrome Support Group

Aim to provide support and information on resources and condition management.
(Web site not available)

Additional Website: <http://www.costellokids.co.uk>

Cri du Chat Support Group of Australia Inc



Genetic Support Council of WA Inc

The group provide support, information and contact to families who have a family member with Cri du Chat syndrome in Australia, New Zealand and other countries of the Southern Hemisphere.

Website: <http://www.criduchat.asn.au>

Crouzon Support Network's - Online Support

An online support group for individuals and families who are dealing with Crouzon Syndrome and other craniofacial anomalies. A place to share experience, mutual support, inspiration, and information.

Website: <http://www.crouzon.org>

Cushing's Disease Support Group WA

The group provide emotional and psychological support for individuals with CD. (Web site not available)

Additional Website: <http://www.cushings-help.com/intro.htm>

Cystic Fibrosis WA

Aim to contribute to the social, physical and emotional wellbeing of those affected by CF and assist in the promotion of research.

Website: <http://www.cysticfibrosis.org.au>

Cystinosis Support Group, Australian

The group endeavour to try to find all the families in Australia and New Zealand that are affected by Cystinosis and provide support to newly diagnosed families and put them in touch with others in a similar situation within their state.

Website: <http://australia.cystinosis.com>

Deaf Society Inc, The Western Australian

The objectives of the society are to empower Deaf people to achieve equality of opportunity and independence in all aspects of life.

Website: <http://www.wadeaf.org.au>

Diabetes WA

Diabetes WA Vision: Freedom from Diabetes through Research, Education (prevention and managing diabetes), Advocacy and Support.

Website: <http://www.diabeteswa.com.au>

Down Syndrome Association of Western Australia Inc

Aim to support the community in developing the potential of individuals with Down syndrome to lead a valued life and provide support and information to individuals with Down syndrome and their families.

Website: <http://www.dsawa.asn.au>

Dyslexia SPELD Foundation WA Inc

The Dyslexia-SPELD Foundation provides a range of services and family support throughout Western Australia to enable children and adults with specific learning disabilities to realise their greatest potential.

Website: <http://www.dyslexia-speld.com>



Genetic Support Council of WA Inc

Dystrophic Epidermolysis Bullosa Research Association Western Australia (DEBRA)

Epidermolysis Bullosa is rare skin disorder and Australia is geographically large, for many years individuals and small state groups have been the primary source of services and have supported the EB skin disorder.

Website: <http://www.debra.org.au>

Ectodermal Dysplasia Support Group (WA Branch) - ozED

The group provide support and referral advice to all persons and families that are diagnosed with Ectodermal Dysplasias. They provide advice and information to health care professionals to assist in provision of quality care being provided to people and families affected by Ectodermal Dysplasias.

Website: <http://www.ozed.org.au>

Ehlers Danlos Support Group, Australian

A fun place to be where people can share information and support with each other.

Website: <http://groups.msn.com/AustralianEhlersDanlosSupportGroup>

Ehlers Danlos Support Group WA

Contact WISH on 9228 4488

Website: <http://www.wish.org.au>

Ehlers-Danlos Foundation of New Zealand

They provide emotional support for sufferers of the Ehlers-Danlos Syndrome and HMS, their spouses and family members. They distribute information amongst the medical profession and general public.

Website: <http://www.edfnz.org.nz>

Epilepsy Association of WA Inc

The group aim to educate and support individuals with epilepsy, their family, friends and the community and assist individuals with epilepsy to integrate successfully into the community, allowing them to enjoy a full and productive lifestyle.

* There is a Teenage webpage designed and maintained by Teenagers.

Website: www.epilepsywa.org.au

Even Keel Bi-Polar Support Association Inc

The group aims to reduce the stigma associated with mental illness and empower individuals who have Depression and Bi-polar Disorder. They provide friendship and support to individuals and families as well as information and community education about Bi-Polar Disorder. In addition to Bi-Polar Affective Disorder, the Association provides support for schizophrenia and other related disorders.

Website: <http://www.evenkeel.org.au>

Fabry's Support Group Inc

The group provide support to those affected directly or indirectly by Fabry's disease throughout Australia and aim to increase recognition awareness and understanding of Fabry's disease, its effects and potential solutions.

Website: <http://www.fabry.net.au>



Genetic Support Council of WA Inc

Facial paralysis – KidswithFacialParalysis online support group.

A group of parents of children born with Facial paralysis, Facial palsy, Moebius syndrome or Facial differences. Share your stories and meet new friends. There are links to Bell's palsy and Facial paralysis.

Website: <http://groups.msn.com/kidswithfacialparalysis>

Fragile X Support Group of WA Inc

The group promote awareness of appropriate educational and social opportunities for individuals with Fragile X syndrome and support appropriate planning for the future lives of individuals with Fragile X syndrome. It provides family contact and social interaction between members and their families.

Website: <http://www.fragilex-wa.websyte.com.au>

Freeman-Sheldon Parent Support Group (FSPSG) - International

An international self-help organization for individuals and families touched by Freeman-Sheldon syndrome. They are an information resource for affected individuals, healthcare providers, educators, and the general public.

