



# Gene Advocate

Issue 54

2008

## Australian experts criticise unregulated direct-to-consumer genetic testing industry

Government officials in Australia have held a joint public meeting to discuss the dangers of the growing but largely unregulated direct-to-consumer genetic testing market. Chair Professor Ron Trent from the National Health and Medical Research Council, Human Genetics Advisory Committee (HGAC) and Professor David Weisbrot, the president of the Australian Law Reform Commission, warned that the predictive genomic testing industry lacks a regulatory entity to ensure the medical validity or accuracy of available tests and lacks standards to help consumers understand test results.

It is estimated that 1,400 such tests are currently available, predominantly online, by genomic companies mainly based in the US and Europe. Over 30 US compared with only six Australian companies test for serious diseases like cancer. HGAC Chair Professor Ron Trent worries that online testing based abroad particularly denies Australian residents proper recourse or access to advice which he stresses should accompany results: 'Sometimes counseling requires one or two visits, sometimes it requires family members to come in and get involved.'

Trent also warns that interpreting the significance of genetic test results can be complex due to multiple inter-related genetic and environmental causes, so that allowing individuals to bypass physicians and obtain their personal DNA results could 'do more harm than good'. He criticises claims that identifying diabetes-linked genetic markers, means they can predict if you're going to develop diabetes. 'I think that's taking it a little bit too far', he said.

'We want consumer authorities to be looking very carefully at the claims that are being made for some of these tests. Some are patently ludicrous, some are a little bit exaggerated,' said Weisbrot. Both fear that without better regulation and medical supervision, bogus testing may give legitimate genetic testing a bad reputation.

The majority of online tests offer 'lifestyle' non-medical DNA information - such as about balding or wrinkles - but experts fear that the distinction is unclear. The ability of many of these tests to reliably predict risk of disease and scan for traits like lactose-intolerance is largely unknown. Experts fear that predictive genomic test results, particularly for serious diseases, may cause needless worry or give false reassurance. However, Ryan Phelan, CEO of DNA Direct, which screens for breast cancer, criticises any blanket policy approach. He suggests 'nuanced regulation' that distinguishes between tests predicting serious disease from non-medical or interesting information is required.

The meeting coincides with the release of results from the first national audit of consumer genomics. A total of 160,000 tests - for more than 400 medical conditions - were performed in 2006. The study, funded by Australia's federal Department of Health and Ageing, was led by Dr Graeme Suthers, who said 'we're in transition from a cottage industry to the inclusion of genetic testing in mainstream medicine.' The study found that around 40 per cent of the tests involved screening healthy people for genes that could cause diseases such as cystic fibrosis in their children or screening for tissue compatibility; 28

## Australian experts criticise unregulated direct-to-consumer genetic testing industry continued . . .

per cent performed diagnostic testing to seek or eliminate genetic factors, and eight per cent were conducted on cancer cells to check for genetic damage. Tests for inherited cancer-causing mutations on family members comprised five per cent. Suthers also found that genetic testing to reveal cancer drug-treatment efficacy is increasing and successful. The varied uses and high-volume of certain testing suggests that genetic testing has an important and increasing role in healthcare and many argue that all genetic testing should be regulated through healthcare providers.

Previously most governments have concentrated on preventing employers and insurers from misusing the genetic information such tests yield. Recently, leading nations have switched focus: both the UK and US have issued warnings and initiated government consultations for reform whilst California and New York aggressively cracked down on companies based there. Australia now joins these efforts and already allows genetic testing for medical conditions only by physician-referral to licensed laboratories. However, the direct-to-consumer market circumvents requirements for physician involvement because such tests generally classify as 'low-risk' under existing consumer laws.

Their online availability raises concerns of how the international service aspect can effectively be regulated by federal/state regulations if companies are able to out-source DNA-analysis to nations that lack oversight laws. Genomic companies welcome good-practice standards but object to physician involvement preventing a direct-to-consumer market. They contend that DNA-analysis is not medical testing but personal genetic 'informational services' and should be regulated like over-the-counter tests

Source: ABC news 06 August 2008

## Hope for treating spinal injuries

Researchers have generated a specialised type of nerve cell - astrocytes - from embryonic stem (ES) cells. The astrocytes were used to treat spinal injury in rats, with impressive results, restoring their ability to move freely. The team of scientists from the University of Rochester, New York, and the University of Colorado, Denver, US, published the work last week in the online Journal of Biology.

The researchers developed a system to generate astrocytes from ES cells and found that two different types could be grown, by using different conditions to nurture the stem cells. Astrocytes are nerve cells that have a star-like shape, and account for 70 per cent of all cells in the central nervous system. They play numerous roles in maintaining the structure, metabolism and function of the brain and spinal cord.

When transplanted into spinal injury sites in rats, the two types of astrocyte had completely different effects. One promoted the regeneration of nerve cells, and limb movement was recovered within four weeks. The other type failed to promote nerve fibre regeneration or recovery of movement and, in addition, caused severe pain.

Controlling the development of stem cells immediately before transplanting them into injured spinal cords is essential. This is because the injured tissues of the body cannot be relied on to create the right types of cells from stem cells. This is illustrated by the fact that when the researchers implanted the stem cells (before they were astrocytes), they failed to promote nerve regeneration and caused pain. The researchers say this is a breakthrough that will change the way spinal cord injuries are treated with stem cells.

