

Directory of Genetic Support Groups and Community Support Organisations in Western Australia

is published by:

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Introduction

The purpose of the Directory is to provide genetic support information to health professional's, individuals and Genetic Support Groups. The aim of the Directory is to assist with referral for individuals and families with either a known or newly diagnosed genetic condition or predisposition to these Genetic Support Groups.

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

Another important aspect of these Genetic Support Groups is to provide information and resource materials about these specific genetic conditions that affects its members and their 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.

Whilst the Genetic Support Council has endeavoured to ascertain all existing Genetic Support Groups in Western Australia there may be some that are not included in this edition.

Acknowledgments

The GSCWA wishes to convey its appreciation to all the Genetic Support Groups, agencies and organisations who supplied the information included in this publication. Additionally, the GSCWA wish to thank and acknowledge the Office of Population Health, Department of Health Western Australia, without whose ongoing support, this publication would not be possible.

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Foreword

It gives me great pleasure to provide the opening words for the latest edition of the Directory of Genetic Support Groups and Community Support Organisations. Since its inception in 2002 the Genetic Support Council has worked assiduously 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.

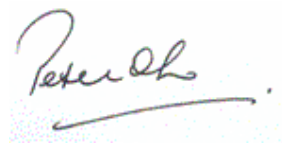
I welcome the lead advocacy role taken by the Genetic Support Council in representing members' interests in State and national genetics issues. It has been encouraging to see the Council participate in the Australian Law Reform Commission Inquiries into genetic privacy and gene patenting. The Council's 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 organizations 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.

The inclusion of more than seventy support groups in this Directory is testament to the increasing recognition of the Genetic Support Council as a reputable and reliable source of information.

The Directory is a valuable resource for the public, genetic support groups and health professionals. Its potential to assist in providing appropriate referral to support groups for people with known or newly diagnosed genetic conditions is important in providing holistic care.

I trust you will find this issue of the Genetic Support Services Directory valuable and look forward to working with you on continuing to improve genetic knowledge and health in Western Australia

Yours truly,



Dr Peter O'Leary
Director
Office of Population Health Genomics

The Genetic Support Council of WA

The Genetic Support Council WA (Inc) is a not for profit organisation that acts as a peak body for genetic support groups in Western Australia. The Council provides information to individuals and families about genetic conditions including information on the services provided by Genetic Support Groups.

Genetic support groups can be a useful resource for individuals and families affected by a genetic condition. Support Groups can provide information about the condition and community resources, as well as an understanding and empathetic ear.

In Australasia, there are hundreds of such groups each focussing 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 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 - online resources, living with a family member with a genetic condition, parenting, and education in association with a genetic condition are some of these.

The Council conducts forums for members on issues of interest or concern to enable member's views to be represented to the wider community and State and Federal Governments. We also provide written and verbal submissions to Government and others in the field of genetics and participate with like bodies nationally to further represent Genetic Support Groups and their members.

We conduct forums and awareness events to enable participants to increase their skills and knowledge and access up to date information about resources for people affected by genetic conditions and their families. The Council maintains an up-to-date website and publishes a bi-monthly newsletter and information sheets for consumers.

The GSCWA actively supports the ongoing development of Genetic Support Groups. We are able to assist with the development of resources such as information packages, pamphlets and the printing of promotional material. Groups can also publish articles and advertise and promote awareness of their Support Group's activities on the GSC website and in our bi-monthly newsletter the 'Gene Advocate'.

Staff can assist groups and individuals in researching information regarding particular genetic conditions or predispositions and help keep members aware of matters of interest such as changes of legislation etc.

All GSC services are free to member groups and individuals. Please call us for further information or to access any of these services.

What causes genetic conditions?

There are three types of genetic conditions:

1. **Heritable conditions:** Due to a mutation in a single gene
2. **Chromosomal conditions:** Occurs when an individual is affected by a change in the number, size or structure of his or her chromosomes
3. **Multifactorial conditions:** Due to the interaction of the genetic information and environmental factors such as diet, chemical exposure and lifestyle.

What can be done about Genetic Conditions?

(a) Prevention

Some people are more at risk than others for developing a condition that is due to the interaction of environmental factors with their inherited genetic information. They are "genetically predisposed" to develop these conditions. However, the presence of an environmental "trigger" is necessary for the person to be affected with the condition. In some cases, prevention of the condition can be achieved by the person avoiding being exposed to the particular environmental factor that will trigger the condition.

For example, it is possible to prevent about 70% of the cases of spina bifida (a neural tube defect) in babies if women who are more likely to have a baby affected with spina bifida, because they are genetically "predisposed", take the vitamin folic acid before, and continue it during early pregnancy.

(b) Early Diagnosis and Treatment

In some genetic conditions, early diagnosis, sometimes even before the symptoms appear, can lead to specific treatment. For example, all newborn babies in Australasia are screened for phenylketonuria (PKU) by a simple blood test. Diagnosis and treatment within the first month of life are crucial to avoid intellectual disability. Also, some cancers which have a genetic component, e.g. breast cancer, bowel cancer and melanoma, can be detected early enough to enable treatment to take place.

Checking the family health history may determine if a person or another blood relative are at risk for developing a genetic condition or for passing it on to their children.

(c) Genetic Counselling

Genetic counselling is available to families and individuals that have concerns about a condition in their family which may have a genetic basis. A team of health professionals which may include clinical geneticists, genetic counsellors and social workers, work together to provide information and supportive counselling so that families may be better able to understand, and adjust to, the diagnosis of a genetic condition.

Genetic testing, if it is available and appropriate, can also be organised on the basis of informed consent. Genetics Services are available throughout Australasia and provide genetic counselling to assist in informed decision making regarding genetic testing.

- (d) **Support Groups:** 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 200 genetic conditions for which there are over 850 support groups/branches in Australasia.

- (e) **Some points to remember when contacting a group:** Many of the telephone numbers provided in this directory are home numbers, so please be considerate of the hours at which you call. Many support groups do not receive funding and rely on their group members for income. Offering to pay for postage, photocopying and/or materials provided will be appreciated by many groups.

(Information Source: Centre for Genetics Education, NSW)

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Acoustic Neuroma Association of Australasia (WA Branch)

10 Andrews Way
DUNCRAIG WA 6023
Ph: (08) 9447 3069

Email: nancy.verco@dhw.wa.gov.au
Website: <http://www.anaa.org.au>

Acoustic Neuroma

Acoustic Neuroma is a genetic condition resulting in benign tissue growth in the ear canal. It is characterised by the loss of hearing on one side and is often accompanied by ear ringing and balance disturbance. Most acoustic neuromas occur spontaneously without any hereditary component.

Objectives of the Group

- To 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)
- To provide information on individual rehabilitation to physicians and health care personnel interested in the treatment of benign tumours
- To promote and support research into the cause, development and treatment of acoustic neuromas and other benign tumours
- To educate the public about the symptoms of acoustic neuromas, thus promoting early diagnosis and successful treatment.

Activities and Services

- Provide opportunities for individuals with acoustic neuromas to communicate with others
- Respond to individual members non-medical needs
- Provide information to the public about symptoms which may indicate a tumour
- Quarterly meetings.

Publications/Resources

The Association produces a quarterly newsletter. Booklets and information sheets are available to members.

Alzheimer's Australia WA Ltd

PO Box 1509
SUBIACO WA 6904

Ph: (08) 9388 2800
Freecall: 1800 639 331
Fax: (08) 9388 2365

Email: alzwa@alzheimers.asn.au
Website: <http://www.alzheimers.asn.au/wa>

Alzheimer's Disease

Alzheimer Disease (AD) is the most common form of dementia. It is a progressive, irreversible condition which attacks brain cells, leading to confusion, memory loss and total personality change. Up to a third of individuals with AD have a close relative (parent, sibling) who has, or has had, dementia. At least two thirds of individuals with AD do not have any family history.

Objectives of the Group

- To represent and support individuals with dementia and advance interests at a personal, community and political level
- To provide carers of individuals with dementia with an opportunity for giving and receiving support, sharing experiences, and gaining knowledge and information in a small, informal group setting.

Activities and Services

- Respite services including home respite, host family respite, centre based respite, and mobile dementia respite teams in some areas
- Support Services including counselling, carer's support groups and early stage intervention programs for people with dementia
- Education and training with short courses and workshops for carers, community service workers, residential care staff, volunteers and the general public
- Mind Your Mind Community Awareness Program.

Publications/Resources

The Association has a library which offers a growing collection of books, videos, journals and other reports on dementia and carers' issues, including nationally developed "Help Sheets". Some information is available in other languages. Anyone can browse through the library, members can borrow and individuals in rural and remote areas can telephone for information.

Androgen Insensitivity Syndrome Support Group

P.O. Box 1089
ALTONA MEADOWS Vic 3026

Contact:
Tony Ph: (03) 9315 8809
Andie Ph: 0411 406 935

Email: aissg@iprimus.com.au
Website: <http://vicnet.net.au/~aissg>

Androgen Insensitivity Syndrome

Androgen Insensitivity Syndrome (AIS) is a genetic condition that affects the development of the reproductive/genital organs. AIS occurs due to a genetic alteration of the X chromosome, which leads to an inability of the body to recognise and respond to androgens (male hormones). A foetus with XY sex chromosomes will therefore develop a female body type. Appearance can vary from complete female to quasi-male.

Objectives of the Group

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

Activities and Services

- Provides a 24 hour telephone support service
- Advocacy, educational and informational services
- Self help support group meetings and fellowship
- Provides training workshops and seminars
- Liaison with Government departments.

Publications/Resources

The Association produces:

- Brochures and newsletters
- AIS fact sheets
- Guide for parents of children with ambiguous genitals
- Access to up-to-date research
- Legal information.

Angelman Syndrome Association (WA Branch)

16 Kirkcolm Way
WARWICK WA 6024

Contact Person: Liz

Ph: 9447 8606 9343 4430
Fax: 9343 4431

Email: allaboutbread@bigpond.com
Websites: <http://www.angelmansyndrome.org>

Angelman Syndrome

Angelman Syndrome (AS) is a rare neurogenetic condition caused by a deletion on chromosome 15. AS is characterised by severe intellectual disability, speech impediment, sleep disturbance, an unstable jerky gait, seizures and an unusually happy demeanour.

Objectives of the Group

- To increase the understanding of AS in the community
- To provide support and information to individuals, families and carers of individuals with AS
- To provide information to students, carers and allied health professionals.

Publications/Resources

The Association provides resources for families and medical students, including a variety of:

- brochure and journal articles
- *Angelman Syndrome* quarterly newsletter.

Arthrogryposis Support Group

1 Kiah Court
KINGSLEY WA 6026

Ph: 043 9977 020

Arthrogryposis Multiplex Congenita

Arthrogryposis Multiplex Congenita (AMC) is a condition characterised by the presence of multiple joint contractures (contracture refers to a limited range of motion). AMC may exist in isolation or be part of a genetic condition, and varies from mild to severe.

Objectives of the Group

- To offer support to others affected by AMC
- To find new and relevant information on Arthrogryposis Multiplex Congenita
- To treat each person as an individual.

Activities and Services

- The group meets twice a year
- Trip to the zoo and a BBQ.

Batten Disease Support and Research Association (Australian Chapter)

9 Norton Ave
KILLARNEY VALE NSW 2261

Contact: V. Anderson

Ph: (02) 4334 5785

Email: gvjeando@ozemail.com.au
Website: <http://www.battens.org.au>

Batten Disease

Batten disease is a rare neurological disorder that affects children. It is one of a group of disorders called neuronal ceroid lipofuscinoses (or NCLs) and is an inherited disorder of the nervous system that usually manifests itself in childhood.

