



# Gene Advocate

Issue 52

2008

## The Impact of a Genetic Diagnosis

*Genetic disorders impact not only the physical health, but also the psychological and social well-being of patients and their families. Understanding the unique aspects of genetic information and anticipating reactions to genetic tests and diagnoses can help guide a course of action to minimize distress and maximize benefit for both families. Referrals to support groups can also help address the psychological well-being of the patient and family.*

Genetic disorders have powerful effects on families. Like many chronic conditions, they may require continual attention and lack cures or treatments. They have implications for the health of relatives, so a genetic diagnosis for one family member may mean other blood relatives are also at risk, even if they currently show no symptoms. In addition to the medical implications, genetic disorders present emotional challenges and special reproductive implications. Families may be concerned about the risk that additional offspring will inherit the condition, prenatal and newborn testing decisions, and difficult treatment options.

A genetic diagnosis generally provides great benefit to patients. It helps patients understand their disorder, especially when the condition is rare and the patient has struggled to find a diagnosis. Oftentimes, patients spend years living with a condition without knowing its name or cause. Diagnoses usually lead to improved treatment options and access to support services. They can also help other family members make decisions about their own lives.

A genetic diagnosis may lead to negative reactions, too. The science of genetics can be confusing, and patients are often frustrated until they understand the nature of their condition. Patients identified with a mutation may consider themselves at fault or "broken" or interpret their diagnoses as leading to something they cannot

fight. A genetic diagnosis can lead to fears about insurance and employment discrimination.

The reaction to a diagnosis varies from individual to individual and is affected by many factors including gender, education, and religious and cultural beliefs. By being aware of these differences and understanding a patients' background, doctors will be able to communicate with them more effectively.

Understandably, the diagnosis of a genetic condition may put stress on a relationship. For adult-onset conditions, unaffected spouses may view their partners differently, and the diagnosis can lead to a breakdown in communication. Couples with an affected child often face difficult family planning decisions because future children may be at higher risk. Depending on the condition, parents may also be faced with hard choices regarding prenatal testing and termination of pregnancy. The magnitude of these decisions and their outcomes has an impact on the individuals involved and on their relationship.

Given the shared nature of genetic information, it is important to consider the family unit. Unaffected family members should not be forgotten in the case of a genetic disorder. When one family member is diagnosed with a mutation, family members who do not have the mutation often feel guilt that loved ones are affected when they are not.

## The Impact of a Genetic Diagnosis

Siblings of children with special needs sometimes feel neglected because parents need to focus more time and effort on their siblings. Including unaffected family members in the planning of care for individuals with special needs can help them come to grips with their own emotional issues. Adults who are diagnosed with a genetic condition and are considering having a child will need to consider the risk of having an affected child as well as their ability to care for the child.

In cases in which a genetic test is predictive, other family members may misinterpret the results as a diagnosis rather than an indicator of risk for a condition. It is important to keep in mind that genetic test results are often complex and may be difficult for families to understand. In some cases, a genetic test may reveal the risk status of other family members who may not wish to know this information, potentially encroaching upon their autonomy or privacy.

The financial burden of a chronic genetic condition can also lead to stress among family members. A family already struggling financially may be intimidated by the costs associated with caring for a child with special needs. Referrals to appropriate support services are crucial to help ease the stress caused by a genetic diagnosis.

When a newborn is diagnosed with a genetic condition, parents are overcome with concern for their child. Some common reactions include fear, confusion, and grief that their child is not “normal,” guilt that they did something to cause the condition, and anger at the lack of a solution, or the belief that the other parent is to blame. The fact that a medical cure or treatment may not exist often comes as a great surprise to parents. This further adds to the parents’ concerns about their ability to care for the child.

In general, support or advocacy groups and community resources can provide ongoing support to patients and their families with genetic conditions. Support groups provide a forum for sharing experiences about caring for a family member affected with a genetic condition, coping with a new diagnosis, obtaining healthcare or other services, and healing. Members of support

groups know first-hand what it means to be faced with a diagnosis and to need accurate, up-to-date information.