'It has long been a concern that therapies that promote growth of nerve fibres in the injured spinal cord would also cause sprouting in pain circuits', said Dr Stephen Davies, from the University of Denver. He added: 'However by using the right astrocytes to repair spinal cord injuries we can have all the gains without the pain, while these other cell types appear to provide the opposite - pain but no gain'.

The team is working on extending its research to human cells. Dr Davies told the Telegraph newspaper: 'We hope to translate this promising new cell replacement therapy to clinical trials within the next two to three years if all goes well.'

Source: Alison Cranage - Bionews.org.uk

# Annual General Meeting

Date: Tuesday 7th October 2008

Venue: Lecture Theatre - Grace Vaughan House  
227 Stubbs Terrace, Shenton Park

Time: 5.45pm – 6.45pm

**Special Guest Presentation by  
Dr Stephen Junk BSc PhD  
Scientific Director of Fertility Specialists of WA**

## **“The Here & Now of Reproductive Technology”**

Dr Junk is currently Chair of SIRT (Scientists in Reproductive Technology), a Deputy Member of the Reproductive Technology Council (RTC) of Western Australia, member of the Pre-implantation Genetic Diagnosis (PGD) Committee for the RTC, a member of the NH&MRC Embryo Research Licensing Committee.

In his presentation Dr Junk will be providing an overview of the current state of reproductive technology in WA and how it impacts on couples looking to conceive. The presentation will discuss issues such as Preimplantation Genetic Diagnosis (PGD) (also known as Embryo Screening) and other aspects of diagnostic testing for reproduction.

*A delicious light supper and refreshments  
will be served after the Meeting..*

**RSVP by 2nd October 2008**

By phone **9389 6722**

or e-mail to

**sharon@geneticsupportcouncil.org.au**

**This event is open all interested  
community members.**



## Free Websites Anyone?

The importance of having a web presence continues to grow. Websites remain increasingly vital to get the word out about your organisation and – in a fundraising sense – to provide a link to an online giving facility to raise money.

The good news is that there is a new Australian based service which is giving community groups the chance to build and customise their own website free of charge. The new service is called Comfypage, and it comes from Perth-based firm Affinity Software.

Comfypage ([www.comfypage.com](http://www.comfypage.com)) is touted as a no-cost website builder where “anyone with a PC, internet access and basic Microsoft Word processing skills” can build their website, have a presence on the web within a day and maintain the site for life – all for no charge.

The service has no sign-up fees or web address costs while allowing users to have a “fully functional and fully supported basic website”. And let’s be honest, for the vast majority of organisations a basic website will more than suffice.

The Comfypage website says that each basic site can have “its own web address, is searchable on Google and other search engines, and can carry all the information and pictures you want.”

All these features should be more than enough for most community groups. But, for a one-off charge of around \$7, Comfypage also offers groups the chance to go a step further and incorporate other advanced website options like email ‘contact us’ forms and credit card payment facilities.

For more information about Comfypage, including examples of sample webpages and templates, visit [www.comfypage.com](http://www.comfypage.com).

Information Source: Raising Funds Newsletter June 2008. <http://www.ourcommunity.com.au>

**Please contact the GSCWA if you would like assistance in setting up a website!**

## Online Rare Syndromes/ Diseases Support Group

The online rare syndrome and disease support group at essential baby is a thread for all those mums who have beautiful children suffering from rare genetic disorders, rare syndromes and rare diseases. Essential Baby hosts the largest and most active parenting forum in Australia with an average of 1500 members online in peak times, yet most of the time it feels like being at a get together with friends. The forums are supported by an amazing team of 35 moderators help to oversee more than 10,000 posts per day.

Current conditions include:

- Sacrococcygeal teratoma
- Wolf-Hirschhorn Syndrome
- Late Infantile Batten Disease
- N-B CIE Ichthyosis or non bullous ichyosiform erythroderma
- Juvenile Xantho Granuloma
- Mastocytoma
- Dandy Walker Malformation
- Cerrebelar hypoplasia
- Acrodermatitis enteropathica (AE)
- Persistant Hyperplastic Primary Vitreous (PHPV)
- Haemophilia b
- Haemophilia c

Visit: <http://members.essentialbaby.com.au/index.php?showtopic=96193>

Web: <http://www.essentialbaby.com.au>

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## Australian Charter of Health Care Rights

Australian Health Ministers endorsed the Australian Charter of Healthcare Rights at their meeting in Canberra on 22 July 2008. The Charter applies to the whole health care system and allows patients, consumers, families, carers and services providers to have a common understanding of the rights of people receiving health care. For further information go to the website [www.safetyandquality.gov.au](http://www.safetyandquality.gov.au) or phone (02) 9263 3633.

## Researchers Find Proteins that Directly Control Gene Linked to Parkinson's

Genetic mechanisms involved in blood cells also control a gene and protein that cause Parkinson's disease (PD), according to a group of neurologists and pharmacologists.

Patients with Parkinson's have elevated levels of a protein called alpha-synuclein in their brains. The current study found that the activity of three genes that control the synthesis of heme precisely matched the activity of the alpha-synuclein gene.

The scientists then found that the GATA-1 protein, which turns on the blood-related genes, also acted as a switch for alpha-synuclein expression, increasing its level. Finally, they demonstrated that a related protein GATA-2 was expressed in PD-vulnerable brain cells and directly controlled alpha-synuclein production.