Website: <http://www.fspsg.org>

Haemochromatosis Society of Australia Inc.

The society consists of volunteers who work from our homes and utilise technology to bring this information to you, so distance is no barrier! They provide information and education on Haemochromatosis.

Website: <http://haemochromatosis.org.au>

Haemophilia Foundation WA Inc

The group provide support, information and advocacy to individuals and their families and carers with haemophilia or von Willebrand disease and promote a better lifestyle for individuals with haemophilia.

Website: <http://www.haemophilia.org.au>

Heart Kids WA Inc

Including: Di George syndrome/Velo-Cardio Facial syndrome (VCFS) and VATER Association (also known as VACTERL Association). The Group supports families and children in various ways, including: Visiting families in hospital, Coffee meetings – held on the 1st Monday of each month, information evenings, fundraising events, family and kids camps.

Website: <http://heartkidswa.org.au>

Hemihypertrophy Support Group, Aussie

Hemihypertrophy (Hemihyperplasia) - The enlargement of one side of the body or part of the body. This group is for individuals or families living in Australia who are affected by hemihypertrophy or related conditions.

Available: <http://au.msusers.com/AussieHemihypertrophySupportGroup>

Hermansky-Pudlak Syndrome Network Inc. (New York)

The Hermansky-Pudlak Syndrome Network Inc. is a volunteer self help, not for profit support group for persons and families dealing with Hermansky-Pudlak Syndrome (HPS) and related disorder such as Chediak Higashi Syndrome.

Website: <http://www.hpsnetwork.org>



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Hidradenitis Suppurativa Foundation, Inc. (HSF)

Hidradenitis Suppurativa Foundation, Inc. is a non-profit public benefit corporation dedicated to improving the quality of life for individuals and families affected by Hidradenitis Suppurativa.

Website: <http://www.hs-foundation.org>

Holoprosencephaly Support Group, Australian

This group is intended as a support group for parents and families of children with Holoprosencephaly within Australia.

Website: <http://groups.yahoo.com/group/ausholoprosencephaly>

Huntington Disease Association (Inc) WA, Australian

Aim to provide the best quality of care for individuals with Huntington disease, those 'at risk' of Huntington disease and their carers and families through advocacy, information, referrals and crisis support.

Website: <http://www.wa.ahda.asn.au>

Irlen Syndrome Australasia Inc - WA Group

This is a type of dyslexia - perceptual, it is a genetic condition, not an optical problem.

WA: [irlenaustralasia \(at\) bigpond.net.au](mailto:irlenaustralasia@bigpond.net.au)

Website: <http://www.dyslexiaservices.com.au>

Jeune Syndrome Association Inc., Australian

Our mission is to raise the awareness and level of understanding of this rare condition throughout the wider community. In the long term, we aim to raise funds to:

- * increase research into identifying the Jeune Syndrome gene and the underlying cause of the various symptoms such as renal failure; and
- * research various treatments such as rib expansion in order to provide a better quality of life for our children.

Website: <http://home.vicnet.net.au/~jeunesyn>

Kabuki Syndrome, SAKKS Supporting Aussie Kids with Kabuki Syndrome

Aim is to raise awareness of this rare condition and help other families feel less alone.

Website: <http://www.sakks.org>

Klinefelter's Support Group WA

Aim to help boys and men with this syndrome adjust to life, raise public awareness and provide information.

Website: <http://www.klinefelterswa.websyte.com.au>

Klinefelter's Support Group

Living With Klinefelters Syndrome: Canberra Support Group

Provide support information for Men who are living with Klinefelters, with an opportunity for giving and receiving support, sharing experiences, and gaining knowledge and information in a small, informal group setting.

Services:

- * A Social Group of Guys with Klinefelters Syndrome
- * Support Information and Resources
- * Phone & Email Support

Website: <http://www.xxwhy.com>



Genetic Support Council of WA Inc

Learning and Attentional Disorders Society of WA (LADS)

The group provide up to date information, support and referral advice to adolescents, adults and parents of children with learning difficulties and attention disorders. They aim to increase awareness and acceptance of Attention Deficit Hyperactivity Disorder and improve the quality of life for individuals with this condition.

Website: <http://www.ladswa.com.au>

Leukodystrophy Support Group Inc (ALDS), Australian

ALDS provide assistance and information to those affected by Leukodystrophy and supporting research into Leukodystrophy.

Website: <http://avoca.vicnet.net.au/~leuko>

LQTS Support Group of WA Inc

To raise awareness, provide information about Long QT Syndrome and support the families of children and young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

Website: <http://www.sads.org.au>

Lupus Group of WA Inc, The

The group act as the principle resource for lupus patients, their families, doctors and the community to provide educational awareness, support and facilitation of research activities.

Website: <http://www.lupuswa.com.au>

Marfan Support Australia

The group provide support and information to individuals, family members and the health care community about the syndrome.