Symptoms vary with each child. Early symptoms of Batten disease can be difficult to diagnose and not easily recognised. The following is an outline of the most typical symptoms:

- Visual impairment often progressing to complete blindness
- Seizures, which may be frequent and difficult to control
- Decline in cognitive function
- Personality and behavioural changes
- Loss of communication skills
- Loss of fine and gross motor skills
- A general progressive deterioration.

There are many other less common symptoms that may develop – please refer to our website for further information.

Objectives of the Group

- To support families affected by Batten disease
- To create awareness and provide information about Batten disease
- To fund research into Batten disease.

Activities and Services

Provide group meetings and ongoing support.

Publications/Resources

The support group produces a quarterly newsletter and has a library with numerous publications to assist and guide families.

Australian Cystinosis Support Group

1 Clifton Crescent
PINJARRA WA 6208

Contact: Sue

Ph: (08) 953 12135

Email: cystinosis.australia@bigpond.com
Web: <http://australia.cystinosis.com>

Cystinosis

Cystinosis is an inherited (autosomal recessive) metabolic disease characterised by an abnormal accumulation of amino acid Cystine in various organs of the body such as the kidney, eyes, muscles, pancreas and brain. Different organs are affected at different stages.

Objectives of the Group

To provide support, information and contact to all the families in Australia and New Zealand that are affected by Cystinosis.

Activities and Services

- Provide support to newly diagnosed families and (with permission) put them in touch with others in a similar situation within their state
- To assist families in contacting doctors in other states that know about Cystinosis if they should travel and need medical assistance
- Hold conferences and gatherings where families and doctors can discuss Cystinosis
- Raise funds to support families affected by Cystinosis.

Publications/Resources

The group can provide information and resources to assist families affected by Cystinosis.

Australian Huntington Disease Association WA (Inc)

Centre for Neurological Support - The Niche
Suite B, 11 Aberdare Road
NEDLANDS, WA 6009

Ph: (08) 9346 7599
Fax: (08) 9346 7597

Email: ahda@cnswa.com
Website: <http://www.wa.ahda.asn.au>

Huntington Disease

Huntington disease (HD) is a dominant genetic, progressive neurological disorder. It is characterised by involuntary movements and cognitive impairment. Individuals with HD often have speech and language, eating and swallowing difficulties.

Objectives of the Association

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

Activities and Services

The Australian Huntington Disease Association facilitates a number of support groups for members of the Huntington's community – for gene positive people, early symptomatic people and carers. Each year the AHDA organises a retreat for carers and a 'get-away' for the early symptomatic group.

Regional Support: The AHDA visits a number of regional communities (by request) and holds quarterly support meetings in Bunbury.

Counselling & Home visits: A Community Support Officer is available to visit or provide counselling to any member of the Huntington Disease community.

Education: The AHDA promotes public awareness and understanding of HD in the wider community. Educational forums are organized by request for members of the HD community to address issues relevant to managing changes in lifestyle and care issues.

Referral: The AHDA provides referral to the appropriate agencies as required.

Publications/Resources

- A newsletter is produced by the AHDA (Inc.) WA. to disseminate local, national and international Huntington's research and care news.
- The Association has a library of books, articles, fact sheets and videos about HD and a catalogue of resources is available on request or by visiting the website.

Australian Sturge Weber Support Group

8 Golden Grove
THE BASIN Vic 3154

Contact: Jo

Ph: (03) 9762 4630

Email: aswsg@alphalink.com.au

Sturge Weber Syndrome

The Sturge-Weber Syndrome (SWS) is a rare disease in which the presence of a birth mark (port wine stain), usually on one side of the face, is associated with an abnormality of the brain caused by abnormal blood vessels on the surface of the brain. This abnormality usually results in seizures or other problems.

SWS is usually a spasmodic occurrence - in other words it does not run in families. Very rarely one or more family members may be affected.

Objectives of the Group

To provide support for families and individuals living with Sturge Weber syndrome.

Activities and Services

- Provide information to professionals and service providers as well as families and individuals living with Sturge Weber syndrome.
- Conduct meetings offering fellowship and support.

Publications/Resources

The support group produces a quarterly newsletter.

Australian Pituitary Foundation WA Branch

20 Tate Street
WEST LEEDERVILLE WA 6007

Ph: 08) 9380 4979

Email: pituitary@bigpond.com

Pituitary Disorder

A pituitary disorder is characterised by either the over or under secretion of one or more pituitary hormones and may result in problems with growth, body weight and sexual development. A pituitary disorder may be a feature of a genetic condition.

Objectives of the Group

- To improve the quality of life and wellbeing of individuals with a pituitary disorder
- To provide a forum for the exchange of information, ideas and discussion of problems related to pituitary disorder
- To act as a resource group providing support and dissemination of information
- To promote public awareness of pituitary disorders
- To encourage scientific research for the prevention, alleviation, care, treatment and cure of pituitary disorders.

Activities and Services

- Meetings including guest lecturers and videos
- Patient information seminars
- Liaison with similar groups internationally
- Publicity to raise public awareness
- Social activities and networking between members
- Four organised functions each year
- Counselling and support either via telephone or in person.

Publications/Resources

The Foundation provides a newsletter from the Australian Foundation three times a year. Videos about pituitary disorders are also available.

Australasian CHARGE Syndrome Association (WA Branch)

18 Coleman Way
KARRINYUP WA 6018

Contact: Lisa

Ph: 0413 407 009

Email: tonyandlisa99@hotmail.com
Website: <http://www.austcharge.com.au>

CHARGE Syndrome

CHARGE is an acronym for:

- C** - COLOBOMA (incomplete development of the eye)
- H** - HEART (abnormal configurations)
- A** - ATRESIA of the choanae (a blockage of the nasal passage)
- R** - RETARDATION of growth and/or development
- G** - GENITAL defects
- E** - EAR abnormalities and may include hearing loss.

Objectives of the Group

- To provide support to families via networking with others affected by this syndrome
- To raise community awareness
- Provide respite to families.

Activities and Services

- Conferences are held every 2 years
- A newsletter is produced quarterly
- Online Forum where you may to ask a question or seek information about issues regarding CHARGE Syndrome.

Publications/Resources

An information package is available to families of newly diagnosed children with CHARGE on request. Parent and professional representatives are available to discuss CHARGE with any interested persons.

Australasian Tuberous Sclerosis Society (Inc)

76 Coode Street
SOUTH PERTH WA 6151

Ph: (08) 9367 7458

Email: williamson@brightonline.com.au
Website: <http://www.atss.org.au/members>

Tuberous Sclerosis Complex

Tuberous Sclerosis Complex (TSC) is a genetic condition causing tuber-like growths in the brain which calcify with age and become hard or 'sclerotic'. Abnormal TSC growths can affect almost any other organ of the body including the skin, eyes, heart, kidneys and lungs. The condition develops before birth and continues during the individual's lifetime.

Objectives of the Group

- To educate, encourage research and create awareness of this condition within the community
- To provide support for affected families.

Activities and Services

- Telephone contact with other families
- Meetings, social evenings and picnic days.

Publications/Resources

The Society has interstate and internationally produced magazines available.

Fact sheets on various aspects of the condition, videos and books are available for health professionals. Brochures are available for the community.

Cancer Council Helpline

AH Crawford Lodge, 55 Monash Ave
NEDLANDS WA 6009

Enquires Officer
Ph: 13 11 20 (8am - 8pm)
TTY: 9381 6562
Fax: (08) 9381 8616

Email: inquiries@cancerwa.asn.au
Website: <http://www.cancerwa.asn.au>

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.

Activities and Services

- Information on specific cancers
- Information on chemotherapy, surgery, radiotherapy
- Information on new treatments and clinical trials
- Someone confidential and professional to talk to about what you're going through
- Information on prevention, screening and risk factors for cancer
- Information on any of the Cancer Council's support services, including counselling, financial assistance and accommodation for country people accessing health service in the metropolitan area
- Information about services in your community
- Information on how best to navigate your way around the health care system (i.e. finances, appointments, health care professionals)
- On-line questions and answers about cancer (Cancer facts).

Publications/Resources

The Council provides a number of brochures relating to treatment and lifestyle issues. Most publications are available online.

Chromosome 18 Registry & Research Society Australia (Inc), The

Australasian Coordinator:
Marlene

61 Kuroki St
PENSHURST, NSW 2222

Ph: (02) 9580-5707

Email: chromosome18@optusnet.com.au
Website: <http://www.chromosome18.org>

WA Contact:
Veronika

71 The Crest
WOODVALE WA 6026

Ph: (08) 9409 9854

Chromosome 18

There are five major syndromes of chromosome 18. These are 18q deletion, 18p deletion, Trisomy18, Tetrasomy 18p, Ring 18. Also, there are many unique rearrangements that include translocation, mosaic, and inversions. Individuals are affected by a very wide range of characteristics as well as global delays of varying severity.

Objectives of the Group

The Chromosome 18 Registry & Research Society is a lay advocacy organisation of the parents of individuals, extended family members with one of the chromosome 18 abnormalities and professionals. Our mission is to help individuals with chromosome 18 abnormalities overcome obstacles to lead happy, healthy and productive lives.

Activities and Services

- Newsletters
- Annual Conference
- Parent support network
- Syndrome groups
- Regional groups
- Education and syndrome information
- Public advocacy
- Information on current research.

Publications/Resources

Information about these syndromes is available upon request.

Coeliac Society of WA (Inc), The

Suite 1 931 Albany Highway
East Victoria Park

Ph: (08) 9470 4122
Freecall: 1800 449 200
Fax: (08) 9470 4166

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

Coeliac Disease

Coeliac disease, sometimes called Gluten–Sensitive Enteropathy, is a medical condition in which there is a permanent intolerance to dietary gluten. In coeliac disease the cells of the intestine (small bowel) are damaged when they come into contact with gluten. This ineffective absorption leads to deficiencies in vitamins, iron, folic acid and calcium. Sugars, proteins and fats are often also poorly absorbed. Both environmental and genetic factors play a role in coeliac disease, around 10% of all first degree relatives of people with coeliac disease also have the condition.

Objectives of the Group

- To create awareness of coeliac disease within the community and amongst health professionals
- To provide education on the gluten free diet and support for people with coeliac disease, dermatitis herpetiformis and others who require a gluten free diet for medical reasons.

Activities and Services

- Regular information and workshop sessions
- Social events including dinner nights and outings/picnics
- An awareness campaign every March
- Information on gluten free diet
- Personal education and consultation.

Publications/Resources

The Society provides information leaflets on Coeliac Disease and Osteoporosis and Dermatitis herpetiformis and food standards information for health professionals and manufacturers. See the website for available resources.

Congenital Adrenal Hyperplasia Support Group Australia (Inc)

CAHSGA Inc
P.O. Box 100
MITCHAM Victoria 3132

Ph: (03) 9513 9255

Email: lindapowell@optusnet.com.au
Website: <http://home.vicnet.au/~cahsga>

Acting President – Mrs Linda Powell
The Association is located in Victoria but serves the whole of Australia and has Members in Western Australia.

Congenital Adrenal Hyperplasia

Congenital Adrenal Hyperplasia (CAH) is a genetic disorder that causes an enzyme deficiency in the steroid pathway. Specifically, CAH results in 3 disturbances: Lack of Cortisol, lack of Aldosterone, too much Androgen.

Objectives of the Group

To provide support and information to families and those affected by Congenital Adrenal Hyperplasia.

Activities and Services

- We hold a National Conference Day on the first Sunday in July each year. These Conference Days are an opportunity to hear information in a casual environment without the time restraints found in an appointment setting. The topics cover Endocrinology, Genetics, Gynaecology, Adolescent Health and Surgery.

Publications/Resources

The support group publishes a quarterly magazine that contains outcomes of current studies, practical hints, 'Ask the Dr' questions and personal stories.