Clemens Scherzer, M.D., of Harvard Medical School and Michael Schlossmacher, M.D., at the University of Ottawa previously analyzed the blood of PD patients and controls to identify genes that were active in the disease. They were surprised to notice large amounts of alpha-synuclein in the blood.

To understand what it was doing there, Dr. Scherzer's group used gene chip data to see whether any of the thousands of genes active in blood were linked to alpha-synuclein. They found a gene-expression pattern composed of alpha-synuclein and the heme genes. Emery Bresnick, Ph.D., a University of Wisconsin, Madison professor of pharmacology has already shown one of these genes to be a direct GATA-1 target gene.

The three investigators began work together and determined that GATA-1 directly activated the alpha-synuclein gene. That finding led to the discovery that GATA-2 is expressed in regions of the brain that are relevant to PD. They then set out to examine whether common mechanisms activated alpha-synuclein transcription in both the blood and nerve cells.

The studies showed that GATA-1 and GATA-2 proteins find the alpha-synuclein gene, stick to it, and then directly control it. "This is not an indirect pathway; it is direct regulation of the gene," asserts Dr. Bresnick. "This directness provides the simplest scenario for creating a therapeutic strategy."

Drs. Bresnick, Schlossmacher, and Scherzer are working with geneticists to see if possible abnormalities in the GATA-2 gene may exist in PD patients, stimulating more production of alpha-synuclein.

The findings are published in this week's online early edition of the Proceedings of the National Academy of Sciences: <http://www.pnas.org>

Information Source: Genetic Engineering & Biotechnology News.<http://www.genengnews.com/news/bnitem.aspx?name=39130784&source=genwire>

### Support Group information

Parkinson's Western Australia Inc (PWA)

A self-help, non-profit organisation which has traditionally had a strong volunteer base as the core of its operation. It is estimated that there are some 8,000 people in Western Australia living with Parkinson's.

Phone: 9346 7373

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

## Health Translations Directory

This Directory provides web links to third party sites with translated resources including government departments, peak health bodies, hospitals, community health and welfare agencies. The Directory currently links up to over 7,000 resources in 58 languages.

You can search by language and topic. You can view resources by clicking onto the Categories A to Z tab or Languages A to Z tab. This will provide you with a full listing of the resources.

This web based Directory also links to online multilingual health resources in other states.

Web: <http://www.healthtranslations.vic.gov.au>



# Member Profile

## The Short Statured People of Australia

The Short Statured People of Australia (S.S.P.A.) is a non-profit organisation founded in 1968 to support short statured people (people shorter than 150 cm/4'11" at adulthood) in Australia.

The SSPA aims to advance equal opportunities in education, employment and the community for persons of short stature; provide support and work towards the removal of disadvantages involving persons of short stature; provide opportunities for fellowship in social activities; and encourage each other, by example, to live a full and happy life.

The sspa website (<http://www.wa.sspa.org.au>) provides information about the WA branch, founded in 1987. The branch regularly holds meetings and various social activities are held throughout the year as well as a Christmas party.

## Information Guide

The information guide's contents include:

- A brief overview of the S.S.P.A
- Common types of short stature
- Diagnosis of short stature
- Care of babies and young children
- Role of families
- School years
- Higher education
- Teenage years
- Employment
- Complications associated with short stature
- Genetic counselling and inheritance
- Information on support groups and contacts for the S.S.P.A. diagnostic sub-groups

## Conditions of Short Stature

Any person whose height at maturity does not exceed the World Health Organisation's recommendation of 1.45 metres (4ft 10in) is a short-statured person. More than one hundred conditions have been identified. They can differ greatly and result from a variety of causes. It is important that the type of restricted growth condition is identified as precisely as possible. Understanding the characteristics and the potential consequences of a particular type of restricted growth is more important than mastering the medical terminology which can be confusing. It is good to learn and understand both the general and particular effects a disorder is likely to have upon an individual.

Restricted growth can be inherited via genes and earlier forbears. Although they usually don't have signs of any growth disorder, it can appear as a genetic accident at conception.

## Some of the common types of restricted growth are:

**Achondroplasia:** This is by far the most common. The most obvious characteristic is the shortening of the limbs, particularly the upper arm and thigh. The skull is relatively large and the forehead prominent whilst the bridge of the nose does not properly develop. The hands and feet are short and broad with middle fingers the same length. The elbows do not usually extend fully. There are characteristic abnormalities of the base of the skull and spine which can lead to neurological problems, usually causing pain or numbness in the lower back and legs at middle age.

**Hypochondroplasia:** This is distinct from achondroplasia but is often confused with it as it merely seems a milder version. It is not very evident at birth but becomes noticeable as the child develops. The hands and feet are small but the skull is not affected. The spine has some of the same abnormalities as achondroplasia but individuals are less likely to suffer problems.

**Multiple Epiphyseal Dysplasia:** The growing points of the long bones are affected in this condition providing variable growth restrictions but sparing the spine. The most severe symptom of this condition is degeneration of the weight bearing joints which may require corrective surgery. In one particular type there may be problems with the skin, hair, gums and a tendency to develop cataracts.

**Spondylo Epiphyseal Dysplasia:** This is a condition where the growing ends of the bones and spine especially are affected. The two most common are SED Congentia which is apparent at birth and SED Tarda which has a later onset and is only seen in males. In SED Congentia the knees and hips are prone to deformity, the neck is short and the vertebrae weak at the base of the skull which may require fusion. In SED Tarda the main abnormality is in the spine which becomes very shortened and stiff. There is often mild curvature of the spine and hands may reach down to the knees.