Website: <http://www.marfan.net.au>

Mental Illness Fellowship WA Inc

The fellowship provides support services, education and information to individuals, family and carers. They aim to raise community awareness in an attempt to reduce the stigma and ignorance associated with schizophrenia and mental illness and try to influence legislation, policy and procedures used by governments, health systems (public and private) and service providers.

Website: <http://www.mifwa.com>

Metabolic Dietary Disorders Association (MDDA), Australia

A self-help, not-for-profit, family-support group that assists members and their families with the complex issues in dealing with metabolic dietary disorders.

Website: <http://www.mdda-australia.org>

Motor Neurone Disease Association of WA Inc

The association support research into Motor Neurone Disease. They aim to ensure that people with Motor Neurone Disease, their carers families and support networks have access to the resources required to maximise their lifestyle and to increase awareness of Motor Neurone Disease within the community, government and medical profession.

Website: <http://mndawa.iinet.net.au>



Genetic Support Council of WA Inc

Mucopolysaccharide & Related Diseases Society

The society provides support and information to families and other interested people. They promote a partnership between families and professionals and community awareness of the mucopolysaccharide condition and its impact on families and carers.

Website: <http://www.mpsociety.org.au>

Muscular Dystrophy Association of WA Inc

The association provides support for individuals with muscular dystrophy and other neuromuscular conditions, their carers and families. They provide advisory, advocacy and individual and family support services i.e. the Quokka Kids/Teens Club provides support for kids, teens and adults with muscular dystrophy and all other related neuromuscular diseases. They aim to advance research and provide investigative counselling and diagnostic services.

The following MD "Fact Sheets" on specific MDs and Neuromuscular Disorders are available from Muscular Dystrophy Australia [<http://www.mda.org.au>].

- * Chacot-Marie-Tooth disease
- * Duchenne type muscular dystrophy (DMD)
- * Becker type muscular dystrophy (BMD)
- * Friedreich's Ataxia
- * Facioscapulohumeral (FISH)
- * Kugelberg-Welander disease
- * Werdnig-Hoffmann disease

Website: <http://www.mdawa.asn.au>

Myasthenia Gravis Friends & Support Group WA Inc.

Myasthenics, family and friends, gather Quarterly, at a coffee morning. Traditionally these have been held in private homes, with as many as forty attending and on occasions speakers present information on subjects of interest such as "Getting the most out of your GP" and "Mechanisms and Management of Myasthenia Gravis".

Website: <http://www.myastheniawa.info>

Nager and Miller Syndromes - Foundation for Nager and Miller Syndromes (FNMS) International

An international support group dedicated to helping those affected by these two similar genetic conditions which involve severe facial and limb anomalies, but does not usually affect intellect. The group serves as a clearinghouse of information & link families seeking support, hope & advice.

Website: <http://www.nagerormillersynd.com>

Neurofibromatosis Association of WA Inc

The association provides up to date information gathered from national and international sources and support individuals with NF and their carers by bringing families and individuals together. They aim to promote awareness of the condition within the community, particularly amongst medical practitioners and other health care workers.

Website: <http://www.cnswa.com>

Website: <http://www.nfinc.org/clinewa.html>



Genetic Support Council of WA Inc

Osteogenesis Imperfecta Society of Australia, The - WA Contact Available

Aims & Objectives: To offer information and support to individuals and families affected by O.I. To encourage and support research & To provide public and professional education and create awareness.

Website: <http://www.oiaustralia.org/contact.html>

Periodic Paralysis Society WA

Including: Myotonia Congenita

The society provides accurate, current information, support, and representation and to work together to improve the quality of life of people with periodic paralysis and associated conditions, this includes:

- * Hypokalemic Periodic Paralysis
- * Thyrotoxic Periodic Paralysis
- * Hyperkalemic Periodic Paralysis
- * Normokalemic Periodic Paralysis
- * Andersen's Syndrome
- * Paramyotonia Congenita

Website: http://www.e-wire.net.au/~eb_grty/

Pallister-Hall Foundation Australia

The Pallister-Hall Foundation (Aust.) is a non-profitable charitable Organisation dedicated to the care, health, well-being, welfare, support, encouragement and education of the public, Pallister-Hall Syndrome [PHS] patients, their families, carers and medical providers through the provision of information, materials and resources, and to the furtherance of research into PHS worldwide.

Website: <http://www.pallisterhall.com.au>

Pompe's Association, Australia

A National support Association for people living with the rare disease Pompe, their family and friends.

Website: <http://www.pompedownunder.org>

Porphyria Association Australia

The Porphyria Association is a voluntary non profit organisation.

There are at least six separate "porphyrias" (diseases of porphyrin chemistry in the body)

- * Acute Intermittent Porphyria (AIP)
- * ALAD Porphyria (ADP)
- * Congenital Erythropoietic Porphyria (CEP)
- * Porphyria Cutanea Tarda (PCT)
- * Hepatoerythropoietic Porphyria (HEP)
- * Hereditary Coproporphyrin (HCP)
- * Erythropoietic Protoporphyrin (EPP) or Protoporphyrin
- * Variegate Porphyria (VP)

Website: <http://www.porphyrin-association.org>

Prader-Willi Syndrome Association of Australia Inc - WA Branch

Information for those who have had a recent diagnosis of PWS for your infant or toddler. General information about PWS across all age groups. A list of books, publications available.