Cornelia De Lange Syndrome Support Group

33 Grenadier Drive
THORNIE WA 6108

Ph: (08) 9452 7572 (08) 9222 2910
Fax: (08) 9222 2907

Email: ssandilands1@primus.com.au

Cornelia de Lange Syndrome

Cornelia de Lange is a genetic syndrome characterised by distinctive elf like facial features in association with physical, intellectual and mental retardation.⁹

Objectives of the Group

- To support the families of children with Cornelia de Lange
- To support research to identify the genetic cause of Cornelia de Lange
- To promote community awareness of Cornelia de Lange.

Activities and Services

- Annual national general meeting
- Annual picnic in Sydney in January
- Quarterly conference hook-ups
- E-mail service
- Medical question and information service through links in website addresses as follows: www.cdlsusa.org/national_groups.

Publications/Resources

The Group has a variety of brochures available to the community and health professionals. They also provide a quarterly newsletter *KIT (Keeping In Touch)* and an international bulletin.

Costello Syndrome Support Group

Postal Address:
15 Gillibri Crescent
SAWTELL NSW 2452

Ph: (02) 6653 2428
Email: bence@westnet.com.au

Costello syndrome

Costello syndrome is a rare congenital syndrome characterised by failure to thrive, distinctive facial features, joint abnormalities and developmental delay. The syndrome is transmitted as an autosomal recessive trait, some cases are familial. A blood test can be used to identify the condition.

Objective of the Group

To provide support and information on resources and condition management to families and individuals affected by this condition.

Activities and Services

- Provides telephone and email support and referrals
- International Conference – July 2007
- The group are members of the Research Advisory Group (RAG)
- Referral of families to the International Costello Syndrome Support Group (which has a world wide membership of over 200 families).

Publications/Resources

The Group can provide information on Costello syndrome.

Cri du Chat Support Group Australia (Inc)

104 Yarralumba Drive
LANGWARRIN Vic 3910

Contact: Wendy

Ph: (03) 9775 9962 (24hrs)
Fax: (03) 9775 9962

Email: info@criduchat.asn.au
Website: <http://www.criduchat.asn.au>

Cri du Chat

Cri du Chat is a relatively rare genetic condition. The most distinctive characteristic of Cri du Chat is the distinctive high pitched, cat like cry. In addition there are a number of distinguishing facial characteristics present in infancy which aid in recognition of the syndrome.

The effects of this syndrome are extremely variable but almost all children with this syndrome have intellectual disability, delayed speech and language acquisition, and slow development of motor skills.

Objectives of the Group

To 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.

Activities and Services

- Families meet annually in Sydney and Melbourne and occasionally in other states. Contact with families can be arranged
- Provide information to professionals, students and other people with an interest in the syndrome from any part of the world.

Publications/Resources

The Group produces a newsletter three times a year
Brochures and a variety of other materials are available

Cushings Disease Support Group

27 Tamarind Crescent
WESTFIELD WA 6111

Ph: (08) 9390 2132 (24 hours)

Email: jritacca@tmx.com.au
Website: <http://www.cushings-help.com>

Cushing Disease

Cushings Disease (hypercortisolism or hyperadrenocorticism) is a hormonal disorder caused by prolonged exposure of the body's tissues to the hormone cortisol. Many people suffer the symptoms of Cushings Disease (CD) because they take steroids for asthma, rheumatoid arthritis, lupus and other inflammatory diseases or for immunosuppression after transplantation. Others develop CD because of over production of cortisol by the body due to a tumour on the pituitary or adrenal glands or elsewhere on the body.

Symptoms of this condition are weight gain, reddening of the face and neck, excess body and facial hair, raised blood pressure, raised blood sugar levels, the loss of mineral from the bone (causing osteoporosis, brittle bones) and severe fatigue. Other symptoms include excess sweating and sometimes emotional and mental changes. This condition is treatable and individuals can return to good health with treatment.

Objectives of the Group

- To provide emotional and psychological support for individuals with CD
- To provide support on a one to one basis
- To ease suffering due to CD
- To provide education from first hand experience.

Activities and Services

- The Group holds social meetings a few times a year.

Cystic Fibrosis WA

The Niche – Suite C
11 Aberdare Road
NEDLANDS, WA 6009

PO Box 959
NEDLANDS WA 6909

Ph: (08) 9346 7333
Freecall: 1800 678 766 (Country WA & NT)
Fax: (08) (8) 9346 7344

Email: info@cysticfibrosiswa.org
Website: <http://www.cysticfibrosis.org.au/wa>

Cystic Fibrosis

Cystic Fibrosis (CF) is an inherited recessive genetic condition, which affects the lungs, digestive system and the sweat glands. In CF the body produces thick, sticky mucus, which prevents digestive enzymes reaching the food in the digestive system. Mucus collects in the lungs, clogging the airway and trapping bacteria which can cause infection. It is the most common recessive genetic condition affecting Australians.

Objectives of the Group

- To contribute to the social, physical and emotional wellbeing of those individuals and families affected by CF
- To assist in the promotion of research to find a cure for CF.

Activities and Services

The Association offers support through a comprehensive home care program that includes:

- Home Support Service: regular visits by a CFWA home care worker to assist with airways clearance
- Transplant support
- Education & Information
- Recreation programs
- Counselling
- Coffee mornings are held every six weeks for parents, grandparents and friends of individuals with CF
- The Association is also involved with advocacy and lobbying for both individuals and the wider CF community
- Equipment is available for loan, hire or sale
- Supports Research.

Publications/Resources

The Association provides books, videos, brochures and booklets to the community and health professionals. Booklet and brochure titles are available on the website.

Diabetes Australia Western Australia (DAWA)

48 Wickham Street
EAST PERTH WA 6004

Diabetes Information Advice Line: 1300 136 588
Ph: (08) 9325 7699
Fax: (08) 9221 1183

Email: info@dawa.asn.au
Website: <http://www.dawa.asn.au>

Diabetes Mellitus

Diabetes Mellitus is a condition in which there is too much glucose in the blood. This occurs when the body fails to produce insulin or the insulin produced fails to work. Type I diabetes is not preventable; however the onset of type II diabetes can be slowed or prevented.

In Type I diabetes the pancreas does not produce insulin usually because the cells which make insulin have been destroyed by the immune system (genetic condition). Type II diabetes may also be genetic; however by adjusting lifestyles to include physical activity and healthy eating patterns, it can be prevented or delayed. Type II diabetes is mainly a problem of ineffective insulin.

It is important that diabetes is diagnosed and controlled as soon as possible to prevent damage to the eyes, kidneys, nerves, blood vessels and heart.

Objectives of the Group

- To create freedom from diabetes through education, prevention and managing diabetes, advocacy and support
- To make living with diabetes easier
- To increase support for diabetes research
- To enhance the image and profile of diabetes amongst stakeholders and the general community.

Activities and Services

- Education programs for people living with Type I and Type II diabetes
- A telephone counselling and information service staffed by diabetes educators (individual appointments may be made)
- Advocacy
- A retail outlet for the purchasing of products to assist people in managing their diabetes
- D-Links, a newly developed network, links people with diabetes to a range of support services. Those people with type I diabetes are welcome to join 'Insights', which is a network for 17-35 year olds.

Publications/Resources

The Organisation has a resource library and produces a number of pamphlets and fact sheets which can be found on the website.

Down Syndrome Association of Western Australia (Inc)

Unit 4 / 1136 Albany Highway
BENTLEY WA 6102

PO Box 338
BENTLEY WA 6982

Ph: (08) 9358 3544
Freecall: 1800 623 544
Fax: (08) 9358 3533

Email: dsawa@upnaway.com
Website: <http://www.dsawa.asn.au>

Down Syndrome (Trisomy 21)

Down syndrome is the most common form of intellectual disability, occurring once in every 800 births. Physical characteristics and intellectual disabilities vary greatly in people with Down syndrome and may include visual impairment and congenital heart disease. Most people with Down syndrome enjoy good health.

Down Syndrome (Mosaic & Translocation)

A small percentage of people with Down syndrome will have Mosaicism where there is a mixture of normal cells and cells with an extra 21st chromosome. Translocation is the least common form, affecting 2% of people with the syndrome and is the only form which may be inherited.

Objectives of the Group

- To support the community in developing the potential of individuals with Down syndrome to lead a valued life
- To provide support and information to individuals with Down syndrome and their families
- To help raise awareness of Down syndrome in the community.

Activities and Services

The Association provides support and education through various services and activities including:

- One to one parent support
- Hospital or home visits
- Networking between members
- Coffee mornings and social events
- Workshops and Information evenings and awareness displays
- Talks to schools, hospitals, community groups
- Teacher Professional Development.

Publications/Resources

The Association provides a monthly diary-newsletter and an up-to-date resource library for families and for professionals. A Parent Support Folder is available to new families, and Awareness Packages are available to schools and community groups. Education booklets and modified scissors are available for sale and information on file can be viewed or photocopied at the DSA office in Bentley.

Dyslexia SPELD Foundation WA (Inc)

PO Box 409
SOUTH PERTH WA 6951

Ph: (08) 9474 3494
Fax: (08) 9367 1145

Email: support@dyslexiaspeld.com

Specific Learning Disabilities

A specific learning disability can be defined as a significant delay in one or more areas of learning occurring in an individual of average to above average intelligence with intact hearing, vision and emotional status. The genetic component of specific learning disabilities is still being investigated.

Dyslexia is commonly associated with difficulties with phonological awareness and processing. This refers to the ability to hear and manipulate the separate sounds within words (phonemes). Spelling, comprehension, reading accuracy, reading rate, word identification and phonological coding are all affected. There is a strong hereditary component in dyslexia - that is, it runs in families.

Objectives of the Group

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

Activities and Services

- Meetings, information evenings, seminars and workshops for professionals and parents
- Psychological assessments and counselling, tutoring and teacher in-service courses
- Individual consultations are available with a computer specialist for those seeking advice about software
- An information meeting is held on the 1st Wednesday of every month.

Publications/Resources

The Foundation provides information by phone and through open monthly meetings for the general community. Library resources are available for members. Health professionals can obtain information by phone.

Other resources include:

- A bulletin is published for members three times a year.
- Resource material for tutors, classroom teachers and parents to assist with the support and education of students with specific learning difficulties

Ectodermal Dysplasia Support Group (ozED)

WA Representative – Leanne Lewis

Ph: (08) 9454 4967

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

Ectodermal Dysplasia

Ectodermal Dysplasia (ED) has over 150 different forms. The effects of ED include abnormalities to the hair, teeth, nails, sweating ability, skin disorders such as dermatitis and other ear, nose and throat issues.

Objectives of the Group

The Australian Ectodermal Dysplasia Support Group (ozED) provides:

- Support, referral and advice to all persons and families that are diagnosed with ED
- Information to health care professionals to assist in provision of quality care being provided to people and families affected by ED.

ozED will not categorise or prioritise any forms of Ectodermal Dysplasias and recognises all of the ED forms as equal.

Activities and Services

- ozED is committed to assisting families by providing support, information and education
- Information and advice for professionals in both Health and Community Care is available.

Publications/Resources

Education packages for health and other community professionals that interact with ED people and their families are available.

Epilepsy Association of WA (Inc)

The Niche, Suite B
11 Aberdare Rd
NEDLANDS WA 6009

Helpline: 1300 852 853
Ph: (08) 9346 7699
Fax: (08) 9346 7696

Email: epilepsy@cnswa.com
Website: <http://www.ictservices.com.au/~eawa>

Epilepsy

Epilepsy is a sudden disturbance of function of the brain lasting for a few seconds or minutes, and then returning to normal. Epilepsy can occur at any age and may be as the result of many factors, including head injuries, brain infection and stroke. Some types of epilepsy may be inherited.