Staying connected with their community helps individuals fight the feelings of isolation that often surround families living with a genetic condition. Each parent has his or her own way of coping with the stress of caring for an infant with medical needs. It may be helpful for families to share their feelings with others and contact with a support group may facilitate these discussions and help identify resources. Support groups can also help families overcome feelings of isolation often associated with a rare genetic condition, provide first-hand experience about caring for an infant with the condition, provide information about expectations for the affected person, and suggest coping mechanisms for both parents and siblings to adjust to new challenges.

Extract from:

‘Understanding Genetics’ – Genetic Alliance Inc  
[www.geneticalliance.org](http://www.geneticalliance.org)

### Suggested Resources:

- Genetic Support Council of WA:  
[www.geneticsupportcouncilwa.org.au](http://www.geneticsupportcouncilwa.org.au)
- Genetic Services of Western Australia:  
[www.kemh.health.wa.gov.au](http://www.kemh.health.wa.gov.au)
- The Kalparin Centre: [www.kalparrin.org.au](http://www.kalparrin.org.au)
- Australasian Genetic Alliance:  
[www.australasiangeneticalliance.org.au](http://www.australasiangeneticalliance.org.au)



The Genetic Support Council of WA (GSCWA) is starting a genetic support group for families affected by rare disorders and for whom there is no specific support group available.

Any families or individuals interested in finding out more please contact Kristina  
Phone: 9389 6722  
Email: [kristina@geneticsupportcouncil.org.au](mailto:kristina@geneticsupportcouncil.org.au)

## Australians With Terminal Medical Conditions To Receive Superannuation Lump Sums Tax Free

The Minister for Superannuation and Corporate Law, Senator the Hon Nick Sherry, announced on Thursday, February 14, 2008 that the Government will legislate to make superannuation lump sum payments tax free where paid to persons suffering from terminal medical conditions.

Amendments to the tax law to give effect to this measure, contained in the Tax Laws Amendment (2008 Measures No. 1) Bill 2008, were introduced into Parliament today.

'The Government is relieving some of the financial stress which terminally ill persons and their families may be experiencing as a result of their difficult circumstances,' Minister Sherry said.

'We supported this change in the past. However, we have extended the previous government's announced measure so that tax free treatment will apply to payments made on or after 1 July 2007, rather than 12 September 2007.'

Currently, superannuation lump sum payments that are paid from taxed funds to individuals under the age of 55 are taxed at a maximum rate of 21.5 per cent (including the Medicare levy). Higher tax rates apply to lump sums paid from untaxed funds.

The tax free treatment will apply to lump sums from both taxed and untaxed funds paid to persons with terminal medical conditions.

The Government will also introduce a new condition of release to give persons with terminal medical conditions unrestricted access to their superannuation benefits. Details of this are expected to be released shortly.

Contact: Shane May 0402 958 743

Spokesperson:  
Senator Nick Sherry - Minister For Superannuation  
And Corporate Law

## Share your inspiring story

ABC Health: Tell us your story!

Have you attained your health goals and want to tell others the key to your success? Have you recovered from an illness and want to inspire others who are only at the beginning of their journey? Or do you want to share a life event to help guide others through the unknown?

If you have an inspiring story to tell we'd like to hear from you. We're looking for people who want to send us well written, original, narrative style stories.

Please send us some details about yourself and your story of between 700 – 1000 words The best stories will be published on Health and Wellbeing in our Your Stories section.

Visit: <http://www.abc.net.au/health/yourstories/submitform.htm>



Cleft Palate and Lip Society of W.A.

## Annual General Meeting

1.00pm Sunday 25th May 2008

Princess Margaret Hospital  
Administration Building  
Roberts Road, Subiaco

Guest speakers & Crèche facilities  
Afternoon tea provided  
Please RSVP to Kelly by 19th May  
on 9418 3842 or 0416 216 350

Everyone is welcome. Hope to see you there!

## Adverse medicine event line

The Adverse Medicine Events (AME) Line

- ⦿ provides consumers with a mechanism to report adverse experiences with medicines.
- ⦿ provides an opportunity for consumers to consult with a pharmacist about medicine safety.
- ⦿ ensures that consumers' concerns about medicine safety are taken seriously and reported to the relevant authority.