**Pseudoachondroplasia:** This condition is similar to achondroplasia but facial features are unaffected and it is not readily recognisable at birth. Although spinal problems are rare, the loose joints experienced by some may result in wear and tear later on in life.

**Pituitary:** This is caused by hormone deficiency from the pituitary glands. This can be detected in children at about two years old and the earlier treatment is commenced the more likely the individual is to reach their full potential adult stature. It is the rate of growth rather than the short stature itself that is the important criteria. Treatment will involve regular injections of the lacking hormone.

There are another ninety conditions. For more information on conditions of short stature visit our website [www.sspa.org.au/conditions.htm](http://www.sspa.org.au/conditions.htm)

## Support

The S.S.P.A. offers the following advice and assistance for children, teenagers and young adults

- Assistance with education and career opportunities, e.g. Careers and Vocational Guidance Fund.
- Advice re: clothing, shoes, car pedals and Government assistance.
- Advice re: pre-school, school and university choices.
- Medical information e.g. short stature symposiums, recommendations to seek assistance from members of our Professional Advisory Board.
- Personal development e.g. Convention and short stature symposiums; basketball and other sporting activities.

## Support for parents

- Personal counselling and support for new parents e.g. New-parent representatives.
- Medical information <http://www.sspa.org.au/advisoryboard.htm>
- Adoption advice.



## Short Statured People of Australia: Western Australia Branch (S.S.P.A. WA)

Group Contact: 9295 0636

Web: <http://www.wa.sspa.org.au>

## Short Statured People of Australia

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



# Coming Events

## Mental Health Week

Date: 5th to the 11th October 2008

Org: WAAMH

Are you going to take the 'Stress Less Challenge' during Mental Health Week? "How's your Mental Health? Think about it. Talk about it ...Now!" This week aims to increase community awareness and education about mental health issues; decrease the stigma, discrimination and prejudice still faced by people with mental health issue and make it easier for people to both recognise when they have a mental health problem and to seek assistance when they need it.

Contact: WAAMH

Web: <http://www.waamh.org.au/mentalHealthWeek.cfm>

Phone: (08) 9420 7277

Email: [communications@waamh.org.au](mailto:communications@waamh.org.au)

## "Structuring Success"

Date: 9-10 October 2008

Org: The Autism Association WA



The Autism Association of Western Australia is proud to announce that we are bringing one of the world's leading experts on Autism, Professor Gary Mesibov, to Australia to deliver a two day MASTERCLASS on the TEACCH approach to educating and supporting individuals with an Autism Spectrum Disorder.

Professor Mesibov is Director of Division TEACCH in the United States, an internationally acclaimed program dedicated to education and research in the field of Autism.

Web: <http://www.autism.org.au/Teech%20headera.htm>

Contact: Rosemary Miles on 08 9489 8938

Email: [rosemarym@autism.org.au](mailto:rosemarym@autism.org.au)

## WA Health Conference 2008 - Our Health, Our Future

Date: 15th - 17th October 2008

Org: Department of Health

Venue: Perth Convention Exhibition Centre  
WA Health Conference 2008 – Our Health, Our Future will be the third annual event and revolves around our six strategic directions - healthy workforce, healthy hospitals, healthy partnerships, healthy communities, healthy resources and healthy leadership.

Email: [wahealthconference@health.wa.gov.au](mailto:wahealthconference@health.wa.gov.au)

Web: [www.wahealthconference.health.wa.gov.au](http://www.wahealthconference.health.wa.gov.au)

## Palliative Care Course



Date: 15th and 22nd October

Org: The Cancer Council WA

This two day course is designed for Patient Care Aides and Assistants in Nursing who work with individuals with a life limiting illness.

Phone: (08) 9382 3774

Email: [pdadministration@cancerwa.asn.au](mailto:pdadministration@cancerwa.asn.au)

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

## Carers Week 2008



Date: 19th to 25th October

Org: Carers WA

The primary objective of Carers Week is to reach and support hidden carers. It aims to: Heighten awareness of carers in the community, Celebrate the work of carers and encourage carers to recognise themselves as carers, Promote an awareness of other carer services such as Commonwealth Carer Respite and Carelink Centres,

Contact: Andrea Pienaar

Phone: 1300 CARERS (1300 227 377)

Web: [www.carerswa.asn.au](http://www.carerswa.asn.au)

## Public Forum - Rare Conditions and Emergency Departments

Date: Thursday 23 October 2008  
Org: Health Consumers Council  
Time: 9:15am to 1:00pm  
Venue: Grace Vaughan House, 227 Stubbs Terrace, Shenton Park, WA 6008  
Cost: Free

Have your say at this public forum on rare conditions and emergency departments.

RSVP: Rosemary on (08) 9221 3422 or email [rosemary.caithness@hconc.org.au](mailto:rosemary.caithness@hconc.org.au)

## Free Lupus Forum

Date: Saturday 25th October  
Org: The Lupus Group of WA  
Time: 9am to 4pm



Venue: The Bruce Hunt Lecture Theatre, Royal Perth Hospital (Wellington Street entrance)  
The Lupus Forum will include a wide range of topics covering the past, present and future of Lupus from diagnosis, medications, research and coping with a genetic disease. This event is free!  
Speakers include: Ms Durack (Psychologist) - Coping with chronic disease for patients, carers and family members, Dr Hollingsworth (Immunologist) - History of the disease and Lupus today, Dr Ulgiate (Medical Research) - Research today and in future, Dr Chan (Rheumatologist) - Medications today and in future, Dr Foster (GP) - Living with Lupus and managing the symptoms.