Objectives of the Group

- To educate and support individuals and families with epilepsy, their friends and the community
- To assist individuals with epilepsy to integrate successfully into the community, allowing them to enjoy a full and productive lifestyle.

Activities and Services

- Fundraising and awareness program "World of Trivia®" for upper primary school students
- An advisory service and speakers
- A management committee meeting is held monthly and an annual seminar is held in June. An Annual General Meeting is held in October.

Publications/Resources

The Association has a resource library of information brochures, books and quarterly newsletters, audiotapes and videos on a range of related topics.

Even Keel

Bi-Polar Support Association (Inc)

PO Box 1584
MIDLAND WA 6936

Ph: (08) 9388 9869
Fax: (08) 9388 2298
Email: evenkeel@aapt.net.au
Website: <http://www.evenkeel.org.au>

Bi-Polar Affective Disorder

Bipolar disorder, or manic-depressive illness (MDI) , is one of the most common, severe, and persistent mental illnesses. Bipolar disorder is characterized by periods of deep, prolonged, and profound depression that alternate with periods of an excessively elevated and/or irritable mood known as mania.

The symptoms of mania include a decreased need for sleep, pressured speech, increased libido, reckless behaviour without regard for consequences, grandiosity, and severe thought disturbances, which may or may not include psychosis. Between these highs and lows, patients usually experience periods of higher functionality and can lead a productive life.

Objectives of the Group

- To reduce the stigma associated with mental illness
- To empower individuals who have Depression and Bi-polar Disorder
- To provide information and community education about Bi-Polar Disorder
- To provide friendship and support to individuals with Depression and Bi-Polar Disorder
- To provide friendship and support to friends and family of individuals with mental illness
- In addition to Bi-Polar Affective Disorder, the Association provides support for schizophrenia and other related disorders.

Activities and Services

- Counselling to people with Depression and Bi-Polar Disorder and their carers
- Meetings are held monthly at Midland, Fremantle, Perth City, Rockingham and Yokine, Subiaco, Heathridge, Mandurah, Busselton and Mt Barker
- Online support group is available through the website
- Guest speakers available for health professionals.

Publications/Resources

The Association has a resource centre and library situated in the June O'Connor Centre at 2 Nicholson Road, Subiaco: Phone 9388 9869.

Opening hours for the centre are Friday 9.30am to 4.00pm.

Fabry's Support Group (Inc)

P.O Box 269
WILLOUGHBY NSW 2068

Contact: Megan

Ph: (02) 9967 4395

Email: fookes@ozemail.com.au
Website: <http://www.fabry.net.au>

Fabry Disease

Fabry disease is caused by the lack of or faulty enzyme needed to metabolize lipids, fat-like substances that include oils, waxes, and fatty acids. A mutation in the gene that controls this enzyme causes insufficient breakdown of lipids, which build up to harmful levels in the eyes, kidneys, autonomic nervous system, and cardiovascular system.

Symptoms usually begin during childhood or adolescence and include burning sensations in the hands that gets worse with exercise and hot weather and small, raised reddish-purple blemishes on the skin. Some boys will also have eye manifestations, especially cloudiness of the cornea. Lipid storage may lead to impaired arterial circulation and increased risk of heart attack or stroke. The heart may also become enlarged and the kidneys may become progressively involved. Other symptoms include decreased sweating, fever, and gastrointestinal difficulties, particularly after eating.

Objectives of the Group

- To provide information and support to Australasian Fabry sufferers and their families
- To increase recognition awareness and understanding of Fabry's disease, its effects and potential solutions.

Activities and Services

- The group liaise with Government Departments
- Conduct support group meetings.

Publications/Resources

Our Newsletter was created to provide new and information on the ever-growing topic of Fabry Disease. This Newsletter, updated three monthly, provides a quick and easy way for you to stay up to date and get the latest information wherever and whenever you need it. Newsletters can be downloaded from our website or posted on request.

Fragile X Support Group of WA (Inc)

Phone Azma on (08) 9439-1828
Phone Aaron & Sharon on (08) 9439 3184

Email: fraggled@live.com
Website: <http://www.fragilex-wa.websyte.com.au>

Fragile X

Fragile X syndrome is a condition which results in problems with learning and behaviour. It is the most common cause of inherited intellectual disability (mental retardation). It is found worldwide, in all races and throughout society. There is currently no cure for fragile X but special therapies, certain ways of teaching and medication can all help people with the syndrome to perform the best they can.

Developmental delays are the most significant characteristic of those with fragile X. Learning disabilities are often accompanied by delays in speech and communication skills. There can also be delays in both gross motor (such as sitting and walking) and fine motor (such as holding a pencil) skills. People affected by fragile X syndrome are generally healthy. They do not suffer from major medical problems because of the syndrome and have a normal life expectancy.

Objectives of the Group

- To promote knowledge of Fragile X Syndrome within the community
- To provide access to, and to distribute, up-to-date information about the Fragile X Syndrome
- To provide family contact and encourage social interaction between members and their families
- To liaise with, and exchange information with other interested groups
- To promote awareness of appropriate educational and social opportunities for individuals with Fragile X Syndrome
- To promote and support appropriate planning for the future lives of individuals with Fragile X Syndrome.

Activities and Services

- Member meetings
- Parent Link
- Support and contact
- Information.

Publications/Resources

Several excellent books lodged with Activ library, Jolimont are available to members of library.

Haemophilia Foundation WA (Inc)

City West Lotteries House
2 Delhi Street
WEST PERTH WA 6005

Ph: (08) 9420 7294
Fax: (08) 9486 8966

Email: office@hfwa.org
Website: <http://www.haemophilia.org.au>

Haemophilia

Haemophilia is a genetic condition transmitted on the X chromosome (a sex linked chromosome). The deficiency in clotting factor produces a wide range of bleeding episodes which are mostly internal and are usually into the joints or muscles. These bleeding episodes may occur spontaneously or as the result of injury. The bleeding is stopped by the infusion of the appropriate clotting factor by intravenous injection. Haemophilia occurs almost exclusively in boys.

von Willebrand Disease is another bleeding condition. In von Willebrand disease there is a combined deficiency of factor VIII and a platelet abnormality. Unlike Haemophilia, von Willebrand disease is not carried on a sex linked chromosome the condition affects males and females equally.

Objectives of the Group

- To provide support, information and advocacy to individuals and their families and carers with haemophilia or Von Willebrand disease
- To promote a better lifestyle for individuals with haemophilia
- To increase public awareness of this condition.

Activities and Services

- Seminars and conferences
- Child and family camps and outings
- Counselling service
- Limited financial support for equipment for members
- Monthly Committee Meeting with additional meetings as required and an Annual General Meeting.

Publications/Resources

The Foundation provides members with bi-monthly state and national newsletters. Restricted library and Internet use, as well as brochures and other literature covering a wide range of (bleeding condition) issues are available to the community.

Heart Kids WA (Inc)

PO Box 1554
WEST PERTH WA 6872

0417 417 203 (Support Coordinator)
Ph: (08) 9340 7996
Fax: (08) 9340 7997

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

Including:

Di George syndrome/Velo-Cardio Facial syndrome (VCFS)

Contact: Dianne Lunt Ph: (08) 9341 7395

VATER Association (also known as VACTERL Association)

Contact: Michelle Rainsforth Ph: (08) 9388 9238 (08) 9398 5449
Mobile 0409 207 710
Email: m.rainsforth@bigpond.com

Heart Defects

Congenital heart defects result from abnormalities in the foetal development of the heart and major vessels during pregnancy and may be caused by maternal illness (for example Diabetes Mellitus), environmental exposure or as part of a genetic condition. Some children may not develop heart problems until later in childhood (acquired).

Objectives of the Group

To provide support for children and their families with congenital or acquired heart disease and their families.

Activities and Services

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 camps and Kids Camps
- Displays are assembled at medical and community events. Community awareness through displays at community events and medical centres
- Speakers are available.

Publications/Resources

The Group has a library of resources for health professionals and the community, including books and videos and Group produces a quarterly newsletter.

Klinefelter's Support Group

14 Shetland Drive
Henley Brook WA 6055

Ph: (08) 9296 8661

Email: kerrygavey@inet.net.au
Website: <http://www.klinefelterswa.websyte.com.au>

Klinefelter's Syndrome

Klinefelter's syndrome is a genetic condition affecting males in which there are three sex chromosomes (XXY) instead of two (XY). Individuals with this condition are considered male, however the condition *maybe* characterised by the enlargement of the breasts, the absence of facial and body hair, the failure of normal sperm production, and small testes.

Objectives of the Group

One of the important aspects of the Klinefelter's Support Group is to provide support, information and resource materials about Klinefelter's syndrome to affected individuals and families in Western Australia to help men and boys with this syndrome adjust to life.

The Klinefelter's Support Group also endeavours to provide health professionals and the community with information about our support group and Klinefelter's syndrome.

Activities and Services

Information is provided by the Group upon request.

Learning and Attentional Disorders Society of WA (LADS)

The Niche, Suite B
11 Aberdare Rd (cnr Hospital Ave)
NEDLANDS WA 6009

Ph: (08) 9346 7544
Fax: (08) 9346 7545

Email: lads@cnswa.com
Website: <http://www.ladswa.com.au>

Learning and Attention Disorders

Learning and attention disorders are characterised by the inability to acquire or retain information or skills as a result of a deficit in attention, memory or reasoning. Individuals with Attention Deficit Hyperactivity Disorder, may daydream, not seem to listen, find it hard to start or stay on task, procrastinate, be forgetful and disorganised, and may be easily frustrated and quick to anger. A number of genetic conditions are characterised by learning and attentional disorders.

Objectives of the Group

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

Activities and Services

- Talks, seminars, courses and workshops
- Counselling (for a moderate fee)
- Assessment
- Support is provided through informal meetings and a drop in centre
- Meetings are held monthly.

Publications/Resources

The Society publishes a newsletter and has a resource library with an extensive range of books, journal articles, videos and audiotapes available to members for loan. Information kits are available to members and non-members.

LQTS Support Group of WA (Inc)

53 Boston Way
BOORAGOON WA 6154

Ph: (08) 9364-4109

Email: tiko@inet.net.au
Website: <http://www.sads.org.au>

Long QT Syndrome

Long QT Syndrome (LQTS) is an abnormality of the heart electrical system. The mechanical function of the heart is normal however the electrical problem is due to defects in heart muscle cell structures called ion channels. These electrical defects pre-dispose affected persons to a very fast heart rhythm (arrhythmia) which leads to sudden loss of consciousness (syncope) and may cause sudden cardiac death. The QT refers to an interval measured on the electrocardiogram (ECG). This syndrome can be inherited or acquired.

Unfortunately, many times the cause of the syncope is overlooked and the events are called simple fainting spells or seizures. Most often, these events occur during physical exertion or emotional stress. In some they occur during sleep. Fortunately, most deaths are preventable if the condition is recognised and treated.

Objectives of the Group

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

Activities and Services

The group provides information and educational resources to the lay public and to health care providers in order to promote early diagnosis and treatment.

Publications/Resources

Online materials are available for information and public distribution from the website.

Lupus Group of WA (Inc), The

Level 3, N Block (adjacent to the Library and Medicine Information Service)
Royal Perth Hospital
Murray St PERTH

Royal Perth Hospital
C/o GPO Box X2213
PERTH WA 6847

Ph/Fax: (08) 9224 3144 (24 hour message bank)

Email: admin@lupuswa.com.au
Website: <http://www.lupuswa.com.au>

Lupus

Lupus is a widespread and chronic (lifelong) autoimmune disease that, for unknown reasons, causes the immune system to attack the body's own tissue and organs, including the joints, kidneys, heart, lungs, brain, blood, or skin.