Website: <http://www.pws.asn.au>



Genetic Support Council of WA Inc

PXE Support Group WA

To provide information and support to Pseudo Xanthoma Elasticum (PXE) sufferers and their families by supplying the latest updates on information about PXE.

Website: <http://www.pxe.org>

Raynaud's Syndrome Support Group WA

The group support individuals living with this condition and aim to promote greater awareness and educate individuals and health professionals about this condition.
(Web site not available)

Additional Website: <http://www.raynauds.org.uk>

Retinitis Pigmentosa Foundation WA Inc.

The foundation is affiliated with Retina Australia and Retina International and to cooperate with all blind welfare and low vision agencies. They offer support for newly diagnosed individuals, ascertain the cause and means to cure or arrest all forms of hereditary retinal dystrophies, seek by all practical means ways to assist those affected and their families and gather and disseminate information on RP and all forms of hereditary retinal dystrophies. (Usher syndrome Type 1 & 2, Macular Degeneration, Stargardt's disease).

Website: <http://www.retinitispigmentosa.com.au>

Retinal Dystrophy Research, Inherited

involved in research into inherited retinal dystrophies such as retinitis pigmentosa, Usher's syndrome, Stargardt's disease and Best's disease. Project supported by **Retinitis Pigmentosa Foundation WA** has been approved by the Sir Charles Gairdner Hospital Human Research Ethics Committee.

Website:

http://www.scgh.health.wa.gov.au/departments/medical_technology/inherited.html

Retina Australia

Retina Australia is a voluntary organisation that provides scientific research and support to people and families affected by retinal degenerative diseases.

Website: <http://www.retinaaustralia.com.au>

Rett Syndrome Association of WA

The group collect and disseminate accurate and objective information regarding the cause, identification, treatment, prevention and cure of Rett syndrome. They promote the general welfare of individuals with Rett syndrome and support families in coping with the condition and aim to further the advancement of study, research, therapy and care.

(Web site not available)

Additional Website: <http://www.rettsyndrome.org>

SADS Australia (Sudden Arrhythmia Death Syndromes)

To assist families and friends of those affected by the Long QT Syndrome and other arrhythmia disorders. To provide information and educational resources to the lay public and to health care providers in order to promote early diagnosis and treatment.

Website: <http://www.sads.org.au>



Genetic Support Council of WA Inc

Senses Foundation Inc WA

The Senses Foundation is a non government, not for profit organisation which was formed in 2001 from the amalgamation of two organisations, the Royal WA Institute for the Blind and the Deafblind Association. Their vision is that Western Australians who are blind or deafblind live a life of meaning and purpose as valued individuals in the community.

Website: <http://www.senses.asn.au>

Short Statured People's Association WA Branch,

The association supports individuals of short stature and their families and parents who have short statured babies and assist in the assimilation, of short statured individuals into society with the goal of equality of educational and social status and of employment opportunities. Support Groups are available for the following Sub-Groups

- * Acrodysplasia
- * Chondrodysplasia
- * Ellis-van Creveld syndrome
- * Kniest dysplasia
- * Morquio's & Hurlers syndrome
- * Cartilage-hair hypoplasia
- * Diastrophic Dwarfism
- * Hurlers syndrome
- * Multiple epiphyseal dysplasia
- * Multiple epiphyseal dysplasia

Website: <http://www.sspa.org.au>

Shwachman-Diamond Syndrome Australia (SDSA)

A non-profit organisation dedicated to assisting families through mutual sharing of experiences and working together with the medical community to improve treatment for our children/adults with this syndrome.

Website: <http://www.shwachmandiamondsyndrome.com.au>

Sjögren's Syndrome Support Group WA

The group support individuals with the condition and promote awareness and educate the community and health professionals regarding diagnosis and treatment.

(Web site not available)

Additional Website: <http://www.sjogrens.org>

Spinocerebellar Ataxia Support Group

A national support group for people living with Spinocerebellar Ataxia (also known as Friedreich's Ataxia), their carers and family.

E: [vjpedler\(at\)bigpond.net.au](mailto:vjpedler(at)bigpond.net.au)

(Web site not available)

Additional Website: Western Australian Contact

<http://www.ataxia.org/chapters/ReneeMoore/default.aspx>

Stargardt's Australia

Stargardt's Disease, a disease of the eye, is a form of macular dystrophy that begins early in life. Stargardt's Australia purpose is to provide information and support for those with the disease, their parents and friends. This support includes News and Developments regarding treatment, assistance in coping with the Disease and helping others understand what a person with Stargardt's is experiencing. It has a forum to allow people to share experiences and discuss problems with each other.