For reporting or advice on adverse drug reactions or errors associated with medicine use call 1300 134 237. Available Australia wide for the cost of a local call (9am - 5pm AEST)



**NPS**  
National Prescribing Service Limited

**PHARM**

### National Medicines Symposium 2008

Wednesday 14 – Friday 16 May 2008  
National Convention Centre, Canberra, Australia



QUM – what does it really mean for you?  
The science, the policy and the practice.

#### Important Deadlines Approaching

**Early bird registration and  
accommodation bookings close: April 7**

For more information and to register online  
[www.nps.org.au](http://www.nps.org.au)



## What is Nutritional Genomics?

Nutritional genomics, or nutrigenomics, is the study of how foods affect our genes and how individual genetic differences can affect the way we respond to nutrients (and other naturally occurring compounds) in the foods we eat. Nutrigenomics has received much attention recently because of its potential for preventing, mitigating, or treating chronic disease, and certain cancers, through small but highly informative dietary changes.

The conceptual basis for this new branch of genomic research can best be summarized by the following five tenets of nutrigenomics:

1. Under certain circumstances and in some individuals, diet can be a serious risk factor for a number of diseases.
2. Common dietary chemicals can act on the human genome, either directly or indirectly, to alter gene expression or structure.
3. The degree to which diet influences the balance between healthy and disease states may depend on an individual's genetic makeup.
4. Some diet-regulated genes (and their normal, common variants) are likely to play a role in the onset, incidence, progression, and/or severity of chronic diseases.
5. Dietary intervention based on knowledge of nutritional requirement, nutritional status, and genotype (i.e., "personalized nutrition") can be used to prevent, mitigate or cure chronic disease.

Information Source: The Center of Excellence in Nutritional Genomics.

Web: click on the information tab  
<http://nutrigenomics.ucdavis.edu/nutrigenomics>

## Get to know your medicines

Seven fact sheets explaining medicines in clear, plain language have been published as a joint project between Consumer Health Forum of (CHF) and the National Prescribing Service.

Almost 300,000 free Get to Know Your Medicines fact sheets were ordered in the six months following publication in July last year. Over 79% of community pharmacies have ordered them. General practices, community organisations and hospitals are also ordering significant numbers.

We encourage more community, professional and government groups to order the fact sheets so they are in all public and private health professionals' waiting rooms, community centres and other places people seek health information,' CHF Executive Director Helen Hopkins said. 'There is a huge public demand for information about medicines and how to use them. When health information is easy to understand, people are better able to make decisions about their own health care.'

The Get to Know Your Medicines campaign is part of the Community Quality Use of Medicines Program, which CHF was instrumental in getting established. The Australian Government funds the National Prescribing Service to undertake the Community Quality Use of Medicines Program in partnership with CHF and other consumer groups.

Figures courtesy of the Community Quality Use of Medicines Working Group of the National Prescribing Service Consumers Shaping Health © 2008 Consumers Health Forum of Australia ISSN 1835-2057 PO Box 3099

Fact Sheets available include

- Generic Medicines
- Talking with your Doctor or Pharmacist
- Remembering your medicines
- Read the Label. It's important
- New medicines – are they always better?
- Using the Internet to find reliable health information
- What is a medicine?

See the fact sheets at [http://www.chf.org.au/public\\_resources/medicines.asp](http://www.chf.org.au/public_resources/medicines.asp).

Order them at <http://www.nps.org.au/resources/content/ConsumerOrders.php>.

Phone: 1300 888 763

**MYATTS FIELD**  
VINEYARDS

**BICKLEY HARVEST FESTIVAL CARMEL 2008**

Myattsfeld Vineyards and the Muscular Dystrophy Association of WA invite you to the

**Launch of the 2008 Bickley Carmel HARVEST FESTIVAL**  
**6.30pm**  
**Friday 2nd May**

*Enjoy superb Myattsfeld Vineyards wines teamed with local gourmet food, take in the wonderful valley views, be entertained by local musicians and participate in the deluze raffle!*

Tickets are available for **\$75 per person** and proceeds from this night will be donated to the **Muscular Dystrophy Association of W.A.**

For more information and to purchase your tickets for the Launch, contact Fundraising & Events Manager Brooke Anthony on **9382 2700** or **mda@cyllene.uwa.edu.au**

The Annual Bickley-Carmel Harvest Festival will be held on Saturday 3rd and Sunday 4th May. The Harvest Festival provides an exciting weekend for all, celebrating and discovering the picturesque Perth Hills.