Bookings essential. Call 9224 3144 or email [admin@lupuswa.com.au](mailto:admin@lupuswa.com.au)

## Make a Difference for Muscular Dystrophy

Dates: October 28th - November 12th 2008  
Org: Muscular Dystrophy  
That's right we are trekking through Nepal in October! People need to register and become a trekker and then have to fundraise a minimum of \$5000 each. Why not sponsor a trekker!

Phone: (08) 9382 2700  
Email: [mda@cyllene.uwa.edu.au](mailto:mda@cyllene.uwa.edu.au)  
Web: [www.mdawa.asn.au](http://www.mdawa.asn.au)



## World Diabetes Day



Org: Diabetes WA  
Date: 14 November 2008

Primary global awareness of the diabetes world. It was introduced in response to concern over the escalating incidence of diabetes around the world.

Contact: 9325 7699  
Web: [www.diabeteswa.com.au](http://www.diabeteswa.com.au)

## Relationships, Sexuality & Disability Awareness Day

Date: 20 November 2008  
Org: secca

Increasing knowledge and capacity to access services for people with disabilities. This event targets service providers, agencies, carers, families and health professionals in the disability field in relation to sexuality, sexual health and relationships.

Contact: (08) 9420 7226  
Website: [www.secca.org.au](http://www.secca.org.au)

## Retinitis Pigmentosa Street Appeal



Date: 21 November 2008  
Org: WA Retinitis Pigmentosa Foundation  
Street Appeal to collection funds to support research into Retinitis Pigmentosa.

Contact: (08) 9227 7585  
Website: [www.retinitispigmentosa.com.au](http://www.retinitispigmentosa.com.au)

## Carers Symposium & Expo 2008

Date: 24th & 25th November 2008  
Org: Carers WA  
Two day Carers Symposium & Expo which explores how carers are being HEARD, INCLUDED & SUPPORTED. The Expo is designed to showcase and display three key areas for carers, taking a break, links to services and support for carers.

Contact: Emma Toovey on (08) 9389 1488



Do you have an event coming up? Promote your it here and on our website at no cost! Contact Kris on (08) 9389 6722 or e-mail [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au)



# Resources

## Grant Support - Free reviews of funding submissions for community organisations

Granted is a not-for-profit organisation that provides advice to community sector organisations that are developing funding applications. They focus on assisting organisations that aim to make a positive social or environmental impact but which have limited resources to seek funding. The service is free, independent and confidential.

Web: [www.granted.org.au](http://www.granted.org.au)

## Accessible Events - A Guide for Organisers

This is a useful resource for anyone planning a consumer participation event. The guide was developed by Meeting Events Australia and the Human Rights and Equal Opportunity Commission. It discusses the legal responsibilities organisers have for making sure that their event is accessible for people with disabilities and gives practical suggestions on how to do this from start to finish.

Web: <http://www.meetingsevents.com.au/research>

## Auslan Signbank

Signbank is an interactive dictionary of Auslan (Australian Sign Language). Auslan is the language of the deaf community of Australia. Whoever you are; a deaf person, deaf student, sign language interpreter, student of Auslan, or a parent of a deaf child, we invite you all to explore our visual language.

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

## The Cochrane Library

Healthcare consumers and patients need high-quality evidence about the effectiveness of treatments. This empowers them, with their healthcare practitioners, to make the best possible decisions. The Cochrane Library provides fast access to the most reliable evidence. The Cochrane Library contains other databases of reviews and controlled trials, provides quality-assessed review evidence on diagnostic tests, health technology assessments, economic evaluations, and methods studies from the world's medical literature, all accessible using a single search. The information is written for Patients/Consumers in 'Plain Language Summaries' are written specifically for consumers and patients to highlight information and research findings on the effectiveness of a treatment in a Cochrane review.

Web: [www.cochrane.org.au](http://www.cochrane.org.au)

## Bioethics Research

Southern Cross Bioethics Institute is an independent, non-sectarian, autonomous institution committed to research into important bioethical issues affecting the whole community - locally, nationally and internationally.

Web: [www.bioethics.org.au](http://www.bioethics.org.au)

## Need IT assistance?

This directory contains a list of WA ICT companies that provide products and services in hardware, software, call centre services, data management, telecommunications, internet, multi-media and professional training and consultancies.

Web: [www.ictwa.com.au/home.asp?cmd=](http://www.ictwa.com.au/home.asp?cmd=)

## Lifeline Service Finder

The Lifeline National Service Finder lists details of around 20,000 services and service providers around the country. You can search the database using keywords for the type of service and location required. Alternatively you can direct your search by typing in your postcode. This service is a resource available to both health professionals and the public. Search for agencies, services and programs close to home, using this confidential search engine. The Lifeline National Service Finder has been developed with the support of the Australian Government Department of Health and Ageing.