Website: <http://www.stargardts-au.org>



Genetic Support Council of WA Inc

Stickler Syndrome - Australia

We are a small group with few inquiries. Newsletters are produced 1-2 years, depending on demand. Contact can be by either internet, phone or writing, though internet is preferred. Stickler Syndrome Australia Support Service (SSASS). (Web site not available)

7 Noojee Court, Kallangur Qld 4503 AUSTRALIA

Ph: (07) 3886 0665

E-mail: ssass@hotmail.net.au

Additional Websites: www.stickler.org.uk & www.stickers.org

Sturge Weber Support Group, Australian

Provide support for families and individuals living with Sturge Weber syndrome. (Web site not available)

Additional Website: <http://www.sturgeweber.org.uk>

Spina Bifida Association of WA Inc

The objectives of the group are to provide support for individuals with spina bifida and their families.

Website: <http://www.sbawa.asn.au>

Thalassaemia Association of WA Inc

The association assist individuals with Thalassaemia and related conditions to obtain a better quality of life through education and direct medical assistance and aim to educate Western Australians about Thalassaemia.

(Web site not available)

Additional Website: <http://www.tssa.org.au>

Thyroid, Australia Ltd

Thyroid Australia is a support organisation for people with thyroid conditions as well as their families and their friends. It is a voluntary organisation whose founding members have suffered or been affected by various thyroid conditions and who wish to help others in similar situations.

Website: <http://www.thyroid.org.au>

Tourette Syndrome Organisation Inc

The organisation support individuals with Tourette syndrome and their family and carers and aim to increase public and professional awareness of this syndrome.

Website: <http://www.tourette.org.au>

Treacher Collins Connection - global community

Mission: To connect, educate and support the global community of people with Treacher Collins syndrome by providing medical and networking resources, while imparting to our children the strength, courage and importance of not allowing a facial difference to define who we are.

Website: <http://www.tcconnection.org>

Trisomy and Related Disorders of WA (SOFTWA), Support Organisation for

The group helps and support families dealing with a child with a rare chromosomal disorder. There are different Trisomy conditions, including Trisomy 18 (Edwards Syndrome), Trisomy 13 (Patau Syndrome), Trisomy 9 and Trisomy 22 .

Website: <http://www.trisomy9.org/softwa.htm>



Genetic Support Council of WA Inc

Tuberous Sclerosis Society Inc, Australasian

Aim to educate, research and create awareness of this condition within the community and provide support for affected families.

Website: <http://www.atss.org.au/members>

Turner Syndrome, Association of Australia Ltd (WA)

The association assist individuals, families to have a healthier and better adjusted life and educate and help people gain a greater knowledge of what Turner syndrome means.

Website: <http://www.turnersyndrome.org.au>

Unique In Australia (Chromosome Disorder Support Group)

The group works to ensure that the public at large are aware of rare chromosome disorders and informs, support and alleviate the isolation of anyone affected by a rare chromosome disorder and to raise public awareness.

(Web site not available)

Additional Website: <http://www.rarechromo.org>

Vasculitis Foundation (VF) - International

The only international organization for patients with Vasculitis. Founded in 1986, VF provides patients and family members with practical information and coping strategies to live successfully with Vasculitis.

Types of vasculitis:

- * Behcet's Disease
- * Central Nervous System
- * Cryoglobulinemia
- * Henoch-Schönlein Purpura
- * Kawasaki Disease
- * Polyarteritis Nodosa
- * Rheumatoid Vasculitis
- * Wegener's Granulomatosis
- * Buerger's Disease
- * Churg Strauss Syndrome
- * Giant Cell Arteritis (Temporal Arteritis)
- * Hypersensitivity Vasculitis
- * Microscopic Polyangiitis
- * Polymyalgia rheumatica
- * Takayasu's Arteritis

Website: <http://www.vasculitisfoundation.org>

Velo-Cardio-Facial Syndrome Foundation of NSW

Families and Professionals caring for people with VCFS / Shprintzen Syndrome / Di George Syndrome.

Website: <http://www.vcfsfa.org.au>

Von Hippel-Lindau Syndrome (WA Contact)

The group provides information relating to the condition and to the VHL Family Alliance and assists in contacting other Australian VHL Family Alliance representatives.

(Web site not available)

Additional Website: <http://www.vhl.org>

Williams Syndrome Association of Australia.

C/- Association of Genetic Support of Australasia

66 Albion St, Surry Hills, NSW 2010

Ph: (wk) (02) 9211 1462, (hm) (02) 9332 1361 Fax: (02) 9211 8077

Website: <http://www.agsa-geneticsupport.org.au/Index.html>



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Williams Syndrome Forum, Australian

Online forum.

Website: <http://wsaustralia.proboards55.com/index.cgi>

Wolf-Hirschhorn Syndrome Association (AWHSA), Australian

Wolf-Hirschhorn Syndrome (WHS), also known as Wolf Syndrome along with Pitt Rogers Danks Syndrome (PRDS), are both rare chromosomal disorders caused by a deletion from the short (p) arm of the fourth chromosome known as 4 p minus (4p-). Support Group is a voluntary not-for-profit self-help organisation dedicated to educating parents about Wolf-Hirschhorn Syndrome and networking them with other parents of affected children. * We currently are in contact with over 30 families from all over Australia and New Zealand.