**For more details go to [www.bickleycarmeltourism.jkwh.com](http://www.bickleycarmeltourism.jkwh.com)**

**M D**  
MUSCULAR DYSTROPHY

Together, we will beat muscular dystrophy!

For more information about how YOU can help people with muscular dystrophy, phone 1800 654 632 or visit [www.mdawa.asn.au](http://www.mdawa.asn.au)



# Member Profile

## What is Lupus ?

Lupus is an autoimmune disease. When you have lupus you produce an excess of proteins - called antibodies - which instead of protecting the body, react against substances normally present in the body to cause many symptoms. Lupus is not infectious or contagious, however, can result in pain, career, lifestyle and emotional changes for those affected.

## Who Does Lupus Affect ?

Lupus is not a rare disease. It affects over 20,000 Australians, at least 1 in 2000 West Australians and is increasingly significantly in incidence due to improved detection by medical tests.

90% of those affected will be women and develop lupus between the ages of 15 and 45 years. Lupus is at least twice as prevalent in Aboriginal Australians.

International Studies have reported lupus as a leading cause of morbidity among women, with women five times more likely to die from complications of lupus than men.

Lupus is an important health issue for women and the entire family structures upon which it impacts.

## What Causes Lupus ?

Medical researchers do not know the cause of lupus. It is known that the body's immune system attacks its own tissues instead of protecting them, as is the case normally.

Also, recent studies have shown that there is a link between lupus and certain hormones, together with environmental and genetic factors.

## Types of Lupus

**Systemic Lupus Erythematosus (SLE)** : Can affect almost any organ or system of the body. Affected areas can range from skin and joints, to kidneys, lungs, heart, blood vessels and/or brain. Often people affected have another autoimmune disease, in addition to SLE.

**Discoid Lupus** : Is generally a milder disease than SLE, and affects the skin, with skin rashes and sun sensitivity being the main symptoms. A disc-shaped rash often occurs on the face, but can also be seen on the arms and chest. Internal organs and general health is usually not affected. A small percentage of people with discoid lupus will later develop SLE.

**Drug-Induced Lupus** : Develops as a reaction to certain medications used to treat other medical conditions. It usually goes away when the medication that triggered the lupus is stopped.

## What are the Main Symptoms ?

SLE has a wide range of symptoms. It can remain undiagnosed or misdiagnosed for years. It is important to see your doctor if you have concerns with regard to your health and the symptoms below.

**Discoid** - internal organs are rarely affected:

- ⦿ Rashes on face, scalp or other areas.

**Systemic** - a wide range of symptoms which vary between each person with periods of wellness (remission) and illness (flares):

- ⦿ Fatigue
- ⦿ Muscular pain/inflammation in tendons/joints
- ⦿ Skin rash - face, neck or arms

- ⦿ Fever and weakness. feeling of poor health
- ⦿ Sensitivity to sunlight
- ⦿ Hair loss
- ⦿ Unexplained headache, depression or anxiety
- ⦿ Chest pain including pleurisy
- ⦿ Mouth ulcers
- ⦿ Kidney problems
- ⦿ Miscarriages ( lupus flares during pregnancy )

## How is Lupus Diagnosed ?

Lupus is not an easy disease to diagnose as it affects different people in different ways and may imitate other arthritic conditions.

Currently there is no single test that can show whether a person has lupus, but several tests may help diagnose it. In general however, if a person is suspected of having lupus, the doctor will review the medical history of their patient and carry out :

- ⦿ a complete physical examination to identify characteristic features,
- ⦿ a blood count to establish whether the patient has too few red cells, white cells or platelets ( blood cells that control bleeding ),
- ⦿ an anti-nuclear antibody (ANA) test to confirm the presence of the antibodies that are present in lupus,
- ⦿ other tests to determine the amount of inflammation in the body and whether kidney involvement is suspected.