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

## Brain Tumour Support Online Resource Centre

The James Crofts Hope Foundation is committed to providing assistance to people diagnosed with brain tumours and for their families, advancement of treatments, and research of these conditions. Their aim is to establish a world-class brain tumour research facility in Perth. The Foundation established this online resource where patients and families can source information regarding options for treatment and other services.

Phone: (08) 9445 7661

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

Web: [www.jamescroftshopefoundation.org.au](http://www.jamescroftshopefoundation.org.au)

## Support for teen Diabetics

'myD' (my diabetes) is a site that has been developed specifically for people aged 16 to 25 years living with diabetes. The site provides general information on living with diabetes and covers 'everyday' topics like school, work, travel, driving and general health. The site also provides information and links to other sites of interest, places to go for more information, and there is a section for you to tell your story and talk about how you live with diabetes, here and now.

Web: <http://www.ndss.com.au/myD>

## KidsHealth For Kids

KidsHealth has info about health problems like cancer, asthma, coeliac, cleft palate, guillain-barré syndrome, spina bifida, muscular dystrophy, and more. Articles are written by a Medical Review Board. The subject areas include: Allergies and Immune System, Asthma, Birth Defects & Genetic Problems, Bladder, Kidneys & Urinary Tract, Blood, Bones, Muscles & Joints, Brain & Nervous System, Cancer, Diabetes, Glands and Hormones, Heart & Lungs, Infections, Learning & Emotional Problems, Sight, Speech & Hearing, Skin, Stomach, Intestines & Liver and Teeth & Mouth,

Web: [http://kidshealth.org/kid/health\\_problems/index.html](http://kidshealth.org/kid/health_problems/index.html)

## Australian Government Lobbyists Register

The Register is a public document that contains information about lobbyists who make representations to Government on behalf of their clients. Any lobbyist who wishes to contact a Government representative for the purpose of lobbying activities must be registered and must agree to comply with the requirements of the Lobbying Code of Conduct.

Web: <http://lobbyists.pmc.gov.au/lobbyistsregister/>

## Guidelines for Clinical Practice 2008

Family Planning Association of WA Inc (FPWA) Has produced these guidelines for those working in the field of reproductive and sexual health. Each topic can be used as an easy reference point. New and updated topics covered in this edition include ovarian cancer, HIV and pregnancy and menopause.

Web: [http://fpwa.org.au/resources/clinic\\_guidelines08\\_orderform.pdf](http://fpwa.org.au/resources/clinic_guidelines08_orderform.pdf)



Information accessed through the World Wide Web is of varying levels of quality and accuracy. The material supplied is for information purposes only & is not to be used for diagnosis or treatment.



# Grants

## Local Government and Regional Development Grants Directory

Funder: Various  
Closing Date: Various

Grants for communities and local governments in regional and metropolitan Western Australia. The Grants Directory is a compilation of grants available to communities and local governments in regional and metropolitan Western Australia. The Directory contains programs provided by the Western Australian Government as well as private sector organisations.

**Download the Grants Directory 2008** (PDF 1.6Mb)  
Web: <http://grantsdirectory.dlgrd.wa.gov.au/Publications/GRDirectory.pdf>

### For assistance with Applying for Grants

The Department's Guide to Submission Writing (PDF 125Kb) contains practical information and examples on writing a submission.  
Web: <http://grantsdirectory.dlgrd.wa.gov.au/Publications/GuideSubmissionWriting.pdf>

## Community Funding idea

Funder: Rotary  
Closing Date: Various

Rotary clubs will often have several thousand dollars that can be put to quick use for a worthy cause nominated by a member. There are thousands of Rotary members across Australia and most of them are heavily involved in community life so there's a good chance one of them is a member of your community group - or knows someone who is.

Rotary in Australia: <http://www.rotary.org.au>

Funder: Australian Lions Foundation  
Closing Date: Various

Lions groups often provide a similar service to Rotary and so they may be worth approaching as well.

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

## City of Mandurah Western Australia

Funder: City of Mandurah  
Closing Date: Ongoing

Aim: To offer public liability and other insurances to community groups at a significantly lower rate.

Municipal Insurance Broking Services have joined forces with Western Australian Local Government Association and the City of Mandurah to provide discounted public liability insurance cover for many local groups which have not been able to afford it in the past. Public liability and other insurances are being offered to community groups at a significantly lower rate, with time payment available through premium funding. This new scheme will relieve some of the financial pressure which community groups are currently facing.

To download Affordable Public Liability Insurance for Community Groups document (PDF document 31Kb) go to the City of Mandurah website <http://www.mandurah.wa.gov.au> Click on the menu item Forms / Council meetings click on forms and information sheets and click on general the document is item 17 [affordable\\_public\\_liability\\_insurance\\_for\\_community\\_groups.pdf](#)

Contact: City of Mandurah  
Phone: (08) 9483 8888

## The St. George Foundation

Funder: St. George Foundation  
Closing Date: Ongoing  
Funding: Max: \$5,000

Aim: To provide financial support to charities throughout Australia to help them assist children and young people up to 18 years of age with special needs.

The St. George Foundation provides financial support to charities throughout Australia to help them assist children and young people up to 18 years of age with special needs. The Foundation supports innovative projects that enable disadvantaged and disabled children to reach their potential.

To be eligible for funding, an organisation will:

- assist children under the age of 18 years
- focus its efforts on Australian children
- be a registered Australian charity endorsed as a deductible gift recipient (but not another ancillary fund). Deductible Gift Recipients must be listed with the Australian Taxation Office under Item 1 of the Table in Section 30–15 of the Income Tax Assessment Act, 1936.