The symptoms of lupus often mimic other less serious illnesses and can range from mild to life-threatening. Lupus can go into periods where symptoms are not present, called remission and although lupus can affect any part of the body, most people experience symptoms in only a few organs.

Objectives of the Group

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

Activities and Services

The Group provides support and education services that are reviewed by the Board and Medical Advisory Panel.

Some of the services include Community, Medical and Corporate Education, and Awareness via:

- Seminars, workshops, community Expo's and educational displays
- Advertising and media liaison
- Annual Lupus Awareness Month activities (October)
- Web access: <http://www.lupuswa.com.au>
- Phone-line help: Assistance with 'living with lupus', provision of mutual support to share information, personal experiences and coping strategies
- Advocacy via Provision of information to relevant policy and decision-makers to improve awareness, funding and service provision towards lupus
- Fundraising: Generation of income for expansion and improvement of services.

Publications/Resources

Fact Sheets on a wide range of issues relating to lupus as well as brochures and a Newsletter is available upon request.

Mental Illness Fellowship Western Australia (Inc)

212 Bagot Rd
SUBIACO WA 6008

PO Box 1243
SUBIACO WA 6904

Ph: (08) 9380 6688 (10am-4pm, Monday to Friday)
Lorikeet Clubhouse Ph: (08) 9381-9144 Fax: (08) 9380 6699

Email: mifwa@bigpond.com

Schizophrenia

Schizophrenia is a condition characterised by disturbances in a person's thoughts, perceptions, emotions and behaviour. It affects approximately one in every 100 people worldwide and first onset commonly occurs in adolescence or early adulthood. Schizophrenia is not a single illness. It is in fact a cluster of illnesses, which have overlapping signs and symptoms. It is therefore important to acknowledge the unique experience of each person living with schizophrenia.

Objectives of the Group

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

Activities and Services

- Seminars and talks
- Self-Care for Carers courses
- Various activities during Schizophrenia Awareness Week, Mental Health Week and Carers Week
- Accredited rehabilitation service for people with a history of mental illness: contact Lorikeet Clubhouse
- Thursday support group for carers and consumers each week.

Publications/Resources

The Fellowship has a resource library with books, videos, audiotapes and reports, which are available for loan for members (a small fee applies to non-members). A quarterly newsletter is published for members as well as regular mail outs.

Motor Neurone Disease Association WA (Inc)

The Niche Suite B,
11 Aberdare Rd
NEDLANDS WA 6009

Ph: (08) 9346 7355
Fax: (08) 9346 7332

Email: mndawa@cnswa.com
Website: <http://mndawa.iinet.net.au>

Motor Neurone Disease

Motor neurone disease (MND) is a group of conditions in which the nerve cells (neurones) controlling the muscles fail to work normally. With the degeneration of the nerves, muscles gradually weaken and waste. There is ongoing research into the causes of MND and approximately 10% of MND cases have been shown to have a genetic link.

Objectives of the Group

- To increase awareness of MND within the community, government and medical profession
- To ensure that people with MND, their carers families and support networks have access to the resources required to maximise their lifestyle
- To support research into MND.

Activities and Services

- Care advisory service by telephone or home visit and advice on timely access to appropriate support services and advocacy
- Carer support meetings monthly
- Equipment library with aids for loan to assist with mobility and communication.
- Bi-monthly social 'Get togethers' between members to share knowledge and experience
- Support vital medical research through the MND Research Institute.

Publications/Resources

The Association provides a monthly newsletter, fact sheets and information booklets. Library resources also include videos and books.

Mucopolysaccharide & Related Diseases Society

10 Spruce Place
FORREST LAKES WA 6108
Ph: (08) 9456 1345

Email: colmax2@primus.com.au

Mucopolysaccharide and Related Diseases

Mucopolysaccharide and related diseases are genetic metabolic conditions characterised by the inability to produce particular enzymes necessary for certain chemical changes to occur in the body. This results in the storage of complex sugars within body tissue causing progressive physical and intellectual damage. There are several types of mucopolysaccharide disease, such as Hurler, Hunter, Sanfilippo, Maroteaux-Lamy and Sly, Mucopolipidosis and Fucosidosis .

Objectives of the Group

- To provide support and information to families and other interested people
- To promote a partnership between families and professionals
- To promote a community awareness of the mucopolysaccharide condition and its impact on families and carers.

Activities and Services

- Get togethers
- Fundraisers
- Annual meetings.

Publications/Resources

The Society has various booklets and information sheets available that cover the different syndromes as well as helpful ideas.

Muscular Dystrophy Association of WA

PO Box 328
WEST PERTH WA 6872

Ph: (08) 9382 2700
Freecall: 1800 654 632
Fax: (08) 9346 3487

Email: mda@cyllene.uwa.edu.au
Website: <http://www.mdawa.asn.au>

Muscular Dystrophy

Muscular Dystrophy (MD) is a genetic condition characterised by the gradual wasting of muscle with accompanying weakness and deformity. There are different types of MD, such as Myotonic Dystrophy, Friedreich Ataxia, congenital muscular dystrophy, spinal muscular dystrophy and Duchenne Muscular Dystrophy.

Objectives of the Group

- To provide support for individuals with MD and other neuromuscular conditions, their carers and families and relieve the suffering caused by MD and other conditions
- To advance research and provide investigative counselling and diagnostic services
- To provide advisory, advocacy and individual and family support services.

Activities and Services

- Loan of specialist equipment
- Information to members and the general public
- Liaison with allied organisations, Federal and State government departments
- Funding of research into MD and allied neuromuscular conditions
- Provide assistance to and support the Quokka Kids/Teens Club
- Provide community education about the Association, muscular dystrophy and other neuromuscular conditions
- Provide diagnostic services to the community through the Australian Neuromuscular Research Institute Clinic and Royal Perth Hospital's Department of Neuropathology
- To fund programs of, scientific research, patient and family services and for the raising of community awareness
- Lecture series on neurological/neuromuscular conditions are held every Friday for health professionals and interested members of the public.

Publications/Resources

The Association has an extensive library for health professionals on muscular dystrophy and other neuromuscular conditions. Fact sheets are available to both the community and health professionals.

Neurofibromatosis Association WA (Inc)

Suite B The Niche
11 Aberdare Rd
NEDLANDS WA 6009

Ph: (08) 9346 7488
Fax: (08) 9346 7534

Email: nfawa@cnswa.com
Website: <http://www.cnswa.com>

Neurofibromatosis

Neurofibromatosis (NF) is a genetic condition characterised by benign tumours (neurofibromas) developing in the body's nervous system. Signs of NF are coffee coloured patches on the skin, bone malformation, speech impediment and sight and hearing defects. NF conditions are divided into two classes - NF1 and the rarer form NF2.

Objectives of the Group

- To support individuals with NF and their carers by bringing families and individuals together
- To promote awareness of the condition within the community, particularly amongst medical practitioners and other health care workers
- To provide up to date information gathered from national and international sources
- To raise funds to support these objectives and also to support ongoing medical research.

Activities and Services

- Awareness Month (with International Awareness Month)
- Meetings on the second Thursday of each month at 7.30pm.

Publications/Resources

The Association provides various brochures and specific topic booklets to health professionals and the community.

Parents of Children with Disabilities

The Kalparrin Centre
GPO Box D184
PERTH WA 6840
Corner Roberts Rd & Thomas St Subiaco
Next to Princess Margaret Hospital

Coordinator: Linda Macdonald

Ph: 9340 8094
Fax: 9380 6114

Email: kalparin@iinet.net.au
Website: <http://www.kalparrin.org.au>

Objectives of the Group

To provide practical and emotional support for families of children with special needs to assist them to achieve a better quality of life.

Activities and Services

- Support groups can make use of the Kalparrin Centre, free of charge, to use as their monthly meeting place
- The Kalparrin Centre is available for day or night time Meetings
- Parent lounge, toy room, free tea and coffee
- The Centre is open to any family member of a child with a disability or special needs regardless of degree of severity or type of impairment
- Information can be forwarded to parents free of charge
- Twice yearly mother respite weekends
- Parent link program for all disabilities.

Resources/Publications

- The Centre has a comprehensive collection of directories, and contact points for support groups and community organisations that maybe of value to you or your family
- Kalparrin has an up to date selection of pamphlets available from most agencies, support groups and Disability Services Commission and Family and Children Services
- Comprehensive information via the internet and an up to date reference and leaflet collection
- Quarterly newsletter 'Kalparrin Cares' which provides up to date information on disability issues.

Periodic Paralysis Society

24/152 Great Eastern Hwy
ASCOT WA 6104

Ph: (08) 9477 4249

Email: suefraser@amnet.net.au

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

Including: Myotonia Congenita

Periodic Paralysis

The Periodic Paralysis are a group of rare, genetic, muscle-membrane disorders (channelopathies) that cause episodes of muscle weakness and/or paralysis. Symptoms vary from muscle weakness and/or stiffness to complete paralysis that may be life threatening.

Objectives of the Group

To provide accurate, current information, support, representation and to work together to improve the quality of life of people with periodic paralysis and associated conditions.

Activities and Services

- Website information
- Meetings every second month
- Phone support
- Information on International Support Groups and International Medical Information.

Publications/Resources

- Periodic Paralysis Society of Australia Pamphlets
- Access to medical journal articles and several texts.

PXE Support Group

8 Cook Street
Darlington WA 6070

Ph: (08) 9299 6043

Email: frederikz@aapt.net.au
Website: <http://www.pxe.org>

Pseudo Xanthoma Elasticum (PXE)

PXE It is an inherited disorder is an inherited disorder that affects selected connective tissue in some parts of the body. Elastic tissue in the body becomes mineralized, that is, calcium and other minerals are deposited in the tissue. This can result in changes in the skin, eyes, cardiovascular system and gastrointestinal system.

Objectives of the Group

To provide information and support to PXE sufferers and their families by supplying the latest updates on information about PXE.

Activities and Services

- Information (electronic and on paper) is available any time as is personal support
- Group meetings are held occasionally, mainly on a social level.

Publications/Resources

PXE International produces the Magazine 'PXE Membergram' both in printed form as well as electronically and is available to all interested persons.

Raynaud's Syndrome Support Group

19 Ada Street
WATERMANS WA 6020

Ph: (08) 9447 9922 (after 7pm)

Raynaud Syndrome

Raynaud Syndrome is a condition that affects the blood vessels in the extremities – generally, the fingers and toes. It is characterized by episodic attacks, called vasospastic attacks, in which the blood vessels in the digits (fingers and toes) constrict (narrow), usually in response to cold temperatures and/or emotional stress. When this condition occurs on its own, it is called primary Raynaud's phenomenon. When it occurs with another condition such as scleroderma or lupus, it is called secondary Raynaud's phenomenon.

Objectives of the Group

- To provide support and information to individuals with this condition
- To promote greater awareness and educate the community
- To provide information to health professionals about this condition.

Publications/Resources

The Group provides written materials upon request.

Rett Syndrome Association of WA

26 Cardiff Gate
ILUKA WA 6028

Ph: (08) 9305 4339

Email: sanafay@hotmail.com

Rett Syndrome

Rett Syndrome is a neurological disorder occurring primarily in girls, in which individuals exhibit reduced muscle tone, autistic-like behaviour, stereotyped hand movements consisting mainly of wringing and waving, loss of purposeful use of the hands, diminished ability to express feelings, avoidance of eye contact, a lag in brain and head growth, gait abnormalities and seizures.

Objectives of the Group

- To collect and disseminate accurate and objective information regarding the cause, identification, treatment, prevention and cure of Rett syndrome
- To promote the general welfare of individuals with Rett syndrome
- To support families in coping with the condition
- To develop understanding and awareness of Rett syndrome
- To further the advancement of study, research, therapy and care.