There is no cure for lupus. Successful treatment and quality of life depend upon :

- ⦿ good communication
- ⦿ understanding the disease
- ⦿ undertaking lifestyle changes
- ⦿ a positive attitude
- ⦿ regular checkups

## How can Lupus be Treated ?

As lupus is often different in each person, finding the right balance of treatment, with minimal serious side effects, may take time. However, in general, treatment given will depend on the severity of the disease and whether there is organ involvement. Regular monitoring to detect disease changes will be undertaken.

Medications aim to suppress the overactive immune system and reduce the inflammation and associated symptoms. Medications include aspirin, steroids, antimalarials, immunosuppressants ( severe cases ) and broad-spectrum, high-grade blockout suncream.



## The Lupus Group of WA

The Lupus Group of WA was formed in 1979 as a voluntary non-profit organisation, and became incorporated in 1986. The Group is self-funded (receiving no state or federal funding) and relies heavily on memberships, donations and fundraising.

### Mission :

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

### Priorities :

#### **Education and Community Awareness :**

To provide community displays, clinical education seminars, media updates, newsletters and information kits to the general public, medical and political community to raise awareness, early detection and understanding of lupus.

#### **Support Services :**

To act as a source of support and information to people with lupus, their families and friends.

#### **Research :**

To actively fund and participate in research to enhance management practices and discover the potential cause and cure for lupus.

Phone/fax: (08) 9224 3144

Email: [admin@lupuswa.com.au](mailto:admin@lupuswa.com.au)

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



# Coming Events



*dedicated to finding a cure*

## Jelly Baby Month

Date: Month of May

Org: The Juvenile Diabetes Research Foundation  
Help stop the devastating effects of type 1 diabetes. Australians with type 1 (juvenile) diabetes can develop serious complications such as kidney disease and blindness. Help us find a cure by purchasing Jelly Baby merchandise during May at all Woolworths stores and Amcal pharmacies.

*Remember, Jelly Babies save lives and so can you!*

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



## Bickley Carmel Harvest Festival

Date: Friday 2nd May 2008

The Muscular Dystrophy Association of WA and Myattsfeld Vineyards proudly present the Launch of the Bickley Carmel Harvest Festival. Come along and support Muscular Dystrophy. (see ad page 5)

Phone: 9382 2700

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

## How Patients & Treating Health Care Professionals Can Collaborate On Crohn's and Colitis for Better Outcomes!

Date: Saturday 3rd of May 2008

Time: 12.00 p.m - 2.00 p.m

Venue: F.J. Clarke Lecture Theatre

Sir Charles Gairdner Hospital

Hospital Avenue, Nedlands

Educational forum on understanding Crohn's and Ulcerative Colitis and looking at new ways to manage with living with a diagnosis. This forum is for those with the condition and also for those living with someone who has a diagnosis.

Topics to be covered over the evening include: Diagnosis, Current Treatments and Promising New Treatments, The Psychological Aspects of Living with a Chronic Illness such as Crohns and Colitis, and What You Should Know About Diet in the Management of Crohns and Colitis  
Bookings Essential, please phone Australian Crohns & Colitis Association  
Toll Free No: 1800 138 029

## Tourette Syndrome Awareness Week



Date: Sunday 4th to Saturday 10th May

Org: Tourette Syndrome Association of Vic.

National awareness of Tourette's Syndrome including a education awareness program (TSAA DVD PROJECT). TSAA is currently organizing a DVD project to increase awareness of Tourette Syndrome. The project offers any school in Australia a free DVD - 'What is Tourette Syndrome?'. The DVD was produced by the TS

Association in 2003 in Australia, and it features explanations and interviews on Tourette Syndrome. Has your child's school received their DVD? All schools have to do is contact our office (02) 9382-3726 and a DVD will be sent. This Charity believes in donating!!  
Email: [info@tourette.org.au](mailto:info@tourette.org.au)  
Web: [www.tourette.org.au](http://www.tourette.org.au)

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## Chronic Kidney Disease Model of Care Forum