Website: <http://home.vicnet.net.au/~awhssg>

Related Community Support Organisations

Active Foundation

The foundation aim to provide a better life for people with intellectual disabilities and their families through understanding, commitment and support.

Website: <http://www.activ.asn.au>

ARAFMI Mental Health Carers and Friends Association

The association provide support, information and education to the community, particularly relatives and friends of individuals with a mental health problem.

Website: <http://www.arafmi.asn.au>

Arthritis Foundation of WA

Including: Osteoporosis WA, The Ankylosing Spondylitis Support Group, The LINK Group, Fibromyalgia Support Group and General Arthritis Support Groups. The objectives of the foundation are to reduce the incidence and disabling effects of arthritis, osteoporosis and related conditions.

Website: <http://www.arthritiswa.org.au>

Asthma Foundation of WA Inc

The foundations objectives are to raise awareness of asthma in the community, raise funds for asthma, research and provide educational and support services to individuals with asthma, their families, carers and health professionals.

Website: <http://www.asthmawa.org.au>

Australasian Genetic Alliance

The Australasian Genetic Alliance (AGA) is a network of peak Not for Profit, Non-Government Organisations that represent genetic support groups, individuals and families in the Australasian region who are living with a genetic condition or a genetic predisposition.

For information on genetic support groups and services in your state, contact the relevant state Alliance member:



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- **New South Wales:** Association of Genetic Support of Australasia (AGSA) <http://www.agsa-geneticsupport.org.au>
- **Victoria:** Genetic Support Network Victoria (GSNV) <http://www.gsnv.org.au>
- **Western Australia:** Genetic Support Council of WA (GSCWA) <http://geneticsupportcouncil.org.au>
- **New Zealand:** New Zealand Organisation for Rare Disorders (NZORD) <http://www.nzord.org.nz>
- **Australian Capital Territory:** Self Help Organisations United Together (SHOUT) <http://www.shout.org.au>
- **Queensland:** Self Help Queensland Inc (SHQ) <http://www.selfhelpqld.org.au>

Australian Association for Families of Children with a Disability (AAFCD)

To provide information, support and advocacy for families of children aged under 25 with disability in all States and Territories of Australia.

Website: <http://www.aafcd.org.au>

Bonnie Babes Foundation Inc (WA Branch)

The foundation counsel families who are grieving after the loss of a baby. It has a 24 hour, 7 day per week grief counselling lines in Australia. The Foundation also assists in education to health professionals.

Website: <http://www.bbf.org.au>

Breast Screen WA

The organisation provides a high quality, FREE screening mammography service for women in WA 40 years or over with no breast symptoms.

Website: <http://www.breastscreen.health.wa.gov.au>

Carers Association of WA Inc

The Carers Association is the peak body representing the interests of all carers in Western Australia. A carer is an individual who looks after a family member or friend who has a mental or physical illness or a disability, or who is Frail Aged. To actively enhance the quality of life of all carers in WA. They provide counselling services.

Website: <http://www.carerswa.asn.au>

Clinical Genetics, Australian Resource Network for

To support the clinician's role in genetic services at point-of-care, this website is established to provide, at their fingertips, useful and up-to-date information for clinical genetic practice.

Website: <http://www.arcgenet.org.au>

Crisis Care Support Service - Perth Home Care Services Inc

The Crisis Team offers short-term emergency support for the main carers of frail aged or people with disabilities living in the Perth metropolitan area. This support may be required in the event of critical illness, carer's stress or any other incident that occurs



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without warning and results in the main carer being unable to continue to care for their family member. There is *no charge* for this service.

The Crisis Team is available 24 hours a day, seven days a week by phoning 9204 7801. All Crisis Team members and Support Workers are formally trained and supervised to be able to respond to callers needs.

Website: http://www.phcs.org.au/phcs/phc_services.htm

Crohn's and Colitis Association, Australian

There mission is to generate and foster awareness and educational programs targeted at persons diagnosed with IBD, their families, health professionals and the general public.

Website: <http://www.acca.net.au>

Disability Abuse & Neglect Hotline, National

This is a FREE service that takes reports of abuse and neglect of people with a disability. Phone: 1800 880 052, TTY 1800 301 130 (between 8am-8pm every day incl. weekends).

Website: <http://www.disabilityhotline.org>

Disability in the Arts, Disadvantage in the Arts, Australia

Our focus is on creating opportunities and significant beneficial social change with people who have a disability and/or mental health issue living in local communities across WA.

Website: <http://www.dadaawa.org.au>

Disability First Stop

Disability First Stop is an innovative service that will assist people and their families to get the help they need when a person is newly diagnosed as having a disability. Disability First Stop directs people who have had an accident or have been recently diagnosed as having a disability, towards the appropriate agencies to give them and their families the support they need.

Website: <http://www.disabilityfirststop.asn.au>

Ethnic Disability Advocacy Centre

The objectives are to promote, advocate, support, information, referral, networking, lobbying and training people with disabilities from culturally and linguistically diverse backgrounds and their families and carers.

Website: <http://www.edac.org.au>

Eye, Lions Institute Western Australia

Provides specialist clinical services, medical training and community services.