Activities and Services

- General support and information
- Parent to parent support when required
- Contribute to the Australian Rett Syndrome Study
- Meetings throughout the year and an end of year Christmas picnic.

Publications/Resources

The Association provides an Australian quarterly newsletter and other overseas newsletters, a parent contact list, pamphlets, journal articles, books and videos.

Senses Foundation (Inc)

PO Box 143,
BURSWOOD WA 6100

Phone: (08) 9473 5400
Fax: (08) 9473 5499

Email: admin@senses.asn.au
TTY: +61 8 9473 5488

Email: reception@senses.asn.au
Website: <http://www.senses.asn.au>

The Senses Foundation

Deafblindness is the unique sensory disability of combined loss of hearing and vision which significantly affects communication, socialisation, mobility and daily living. Deafblind individuals are affected to varying degrees with most having some level of hearing or vision. The conditions of deafness or blindness may be acquired or present at birth. The main causes are congenital rubella syndrome, Usher syndrome, CHARGE syndrome and ageing.

Objectives of the Group

The Senses Foundation was formed in 2001 from the amalgamation of two organisations, the Royal WA Institute for the Blind and the Deafblind Association. Our aim is to be a nationally and internationally recognised centre of excellence for people with disabilities particularly those who are blind or deafblind.

Activities and Services

We provide services to people with disabilities, particularly people who are blind or deafblind and to their families and carers. Senses is also a resource for other service providers. We provide information, advice and support including:

- Liaison and referral services and specialist communication services
- Recreation programs throughout the metropolitan area
- Therapy services including occupational therapy and physiotherapy
- Respite programmes; in-home and out-of-home respite to families through the provision of trained staff
- Employment support
- Supported accommodation to maximise independence
- Social Work service providing counselling and support for clients and their families experiencing grief or loss. Also able to provide assistance with funding and grant information
- In-home Assessment, mobility aids and home modification assessments and advice.

Activities

- Regular events including a corporate golf day and Bingo Centre in Bayswater
- Deafblind Awareness Week held every June.

Publications/Resources

Directory of Genetic Support Groups and Community Support Organisations in WA

The Senses Foundation produces a newsletter 'Senses News' for supporters, with plans to produce a client newsletter in the future. A list of publications and resources is available on request.

Short Statured People's Association WA Branch

30 Leslie Street
MUNDARING WA 6073

Ph: (08) 9295 0636

Short Stature

Short stature may occur as one of many genetic conditions causing the abnormal growth or development of the skeleton. Short stature is identified as height less than 1.45 metres tall at maturity and often with disproportionate limbs and skull. There are many different forms of short stature, with different modes of inheritance and different rates of occurrence.

Objectives of the Group

- To support individuals of short stature and their families and parents who have short statured babies
- To assist in the assimilation of short statured people into society with the goal of equality of educational and social status and of employment opportunities.

Activities and Services

- Social meetings approximately 3-4 times per year
- Picnics and other recreational activities for children
- Advice regarding pre-school and school choices
- Support through mutual discussion and contact with other parents
- Community education through seminars and videos on short stature
- Journal informing members of the work being carried out by the national group and state sub-groups
- An annual national convention
- Promotion of personal development and self esteem through contact with others of short stature and of average height
- Advice and assistance on career and TAFE opportunities
- Promotion of research into causes and treatment through National Medical & Scientific Advisory Board.

Publications/Resources

The Association has a range of publications and guides available upon request.

Sjögren's Syndrome Support Group

19 Suiza Place
CARINE WA 6020

Ph: (08) 9447 9922 (after 7pm)

Sjögren Syndrome

Sjögren syndrome is an inflammatory autoimmune condition that can affect many different parts of the body, but most often affects the tear and saliva glands. People with this condition may notice irritation, a gritty feeling, or painful burning in the eyes. Dry mouth or difficulty eating dry foods and swelling of the glands around the face and neck are also common. Some people experience dryness of other mucous membranes (such as the nasal passages, throat) and skin.

Most of the complications of Sjögren's syndrome occur because of decreased tears and saliva. Sufferers with dry eyes are at increased risk for infections around the eye and may have damage to the cornea. Dry mouth may cause an increase in dental decay, gingivitis (gum inflammation), and oral yeast infections (thrush) that may cause pain and burning. Some patients have episodes of painful swelling in the saliva glands around the face.

Objectives of the Group

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

Activities

- Autoimmune condition seminars are held at the Arthritis Foundation periodically.

Publications/Resources

The Group provides various written material providing information for health professionals and the community.

SOFTWA

(Support Organisation for Trisomy and Related Disorders of WA)

16 Ricketts Way,
Rockingham WA 6168

Contact: Mandy

Ph: (08) 9591 3316

Email: softwa@arach.net.au
Website: <http://www.trisomy9.org/softwa.htm>

Trisomy and Other Related Disorders

Trisomy disorders have a range of different characteristics including physical and intellectual disability. There are different Trisomy conditions, including Trisomy 18 (Edwards Syndrome), Trisomy 13 (Patau Syndrome), Trisomy 9 and Trisomy 22.

Objectives of the Group

- To help and provide support to families dealing with a child with a rare chromosomal disorder.

Activities and Services

- Provide information and about the condition
- Provide links to other individuals dealing with the same condition
- Picnics and other recreational activities.

Publications/Resources

The organisation provides information on a range of rare chromosomal conditions to the community and health professionals.

Spina Bifida Association of WA (Inc)

The Niche Suite B,
11 Aberdare Rd
NEDLANDS WA 6009

Ph: (08) 9346 7520
National Information Line: 1300 655 447
Fax: (08) 9346 7519

Email: info@sbawa.asn.au
Website: <http://www.sbawa.asn.au>

Spina Bifida

Spina Bifida is a neural tube defect in which a part of the spinal cord or the immediate covering of the spinal cord protrudes through a gap in the spine. It is thought that some neural tube defects are a result of a genetic disposition. Depending on the size of the defect and where it occurs on the back there may be problems which include leg weakness, lack of feeling in the legs, lack of bladder and bowel control, odd shaped feet, dislocated hips and the curvature of the spine.

The consumption of folic acid as primary prevention has been recommended for women of childbearing age. This does not prevent all neural tube defects.

Objective of the Group

- To provide support for individuals with spina bifida and their families.

Activities and Services

- Family support
- Family camps
- Community education
- Subsidies for tutors' fees (when funds are available)
- A young adults program
- Speakers and education sessions.

Publications/Resources

The Association has a library and information service available for the community and health professionals. The range of information is extensive and includes many conditions associated with spina bifida.

A small section of fictional books incorporating disability issues are available for children.

Stickler Syndrome Australia Support Service (SSASS)

7 Noojee Court,
KALLANGUR Qld 4503

Ph: (07) 3886 0665

Email: ssass@hotmail.net.au

Stickler syndrome

Stickler syndrome is a group of hereditary conditions characterised by a distinctive facial appearance, eye abnormalities, hearing loss, and joint problems. These signs and symptoms vary widely among affected individuals.

Many people with Stickler syndrome have severe nearsightedness (high myopia). Other eye problems are also common, including increased pressure within the eye (glaucoma) and tearing of the lining of the eye (retinal detachment). These eye abnormalities can cause impaired vision or blindness in some cases.

Hearing loss is another feature of Stickler syndrome. The degree of hearing loss varies among affected individuals, and the loss may become more severe over time.

Most people with Stickler syndrome have skeletal abnormalities that affect the joints. For example, the joints of affected children and young adults may be loose and very flexible (hypermobile), though joints become less flexible with age. Arthritis often appears early in life and may cause joint pain or stiffness.

Objectives of the Group

- To provide support to individuals, their parents and their families affected by Sticker syndrome.

Activities and Services

Contact can be by internet, phone or writing, though internet is preferred.

Publications/Resources

Newsletters are produced biannually/annually, depending on demand.

Thalassaemia Association WA (Inc)

PO Box 879
MORLEY WA 6943

Ph/Fax: (08) 9276 1380

Website: <http://www.thalassaemia.org.cy>

Thalassaemia

The Thalassaemias are a group of inherited disorders in which the production of normal haemoglobin is partly or completely suppressed because of a defective synthesis of one or more of its component globin chains. There are three types; major, minor and intermedia, each differing in severity. Thalassaemia Major results in severe anaemia requiring frequent blood transfusions.

Objectives of the Group

- To assist individuals with Thalassaemia and related conditions to obtain a better quality of life through education and direct medical assistance
- To educate the community about Thalassaemia.

Activities and Services

- Psychological support
- Education seminars and workshops at venues including schools, community centres and clubs
- An Annual General Meeting and Support Group meetings
- Executive committee meetings monthly.

Publications/Resources

The Association provides pamphlets and flyers for the community and health professionals. Educational videos are also available for health professionals.

Turner Syndrome Association of Australia Ltd (WA)

PO Box 1291
MIDLAND WA 6936

Ph: (08) 9458-5255

Email: taoneill@bigpond.com
Website: <http://www.turnersyndrome.org.au>

Turner Syndrome

Turner syndrome (TS) results from a chromosomal abnormality in which a female infant is born with only one X chromosome (instead of the usual two) or is missing part of one X chromosome. In most cases, untreated females with this disorder are typically short in stature (average final adult height is 4 feet 7 inches [140 centimetres]) and may have a variety of associated physical features and medical problems.

Because females with TS don't have proper ovarian development, they usually don't develop all of the secondary sexual characteristics expected during adolescence and are infertile as adults. Other health problems that may occur with TS include kidney and heart abnormalities, high blood pressure, obesity, diabetes mellitus, cataracts, thyroid problems, and arthritis.

Girls with Turner syndrome usually have normal intelligence, but some may experience learning difficulties, particularly in mathematics. Many also have a problem with tasks requiring spatial skills, such as map reading or visual organization. Hearing problems are also more common in girls with Turner syndrome.

Objectives of the Group

- To assist individuals, families to have a healthier and better adjusted life
- To educate and to help people gain a greater knowledge of TS.

Activities and Services

- Education conferences
- Support Group meetings.

Publications/Resources

- Quarterly newsletter for members
- The Association provides pamphlets and flyers for the community and health professionals.

Von Hippel-Lindau Syndrome

PO Box 410
WANNEROO WA 6946

Ph: (08) 9206 0349
Fax: (08) 9306 2752

Email: michael@west-coast.com.au
Web: <http://www.vhl.org>

Von Hippel-Lindau Syndrome

Von-Hippel-Lindau syndrome (VHL) is an autosomal dominant condition. It is caused by a flaw in one gene, the VHL gene, on the short arm of chromosome 3, which regulates cell growth. Carriers can potentially develop tumours (benign) in the C.N.S., eyes, pancreas, adrenals and malignant in kidney as well as other rare occurrences.

Activities and Services

- Provision of information relating to the condition and to the VHL Family Alliance
- Assistance contacting other Australian VHL Family Alliance representatives.

Publications/Resources

The group has a range of information materials for both the community and health professionals.

Western Australian Retinitis Pigmentosa Foundation (Inc)

2/251-255 Stirling Street
PERTH WA 6000

Ph: (08) 9227 7585
Fax: (08) 9227 7842

Email: warpf@inet.net.au
Website: <http://www.retinitispigmentosa.com.au>

Retinitis Pigmentosa

Retinitis Pigmentosa (RP) is a hereditary retinal dystrophy causing degeneration of the retina. The retina is a light sensitive tissue at the back of the eye that transmits visual images to the brain where 'seeing' actually occurs. As the retina progressively degenerates so does the quality of visual images that the brain can see. Other hereditary retinal dystrophies are macular degeneration, Usher syndrome and Laurence-Moon-Biedl syndrome.