The Foundation cannot give funding to individuals or organisations that are not eligible recipients.

Funding is **not** usually given for: Office equipment, Sponsorship or fundraising appeals, Motor vehicles, Scholarships, Building projects or modifications, Religious purposes, General operations or running costs, Hospitals, Projects outside Australia, Organisations with a high net asset worth

**Contact** St. George Bank  
Phone: (02) 9236 3534  
Fax: (02) 9236 1576  
Email: [stgeorgefoundation@stgeorge.com.au](mailto:stgeorgefoundation@stgeorge.com.au)  
Web: <http://www.stgeorgefoundation.com.au/stgeorgefoundation/gift.asp>



GSCWA can assist with grant applications and resources for your group!

## Extending the Capacity of Not-For-Profit Organisations

Funder: LotteryWest  
Closing Date: Ongoing

Aim: To support initiatives that support community service organisations or sector-wide groups to improve their capacity through organisational development and training activities. Increasing the management and leadership skills of staff, committee and board members, and volunteers.

Grants may support:

- The development of strategic, management, communications, technology and/or fundraising plans
- Volunteer training, management training
- The development of best practice, quality assurance strategies
- Projects that assist not-for-profit organisations develop partnerships with the business sector
- Information technology planning
- The development of operational and induction manuals and purchasing of training resources
- Conference attendance by people from the not-for-profit sector. The organisation running the conference needs to apply for the grant, rather than the organisations wanting to send people to the conference.
- A management committee member, a volunteer or staff member to further their management and leadership skills.

Priority for the Extending the Capacity of Not-for-Profit Organisations Grants is given to:

- Not-for-profit community groups and organisations that support networking forums for specific interest groups, including peak or sectorwide organisations.
- Local government authorities with priority given to their community service activities such as youth, volunteer, seniors, children's or other community service programs.

**Contact** (08) 9340 5270  
Website: [www.lottery.wa.gov.au](http://www.lottery.wa.gov.au)  
Email: [grants@lotterywest.wa.gov.au](mailto:grants@lotterywest.wa.gov.au)  
Freecall: 1800 655 270  
TTY: (08) 9340 5236



# Link Line

Genetic support groups are an important resource for families or people in a similar situation.

The Link Line provides a supportive and confidential means of connecting individuals and families for whom no known genetic support group exists.

If any individual is seeking contact with others in these circumstances, the Link Line is available to you for this purpose.

To date, there appears to be no specific support group for the following conditions/syndromes.

## Isodicentric Chromosome 15

A Melbourne family with a 2 year old son are seeking contact with others affected by Isodicentric Chromosome 15. For initial enquires please contact Zornitza Stark, Clinical Genetics Fellow via email to [Zornitza.Stark@ghsv.org.au](mailto:Zornitza.Stark@ghsv.org.au).

## Wilson's disease

Rose would like to speak with others affected by Wilson's disease. To contact Rose, phone 9879 4887 or mobile 0400 205535 or email [musicsoothes@msn.com](mailto:musicsoothes@msn.com).

## Lissencephaly

A family from Western Australia who have a child severely affected with Lissencephaly would like to make contact with other families in a similar situation. Please contact Kristina at the Genetic Support Council of WA via email [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au) or phone 08 9389 6722

## Osler Weber Rendu Syndrome

Narelle is seeking contact with anyone affected by the condition Osler Weber Rendu Syndrome. Please contact Narelle via email [rel@rapserv.com.au](mailto:rel@rapserv.com.au).

## Noonan Syndrome

John is seeking contact with anyone affected by Noonan Syndrome. Please contact John via email [johnnok2@bigpond.com](mailto:johnnok2@bigpond.com)

## Monomelic Amyotrophy

A person from Western Australia who is living with monomelic amyotrophy would like to make contact with others living with this condition. Synonyms include: Benign Focal Amyotrophy, Hirayama syndrome, O'Sullivan-McLeod syndrome, Sobue disease and Single limb atrophy. Please contact Kristina at the Genetic Support Council of WA on 08 9389 6722 or email [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au)

## Lowe Syndrome

A family from Western Australia who is living with Lowe Syndrome would like to make contact with others living with this condition. Synonyms of Lowe Syndrome include: Cerebro-Oculorenal Dystrophy, LS, Lowe's Disease, Lowe-Bickel Syndrome, Lowe-Terry-MacLachlan Syndrome, OCRL, OCRL 1, Oculocerebrorenal Dystrophy, Oculocerebrorenal Syndrome and Renal-Oculocerebrodystrophy oculocerebrorenal syndrome oculocerebrorenal syndrome of Lowe Please contact Kristina at the Genetic Support Council of WA on 08 9389 6722 or email [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au).