Website: <http://www.lei.org.au>

GAIN – Gynaecological Awareness Information Network Inc.

GAIN is a community-based organisation of dedicated women who, have endured the trauma of being diagnosed and treated for gynaecological conditions.

Website: <http://www.gynsupport.com>

Genetic Alliance Inc. Washington, DC.

<http://www.geneticalliance.org>



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Genetic Services of Western Australia

This service provides a state-wide comprehensive, and fully integrated clinical and laboratory, genetic service with equitable access, to enable informed choice in the prevention and treatment of genetic conditions and to reduce the burden of genetic conditions in the community. It provides both clinical and counselling services.

Website: <http://wchs.health.wa.gov.au/services/genetics>

Health Consumers' Council of Western Australia Inc

The Health Consumers' Council is an independent community based organisation, representing the consumers' 'voice' in health policy, planning, research and service delivery. The Council advocates on behalf of consumers to government, doctors, other health professionals, hospitals and the wider health system.

Website: <http://www.hcc-wa.asn.au>

Hereditary Spastic Paraplegia Research Foundation (HSPRF)

A health promotion charity that is a voice for HSP sufferers throughout Australia. It will raise funds for HSP directed research and make applications for funding by Government. It will promote the establishment of gene testing facilities in Australia and maintain a database of affected individuals. The HSPRF will become a focal point for neurologists, scientists, gene counsellors and academics as well as sufferers.

Email: [rjbligh\(AT\)bigpond.net.au](mailto:rjbligh(AT)bigpond.net.au)

(Website not yet available)

Kalparrin Centre, The Including: Parents of Children with Disabilities

The Kalparrin Centre is an organisation committed to providing practical and emotional support to families of children with special needs who require ongoing care and support and families of children with special needs who are under the unique stress of awaiting diagnosis or whose diagnosis is unknown. They provide disability related self-help or support groups.

Website: <http://www.kalparrin.org.au>

Kidney Health Australia

Kidney Health Australia, formerly the Australian Kidney Foundation, was officially formed 35 years ago. It is a non-profit organisation with a mission to be the lead organisation promoting kidney and urinary tract health through research, advocacy, education and health service excellence.

Website: <http://www.kidney.org.au>

Mums - National Parent to Parent organisation for parents or care providers of a child living with a disability, rare or not so rare disorder, chromosomal abnormality or health condition. MUMS' mission to provide support to parents in the form of a networking system that matches them with other parents whose children have the same or similar condition.

Through a database of over 20,000 families from 54 countries, covering over 3400 disorders, very rare syndromes or undiagnosed conditions can be matched. Parents can then exchange valuable medical information, as well as, the names of doctors, clinics and medical resources or research programs. Families provide each other with emotional support and they don't have to feel so alone when they have each other to reach out to in time of need. MUMS networks with other organizations which do



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matching, thus expanding the possibilities of finding a match.

Website: <http://www.netnet.net/mums>

National Breast Cancer Centre

The centre strives to reduce mortality and improve the well-being of women diagnosed with breast or ovarian cancer.

Website: <http://www.nbcc.org.au>

Neurological Council of WA Inc, The

The Neurological Council of Western Australia was established in March 1992. The Council is a collaborative Organisation which functions as the peak body in neurological disorders in Western Australia, and currently represents the, common interests of 29 neurological organisations.

Website: <http://www.ncwa.com.au>

Office of Population Health Genomics, Department of Health Western Australia

The objectives of this organisation is to minimise the negative impact of genetic disease on the health and wellbeing of Western Australians and facilitate the integration of genetics into all aspects of public health research, policy and programs with maximum benefit to Western Australians and minimal costs to individuals.

Website: <http://www.genomics.health.wa.gov.au>

Parent To Parent New Zealand Inc

Provide information and support network for parents of children who have special needs, disabilities and health impairments from common conditions to the rarest of conditions. The services are free to families in NZ and network with organisations and families overseas. Parents, family members, professionals, siblings, Whanau can access the organisations services.

Website: <http://www.parent2parent.org.nz>

Primary Immune-deficiency Network Ltd. (APIN), Australian

[apin\(AT\)apin.com.au](mailto:apin(AT)apin.com.au)

(Web site not available)

Rare Disease Community, The

NORD [<http://www.rarediseases.org>] has partnered with ClinicaHealth to create a free, unique online community service for rare-disease patients, their families, and caregivers. It will be a place where people can find and support one another, share stories, and build a network of online friends. The online community is not meant to be a substitute for professional medical information, but rather a place where those affected by rare diseases can connect with others who have the same interests or medical conditions.

Website: <http://nord.clinicahealth.com>

SIDS and Kids Western Australia Inc

Incorporating Stillbirth and Neonatal Death Support (SANDS) WA Inc

SIDS Western Australia is a community based organisation that began during the 1970's as a mutual support group for individuals and families affected by Sudden Infant Death Syndrome. SANDS (Stillbirth and Neonatal Death Support) WA Inc was a



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self help group which provided immediate and ongoing support to individuals and families who were affected by perinatal death (miscarriage or stillbirth or neonatal death). SANDS has been absorbed by SIDS in a joint alliance to educate the community on the impact of infant death.