Objectives of the Group

- To raise awareness of RP and associated dystrophies
- To offer support for newly diagnosed individuals
- To ascertain the cause and means to cure or arrest all forms of hereditary retinal dystrophies
- To seek by all practical means ways to assist those affected and their families
- To gather and disseminate information on RP and all forms of hereditary retinal dystrophies
- To affiliate with Retina Australia and Retina International and to cooperate with all blind welfare and low vision agencies
- To raise funds in order to achieve the objectives.

Activities and Services

- Peer support
- Counselling
- Information
- Fund raising
- An annual general meeting in October.

Publications/Resources

The Foundation provides a newsletter and information booklets to the community. A medical library has brochures and booklets for health professionals.

Western Australian Tourette Syndrome Organisation (Inc) WATSO

Ph: (08) 9448 4040

Tourette Syndrome

Tourette syndrome is a genetic condition affecting neurological movement beginning between 2-16 years of age. It is characterised by rapidly repetitive multiple movements (tics) and involuntary vocalisations. Approximately 10% of individuals with Tourette syndrome have a family history of the condition.

Objectives of the Group

- To support individuals with Tourette syndrome and their family and carers
- To increase public and professional awareness of this syndrome.

Activities and Services

- Meetings once a month.

Publications/Resources

- The Organisation provides education packs to health professionals
- A small library of photocopied information, books, videos and pamphlets is available.

Community Support Organisations

Activ Foundation

41 Bishop St
JOLIMONT WA 6014

Ph: (08) 9387 0555
Fax: (08) 9387 0599

Email: info@activ.asn.au
Website: <http://www.activ.asn.au>

Open: 8.30am–5pm, Monday to Friday

Objectives of the Group

Dedicated to promoting a better life by providing a range of choices and opportunities for people with disability and their families living and working in the community.

Activities and Services

- Innovative employment support
- Alternatives to employment programmes
- All ages respite
- Retirement planning
- Recreation and travel services
- Transport services.

Publications/Resources

- The Activ library is a major disability library and has a vast collection of books, journals, training materials and resources suitable for parents, people with disability, carers, teachers and professional staff.
- The Association also produces the 'Activ News' Newsletter.

ARAFMI

Mental Health Carers and Friends Association

First Floor, 275 Stirling Street (Cnr Bulwer St)
PERTH WA 6000

Counselling and information
Ph: (08) 9228 0579
Rural Freecall: 1800 811 747
Administration
Ph: (08) 9228 0577
Fax: (08) 9228 0440

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

Mental Illness

Mental illness includes a variety of conditions such as depression, bipolar, anxiety, schizophrenia, eating disorders, and obsessive compulsive disorder. Mental illness can affect individuals from all walks of life. Research has shown that some individuals have a genetic predisposition to mental illness.

Objective of the Group

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

Activities and Services for Carers and Friends

- Youth Services (for 8 – 18 year olds who have a relative with mental illness)
- Share and care groups (facilitated by carers for carers). Meetings occur regularly across the metro area – call an ARAFMI office for further details
- Counselling
- Community Education
- School Education program
- Psycho-education (covering topics such as stress management, grief and loss, assertiveness skills)
- Holiday Respite program – call (08) 9402 7022 for further details.

Publications/Resources

ARAFMI offices have libraries, including videos, available for members. Members also receive a quarterly magazine to keep them informed on activities within the MH Sector.

Arthritis Foundation of WA

Including:

Osteoporosis WA

The Ankylosing Spondylitis Support Group

The LINK Group

Fibromyalgia Support Group

General Arthritis Support Groups

17 Lemnos Street
SHENTON PARK WA 6008

PO Box 34
WEMBLEY WA 6008

Ph: +61 8 9388 2199
Fax: +61 8. 9388 4488

Email: general@arthritiswa.org.au
Website: <http://www.arthritiswa.org.au>

Arthritis

Arthritis includes a variety of conditions which affect the joints of the body. There are more than 100 different types of arthritis, some of which have a genetic component. The most common forms of arthritis are Osteo-arthritis, Rheumatoid Arthritis and Gout. Other conditions include Ankylosing Spondylitis, Scleroderma, Fibromyalgia, Ross River Virus and Osteoporosis.

Objective of the Group

To reduce the incidence and disabling effects of arthritis, osteoporosis and related conditions.

Activities and Services

- Provide information to the community and health professionals through seminars and courses, as well as via the telephone
- Gymnasium and hydrotherapy facilities
- Information, services and support for individuals with arthritis, osteoporosis and related musculoskeletal conditions
- Self management courses for people: Osteoarthritis of Knee course, Rheumatoid Arthritis course, Arthritis – Challenge Your Arthritis course, Chronic diseases - Get The Most Out of Life course.

Publications/Resources

The Foundation has a range of information brochures and videos available through their specialist bookshop.

Asthma Foundation of Western Australia (Inc)

36 Ord Street
West Perth WA 6005

PO Box 864
WEST PERTH WA 6872

Ph: (08) 9289 3600
Fax: (08) 9289 3601

Email: ask@asthmawa.org.au
Website: <http://www.asthmawa.org.au>

Asthma

Asthma is a condition in which the airways in the lungs become narrow causing wheezing, coughing or difficulty in breathing. Asthma tends to run in families and generally the stronger the family history of asthma the more likely it is that the child will develop it.

Objectives of the Group

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

Activities and Services

- The Asthma Foundation of WA holds a wide range of activities and services for the community and health professionals including:
- Monthly Community education sessions (across metropolitan areas, and at selected times in country areas)
- AsthmaSwim for adults
- Seminars are held for health professionals, as well as a nationally recognised course in asthma education
- National Asthma Week is held in September each year for the community and health professionals
- Telephone advice for people with asthma and their carers
- Asthma therapy equipment such as nebulisers and spacer devices are available for sale
- Triple 'E' – a day activity program for children aged 8-12 who have asthma or know a child with asthma
- Nationally Accredited Emergency Asthma Management Course – for those who owe a duty of care to someone with asthma e.g. sport coaches, child care workers etc.

Publications/Resources

The Group provides brochures, booklets and pamphlets to the community and health professionals.

Australasian Genetic Alliance

2006/2007 Secretariat

C/- 66 Albion Street
SURRY HILLS NSW 2010

Ph: + 61 2 9211 1462
Fax: + 61 2 9211 8077

Email: info@australasiangeneticalliance.org.au
Website: <http://www.australasiangeneticalliance.org.au>

The Australasian Genetic Alliance

The Australasian Genetic Alliance (AGA) is a network of peak 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.

Objectives of the Group

The AGA works collectively to support people living with a genetic condition, to increase community awareness by networking and sharing resources and representing common interests.

Activities and Services

- To contribute and comment on policy relating to human genetics and health services
- To network and share resources to promote genetic support services
- To participate in public debate on ethical issues relating to genetics
- To raise community awareness of genetic support groups and impact of genetic conditions on individuals and families
- To promote equity of genetic support within Australia and New Zealand
- To participate in international genetic alliances as a regional representative for Australia and New Zealand.

Alliance Members:

Association of Genetic Support of Australasia (AGSA)

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

Genetic Support Network Victoria (GSNV)

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

Genetic Support Council of Western Australia (GSCWA)

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

New Zealand Organisation for Rare Disorders (NZORD)

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

Self Help Organisations United Together (SHOUT)

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

Self Help Queensland Inc (SHQ)

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

Carers Association of WA (Inc)

182 Lord Street
Perth WA 6000

Phone: 1300 CARERS (1300 227 377)
24hr Carer Counseling Line 1800 007 332
Fax: (08) 9228 7488

Email: info@carerswa.asn.au
Website: <http://www.carerswa.asn.au>

Objectives of the Group

The Carers Association is the peak body working to actively enhance the quality of life and represent the interests and 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.

Activities and Services

- Provide information, advice and resources through the Carer Resource Centre
- Support, counselling and referrals through the Carer Support Program: individual and group counselling, referrals to carer support groups
- Carer's Week activities
- Workshops and Forums
- Monthly electronic updates to both carers and service providers
- Advocacy and Carer representation
- Service provider resources
- Public forums, displays, and expos
- Links with Carers Associations in all states and the national peak body: The Carers Association of Australia.

Publications/Resources

- The Association provides carer information packs to carers and health professionals in English, Arabic, Chinese, Croatian, Polish, Italian, Spanish, Vietnamese, Maltese, Greek, Serbian, Dutch, Hungarian and German. An Aboriginal and Torres Strait Islander carer's kit is also available.
- A resource library providing a range of information and materials relevant to both carers and health professionals assisting carers and a Quarterly newsletter is also available.

Disability First Stop

Oasis Lotteries House
37 Hampden Road
NEDLANDS WA 6009

Ph: (08) 9386 7513
Fax: (08) 9386 6705
TTY: (08) 9386 6451

Email: email@disabilityfirststop.asn.au
Website: <http://www.disabilityfirststop.asn.au>

Objectives of the Group

Disability First Stop is an innovative service that will assist people and their families 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.

Disability First Stop is a partnership of agencies (People With Disabilities WA, Kalparrin, EDAC, Carers WA, Headwest and Advocacy South West.) It is coordinated by People with Disabilities WA.

Activities and Services

- Services include advocacy, counselling, facilities for Non-English speaking people, home visits, information and referrals
- Clients in the South Western part of the state are directed to Advocacy South West find out about relevant services within their region. The Country toll free number is 1800 193 331.

Publications/Resources

- A brochure on the service is available in various formats: English, multilingual (Arabic, Amharic, Bosnian, Bahasa Malay, Chinese, Croatian, Dari, Farsi, Serbian, Somali, Spanish, Tigrinya, Vietnamese) and for indigenous populations
- A4 & A5 Posters, stickers and magnets are other forms of promotional material are also available up on request about the program.

Ethnic Disability Advocacy Centre

320 Rokeby Road
SUBIACO WA 6008

Ph: (08) 9388 7455
Fax: (08) 9388 7433
Freecall: 1800 659 921

Email: admin@edac.org.au
Website: <http://www.edac.org.au>

Objectives of the Group

To promote, advocacy, support, information, referral, networking, lobbying and training for people with disabilities from culturally and linguistically diverse backgrounds and their families and carers.

Activities and Services

- EDAC provides information on disability support services, community groups and government agencies/policies
- We have some translated resources and can arrange an interpreter to ensure you understand your options and rights
- EDAC provides a meeting place for the Multicultural Family Support Group, NESB Mental Health Group and Consumer Reference Group
- We organise activities which create a supportive space to relax, share and learn in. This has included retreats for carers and women with disabilities, art workshops and forums
- EDAC can deliver cross-cultural training to organisations on best practice models of service delivery and issues for ethnic people with disabilities.

Publications/Resources

A number of publications including a Quarterly Newsletter and online resources are available.

Genetic Services of Western Australia

Agnes Walsh House
374 Bagot Rd
SUBIACO WA 6008

Ph: (08) 9340 1525
Fax: (08) 9340 1678

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

Objectives of the Group

Genetic Services of Western Australia (GSWA) provides a range of diagnostic, treatment, counselling and investigative services for individuals and families with suspected or known hereditary (genetic) conditions.

These services are provided through a multidisciplinary team which includes clinical geneticists and genetic counsellors, working closely with DNA and cytogenetic laboratories and other associated disciplines.

Activities and Services

- **Early diagnosis and treatment:** Hereditary conditions such as cystic fibrosis, muscular dystrophy and some neurological conditions can be detected early in some high risk families. Diagnosis of a predisposition to some cancers before symptoms appear can provide the opportunity for preventative measures or early treatment.
- **Screening tests:** A range of screening tests can be carried out during pregnancy (prenatal) to detect conditions such as Down syndrome, neural tube defects, muscular dystrophy, cystic fibrosis, haemophilia and many other genetic conditions.

Newborn babies are screened for selected conditions such as phenylketonuria (PKU), hypothyroidism and cystic fibrosis, which are often treatable if detected early.