# GSC Members

## Full Members

Acoustic Neuroma Association of Australia  
Alzheimer's Association of WA  
Angelman Syndrome Association  
Arthrogryposis Support Group  
Australian Cystinosis Support group  
Australian Huntington Disease Association  
Australian Pituitary Foundation WA Branch  
Australian Tuberous Sclerosis Society Inc.  
Australasian CHARGE Syndrome Association  
CleftPALS Inc  
Coeliac Society of WA  
Cornelia De Lange Syndrome Support Group  
Cushing's Disease Support Group  
Cystic Fibrosis WA  
Diabetes Australia - Western Australia  
Down Syndrome Association of WA  
Dyslexia SPELD Foundation WA Inc  
Epilepsy Association of WA  
Even-Keel Bi-Polar Support Association (Inc)  
Fragile X Support Group WA (Inc)  
Haemophilia Foundation WA Inc.  
Heart Kids WA  
Klinefelters Support Group  
Learning and Attention Disorders Society of WA (LADS)  
LQTS Support Group WA  
Lupus Group of WA  
Lymphoedema Association of WA  
Mental Illness Fellowship WA  
Motor Neurone Disease Association of WA  
Mucopolysaccharide & Related Diseases Society (MPS)  
Muscular Dystrophy Association of WA  
Neurofibromatosis Association of WA.  
Parents of Children with Disabilities  
Periodic Paralysis Society of Australia  
PXE Support WA  
Raynaud's Syndrome Support Group  
Rett Syndrome Association of WA  
Senses Foundation Inc.  
Short Statured People's Association WA Branch  
SIDS and Kids Western Australia  
Sjögren's Syndrome Support Group

Spina Bifida Association of WA  
Thalassaemia Association of WA  
Turner Syndrome Association of Australia (WA Branch)  
Support Organisation for Trisomy and Related Disorders of WA (SOFTWA)  
Western Australian Retinitis Pigmentosa Foundation  
WA Tourette Syndrome Organisation (WATSO)

## Corporate Associate Members

ARAFMI Western Australia  
Association of Genetic Support of Australasia  
Australian Kidney Foundation  
Carers Association of WA Inc  
Ectodermal Dysplasia Support Group - OzED  
Health Consumers Council WA  
Lone Parent Family Support Service (LPFSS)  
Office of Population Health Genomics  
The Chromosome18 Registry & Research Society  
The Kalparrin Centre  
The Neurological Council of WA Inc  
Western Australian Deaf Society Inc.

## Individual Associate Members

Anja Hermann  
Darren Webb  
Kristina Johns  
Linda Bovill  
Mark Bovill  
Professor Charles Watson  
Terry Keating



Membership Forms are available on the Web!  
<http://geneticsupportcouncil.org.au>



Our Location and Mailing Address:  
 Oasis Lotteries House  
 Unit 9, 37 Hampden Road  
 Nedlands WA 6009

Attach mailing  
 address label here

# Contact Us

Genetic Support Council WA Inc. (GSCWA)

Address: Oasis Lotteries House  
 Unit 9, 37 Hampden Road  
 Nedlands WA 6009

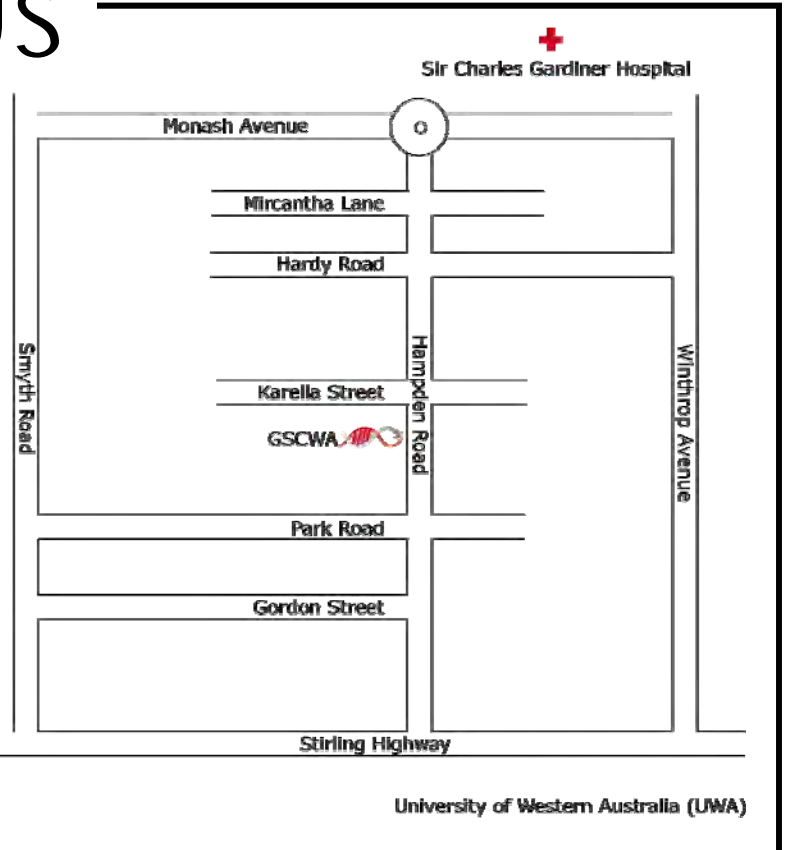
Phone: (08) 9389 6722

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

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

Office hours: 9am to 4pm Monday to Friday.

Staff: Sharon Van der Laan, Executive Director  
 Kristina Johns, Resource Officer  
 Alison Morse, Promotions & Admin Officer  
 Joan Ryder, Book Keeper



## The GSCWA Board of Management

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 Thinking Beyond

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 People with Disabilities WA

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▶▶ The views and opinions expressed in this newsletter are those of the individual authors and not necessarily those of the GSCWA. The material supplied is for information purposes only, and is not to be used for diagnosis or treatment.