Website: <http://www.sidswa.org.au>

Speak Easy Association Western Australia

The association provide advocacy and support to people who stutter and their families.

Website: <http://www.speakeasy.org.au>

Other Organisations

Australian Indigenous HealthInfoNet

HealthInfoNet is an innovative web resource that makes knowledge and information on Indigenous health easily accessible to inform practice and policy.

Website: <http://www.healthinfonet.ecu.edu.au>

American Liver Society

The society's mission is to help with the current national epidemic of liver diseases, liver deficiencies, and liver syndromes through research, advocacy, awareness, support, and information for those affected, or those that may become affected by a liver problem.

Website: <http://www.liversociety.org>

Biotechnology Australia

For general information about biotechnology, gene technology and for specific information on non-regulatory biotechnology policy or public awareness programs. They have a large range of information and educational resources.

Website: <http://www.biotechnology.gov.au>

Centre for Law & Genetics

The mission of the centre is to provide excellence in research for the benefit of the Australian and International communities into the legal and ethical issues arising from the developments in genetic technology and to propose effective and equitable means for developing, applying and benefit-sharing of this technology.

Website: <http://www.lawgenecentre.org>

Comfort Keepers

A growing business offering companionship and other non-medical services allowing individuals to remain in the privacy and comfort of their own home. Services Offered - Comfort Keepers offers a wide range of in-home, non-medical services. Examples of other services offered include:

- * Meal Preparation
- * Light Housekeeping
- * Transportation Services
- * Laundry



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- * Shopping and Errands
 - * Conversation and Companionship
 - * Minimum of only 1 hour
 - * 12 and 24-Hour Care Available
- All Metro Areas Serviced - Fees Apply

Website: www.comfortkeepers.com.au

Genetics Education, The Centre for

The centre is dedicated to providing current and relevant genetics information to individuals and family members affected by genetic conditions and the professionals who work with them.

Website: <http://www.genetics.com.au/services/counsel.htm>

GeneClinics: Medical Genetics

A publicly funded medical genetics information resource developed for physicians, other healthcare providers, and researchers, available at no cost to all interested persons.

Website: <http://www.geneclinics.org>

Genetic Discrimination Research Project - Australia

The Project involves researchers from three Australian institutions and aims to undertake an empirical study of genetic discrimination in Australia.

Website: <http://www.gdproject.org>

Genetic Support Network Victoria

The GSNV offers a range of services including information on genetic conditions, contact details for support groups, and even links between families with the same condition. We can point you towards your local community resources or give you links to the latest information on genetic hot topics.

Website: <http://www.gsnv.org.au/index.php>

Genetic Interest Group: supporting those affected by genetic disorders.

Its primary goal is to promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them.

Website: <http://gig.org.uk>

Health Concessions - Department for Community Development

Website:

http://www.centrelink.gov.au/internet/internet.nsf/payments/conc_cards_hcc.htm

Human Genetics Society of Australasia (HGSA)

HGSA provides a forum for those dedicated to the study, investigation and practice of Human Genetics.

Website: <http://www.hgsa.com.au>

IDEAS (Based in the USA)

A non- profit organization providing support and advocacy for people with chromosome 15q duplications. These duplications most commonly occur in one of two forms which can be grouped under the umbrella of chromosome 15q duplication



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syndrome. These include an extra isodicentric 15 chromosome, abbreviated idic(15), or an interstitial duplication chromosome 15. * Email support available.

Website: <http://idic15.org>

National Heart Foundation

Website: <http://www.heartfoundation.com.au>

MediAlert® Foundation Australia

The foundations mission is to provide personal medical information to protect and save lives in an emergency.

Website: <http://www.medicalert.com.au>

secca - Sexuality Education Counselling & Consultancy Agency

Website: <http://www.secca.org.au>

Support Group Resources

Website: <http://www.onlinehealthresources.com/Support-Groups>

Sussex Street Community Law Service Inc. Perth

Advocacy Service for people with disabilities

Website: <http://www.sscls.asn.au>

The Health Network

Website: <http://www.healthnetwork.com.au>

Travel Concessions - Department for Community Development

Website:

http://www.fcs.wa.gov.au/_content/concessions_guide/travel.html

Thyroid, Australia Ltd

Website: <http://www.thyroid.org.au>

WA Cancer Registry

Website: http://www.ncci.org.au/projects/stage/cancer_stage_WA.htm

Western Australian Community Legal Centre Directory

Website: <http://www.lawsocietywa.asn.au/clc.html>

Connect Groups (formerly, Western Institute of Self Help (WISH))

Website: <http://www.connectgroups.org.au>

Women's & Children's Health Service WA incorporating: King Edward Memorial Hospital for, Women (KEMH) and Princess Margaret Hospital for Children (PMH)

Website: <http://wchs.health.wa.gov.au/index.htm>

Women and Infants Research Foundation Western Australia

Website: <http://www.wirf.com.au>

See also: 2008 - [Online Resources For Support Groups](#) [Other Interesting Links](#)