- **Genetic counselling:** Counselling provides individuals and families with up-to-date information. It also assists with understanding the diagnosis and treatment of conditions, the risks of the condition occurring to other family members, what tests are available to clarify these risks and decision making.
- **Laboratory services:** DNA tests examine an individual's DNA for gene changes, such as the gene change that results in cystic fibrosis. Cytogenetic tests examine an individual's chromosomes for chromosome abnormalities such as the extra 21 chromosome that results in Down syndrome (Trisomy 21). Biochemical tests involve testing for certain substances in the body (such as proteins) for evidence of hereditary conditions and birth defects.
- **Familial Cancer Program:** This program is run by GSWA and provides a comprehensive services to individuals and families with a significant family history of breast, ovarian, bowel and other related familial cancers.

Publications/Resources

Information brochures about the above services are available on request or visit the website for further information.

Office of Population Health Genomics, Department of Health Western Australia

Executive Director, Population Health Division
Department of Health
3rd Floor, A Block
189 Royal Street
EAST PERTH WA 6004

PO Box 8172
Perth Business Centre
PERTH WA 6849

Ph: 9222 4222
Fax: 9222 2165

Email: genomicscontact@health.wa.gov.au
Website: <http://www.population.health.wa.gov.au/Genomics/index.cfm>

Genomics Directorate

The Genomics Directorate is a part of the Division of Population Health within the Department of Health Western Australia.

Objectives of the Group

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.

Activities and Services

- Inform and educate the Western Australian public on the services, information and resources available to them on hereditary diseases, genetic conditions, birth defects and prenatal diagnosis. Improving the knowledge in these areas will assist informed decision-making by the public
- Promote health and prevent disease in WA by developing strategic policy which will enable the appropriate integration of genetic technology into population health practice
- Ongoing evaluation of services available to individuals with genetic conditions to ensure maximum health benefit to all Western Australians.

Publications/Resources

- Resources available to the public include information on Prenatal Screening and Diagnosis, Prevention on Spina Bifida, Genetic Services of WA, Familial Cancer and Check Your Family Health Tree.

To order pamphlets ring 9222 4436 to request a reorder card or go online to <http://www.population.health.wa.gov.au/ordering> and click on Genomics.

Health Consumers' Council of Western Australia (Inc)

Unit 13/14 Wellington Fair
4 Lord Street
PERTH WA 6000

Ph: (08) 9221 3422
Freecall: 1800 620 780
Fax: (08) 9221 5435

Email: info@hconc.org.au
Web: <http://www.hcc-wa.asn.au>

Open 8.00AM - 5.00PM MON - FRI (except public holidays)

Health Consumers Council

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.

Objectives of the Group

We have 5 clear objectives:

- 1) Helping you understand health issues
- 2) Encouraging your participation in decisions that affect the health system.
- 3) Encouraging accountability in the health system to ensure that our money is spent wisely and productively
- 4) Giving people who use the health system access to advocacy, information, training and support
- 5) Helping our community understand the health system.

Activities and Services

- We operate a health information and referral telephone service
- We advocate for individuals with problems with the health system and inform them of their rights
- We run the Health Issues Group where you can discuss health issues affecting you and action can result
- We organise workshops and information sessions on health issues of interest to the community
- We coordinate the placement of consumer representatives on committees.

Publications/Resources

We produce four "Health Matters" newsletters a year. These contain information on current health concerns, changes to the health system and updates on the work of the Health Consumers' Council. All contributions are welcome.

Kidney Health Australia

3rd Floor
68 St George's Terrace
PERTH WA 6000

Ph: (08) 9322 1354
Freecall Information Line: 1800 682 531 (24 hours)
Fax: (08) 9481 3707

Email: wa@kidney.org.au
Website: <http://www.kidney.org.au>

Kidney Disease

Many conditions are associated with kidney disease including urinary infection, kidney stones, glomerulonephritis, urinary incontinence and renal failure. Kidney abnormalities can exist in isolation or they can be part of other conditions. Some of these conditions have a genetic basis.

Objectives of the Group

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.

It achieves this by:

- Implementing awareness and education programs in conjunction with renal specialists, health professionals and educators to reduce the incidence of kidney disease in the community
- Funding cutting edge medical research into cures for kidney and urinary tract disease
- Providing a network of education, care and support for patients, their families and carers
- Promoting organ donation.

Activities and Services

- The Foundation offers a range of non-medical support services for individuals with kidney disease, their families and members of the general community including:
 - Information and services to individuals with genetic kidney disease, their families and their carers
 - Individual support programs and services and links to other support networks
 - Information seminars throughout the year
 - Guest speakers to present a range of issues relating to kidney disease and organ donation.

Publications/Resources

Kidney Health Australia publishes a quarterly newsletter and has a large number and range of regularly updated publications and resources for individuals with kidney disease, their families, and the community and health professionals.

The Neurological Council of WA (Inc)

The Centre for Neurological Support
Suite B, The Niche
11 Aberdare Rd
NEDLANDS WA 6009

Ph: (08) 9346 7533
Freecall 1800 645771
Fax: (08) 9346 7534

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

The Neurological Council of WA

The NCWA 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.

Objectives of the Group

- Peak body in neurological disorders in Western Australia
- Identification of needs in terms of care services, support, treatment and research. Articulation of these needs as necessary and desirable
- Support for neurological organisations and their members directly and through networking. Publication of the NeuroNews, a quarterly newsletter
- Regular carer and mutual support groups relevant to those with neurological disorders.

Activities and Services

The NCWA has Home and Community Care (HACC) funded services in the Perth metropolitan region, the Southwest region, the Great Southern region and the Midwest region. The Council has plans to grow these services to cover much of the state.

These services aim to provide support to people living with neurological conditions so that they can remain in their homes and in the community and include:

- Operation of a "Home and Community Care Program" to provide counselling and respite care and support for those with neurological conditions
- Operation of the "South West Neurological Nurse Specialist Service"

SIDS and Kids Western Australia (Inc)

33 Sixth Avenue
KENSINGTON WA 6151

Ph: (08) 9474 3544 (Monday to Friday, 9 am to 5 pm)
Country Freecall: 1800 199 466 (SIDS and Kids WA Administration)
Fax: (08) 9474 3636

Email: perth@sidsandkids.org
Website: <http://www.sidsandkids.org/wa>

Incorporating: Stillbirth and Neonatal Death Support (SANDS) WA Inc

24 hour Infant/Child Loss Peer Support Line: 1800 686 780

SIDS and Kids Western Australia

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.

Objectives of the Group

- To raise funds for scientific and medical research into the cause and prevention of SIDS and stillbirth
- To give support to parents, family and those affected by the sudden and unexpected death of a child from conception to 12 years of age, regardless of the cause of death (e.g. miscarriage, stillbirth, neonatal death, accident, sudden onset illness).
- To educate the public in the nature, incidence, causes and how to reduce the risk of sudden unexpected death in infancy.

Activities and Services

Services are free to anyone affected by the sudden and unexpected death of a child from conception onwards:

- Support and counselling services
- Craft meeting support groups
- Children's counselling
- Men's Grief Group
- Training sessions – for Health Professionals and Child Care Workers
- Hospital and home visits (during the day)
- Telephone contacts – 24 hour Peer Support Line
- Monthly support meetings
- Telephone information service for new and expectant parents.

Publications/Resources

- SIDS and Kids WA has a variety of booklets and articles relating to different aspects of grief. They also have an on-line catalogue for research articles, which can be found on the National Website www.sidsandkids.org.
- SIDS and Kids WA produces quarterly newsletters for bereaved parents and supporters.

Speak Easy Association Western Australia

Claisebrook Lotteries House
33 Moore St
EAST PERTH WA 6004

Ph: (08) 9225 4111 or 0419 930 903
Fax: (08) 9325 7061

Email: seawa@speakeasy.org.au
Website: <http://www.speakeasy.org.au>

Stuttering

Stuttering affects the verbal communication abilities of a significant proportion of the population. It is characterised by the halting, repetition and disruption of speech. Stuttering is a neurological, cognitive disorder. Current research suggests that stuttering has a neurological basis and that genetics play a part resulting in a loss of coordination of the speech muscles.

Objective of the Group

To provide advocacy and support to people who stutter and their families.

Activities and Services

- Educational services
- Advocacy
- Support group meetings
- Research assistance
- Training workshops and seminars
- Liaison with Government departments
- General information services
- Membership \$35 per annum.

Publications/Resources

The Association has a library for members with resources suitable for the community and health professionals. The Association publishes a quarterly newsletter.

The Kalparrin Centre

GPO Box D184

PERTH WA 6840

Ph: (08) 9340 8094

Freecall: 1800 066 413

Fax: (08) 9380 6114

Email: kalparin@iinet.net.au

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

The Kalparrin Centre

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
- Families of children with special needs who are under the unique stress of awaiting diagnosis or whose diagnosis is unknown
- Families of children with special needs requiring empathy, advocacy, support and empowerment in times of crisis
- Disability related self-help or support groups. For example Williams Syndrome, Fragile X and Heart Kids, can be provided with a central meeting place and links with other parents through the centre's database
- Professional and students and staff of other agencies seeking information about a range of disabilities and services.

Objectives of the Group

To provide a centre where families of children with special needs can be linked with services and other families with similar needs or experiences.

Activities and Services

- A drop in centre: with a parent lounge and a toy room for children
- Free use of the centre to various support groups for meetings
- A parent link, linking parents with support groups and other families through a confidential computer database.
- A weekend mother's camp twice a year. These weekends are a needed break for many mothers and involve workshops on various topics.
- Weekends for mothers, fathers and siblings of children with special needs.
- Weekend workshops for carers.

Publications/Resources

The Centre has a range of information including Internet resources.

Unique In Australia (Chromosome Disorder Support Group)

Unit 1/59 Brown Street
HEIDELBERG Vic 3084

Contact: Mark and Tanya Files

Ph: (03) 9455 2510

Email: takmarj@bigpond.net.au

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

Rare chromosome disorders

Unique is a source of information and support to families and individuals affected by any rare chromosome disorder and to the professionals who work with them.

Objectives of the Group

To inform, support and alleviate the isolation of anyone affected by a rare chromosome disorder and to raise public awareness. We work to ensure that the public at large are aware of rare chromosome disorders.

Activities and Services

- To provide general support and information
- To provide links for families whose children have similar clinical and/or practical problems.

Publications/Resources

A number of pamphlets suitable for families with a new or recent diagnosis and for couples with an unborn baby are available. See the website for further information.

Western Australian Deaf Society (Inc)

Head Office

Suite 46/ 5 Aberdeen St
EAST PERTH WA

Ph: (08) 9441 2677
TTY: (08) 9441 2655
Fax: (08) 9444 3592

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

Regional Office

2 Elliot Street
BUNBURY WA 6230

Ph/Fax: (08) 9791 8032
TTY: (08) 9791 8034
Email: wadeafbunbury@wadeaf.org.au

Deafness

The terms deafness and hard of hearing refer to partial or total loss of hearing in one or both ears. This may be present from birth such as congenital rubella syndrome or may result from injury, disease and/or exposure to loud noise during one's lifetime. Aging is also a cause of deafness.

Objective of the Group

To empower deaf people to achieve equality of opportunity and independence in all aspects of life.

Activities and Services

- Interpreting services
- Support services
- Employment services
- Educational services
- Regional services (in Bunbury)
- Youth Group activities
- *LEAP* (Language Early Access Program for children 0 – 6 years)
- Over 18 Club: The Next Generation
- Seniors activity programs
- Support for the Auslan Community School for Deaf and Hearing Children.

Publications/Resources

The Society produces a quarterly newsletter, *Deaf Magazine*, pamphlets relating to the Society's services, an Annual report and resource information.

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