Date: Thursday 15 May 2008  
Time: 12.30 – 5.00 pm  
Org: The Renal Health Network  
Venue: City West Function Centre,  
Plaistowe Mews, West Perth  
2nd Stakeholders' Forum – 'A Year On'  
Take this opportunity to review the Network's achievements over the past year and identify the priorities for the 'Chronic Kidney Disease Model of Care' implementation by Area Health Services: Registration Forms can be downloaded from [www.healthnetworks.health.wa.gov.au/calendar/](http://www.healthnetworks.health.wa.gov.au/calendar/)  
Contact: Zai Scarff  
Phone: 9489 2856 or  
Email: [zai.scarff@health.wa.gov.au](mailto:zai.scarff@health.wa.gov.au)



## Kidney Health Week

Date: Saturday 24 May to Saturday 31 May  
Org: Kidney Health Australia  
National health awareness campaign which highlights the importance of early detection and better management and prevention of kidney disease to the Australian community.  
Web: [www.kidney.org.au](http://www.kidney.org.au)  
Phone: 1800 682 531 (24 hour freecall info line)

## Cleft Pals Annual General Meeting

Date: 1.00pm Sunday 25th May 2008  
Venue: Princess Margaret Hospital  
Administration Building  
Roberts Road, Subiaco  
Guest speakers & Crèche facilities, Afternoon tea  
Please RSVP to Kelly by 19th May  
Phone: 9418 3842 or 0416 216 350

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## The Human Face in the Media

Date: Wednesday, 28 May  
Time: 1:00-4:00pm  
This workshop will look at how to be an effective group spokesperson when dealing with the Media. Tony Serve will explain the risks and rewards of putting yourself in front of the microphone or camera and mock interviews will be conducted in order to prepare you for an actual interview.  
RSVP 21 May to Christine  
Email: [christine@connectgroups.org.au](mailto:christine@connectgroups.org.au)  
Phone: 9228 4488.



## National Crohns & Colitis Awareness Week

Date: 16-21 June  
Org: Australian Crohn's and Colitis Association  
The Australian Crohn's and Colitis Association (ACCA), the peak patient body representing people with inflammatory bowel disease (IBD) are urging Australians with IBD to break their silence and join in the fight against this debilitating disease during national Crohn's and Colitis Awareness Week.  
Phone: 1800 138 029  
Email: [info@acca.net.au](mailto:info@acca.net.au)  
Web: [www.acca.net.au](http://www.acca.net.au)



Do you have an event coming up? Promote 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

## Medical professional booklets

NORD has a series of free booklets for physicians and other medical professionals. These publications are funded by individuals or organizations to encourage early diagnosis of rare diseases.

To date, there are nine booklets in the series:

- Pediatrician's Guide to Tyrosinemia Type I
- Pediatrician's Guide to Ornithine Transcarbamylase Deficiency...and other Urea Cycle Disorders
- Physician's Guide to Primary Lateral Sclerosis
- Physician's Guide to Pompe Disease
- Physician's Guide to Multiple System Atrophy
- Physician's Guide to Hereditary Ataxia
- Giant Hypertrophic Gastritis and Menetrier's Disease
- Physician's Guide to Amyloidosis
- Physician's Guide to Medullary Thyroid Cancer

Web: <http://www.rarediseases.org/programs/freebooklets>

## Update on copyright amendments

The Round Table on Information Access for People with Print Disabilities has played a major leadership role in attaining changes to the Copyright Act. New provisions in the Copyright Amendment Bill 2006 pave the way for individuals and organisations to make copies of protected documents for people with print disability, as long as there is no accessible copy available. An update of the changes is available on the Round Table website.

Web: <http://www.e-bility.com/roundtable/activities.php>

## New version of GiftPack for deductible gift recipients and donors

The Tax Office has released a new version of its guide GiftPack (NAT 3132-12.2007). The new version replaces the previous version that issued in July 2006 (NAT 3132-7.2006).

GiftPack helps organisations understand what they need to do if they want to receive tax deductible gifts. It also helps donors who want to claim tax deductions for their gifts.

The new version incorporates changes to the tax law since the guide last issued.

These include:

- changes to the gift fund requirements for deductible gift recipients (DGRs)
- making the existing record keeping requirements for DGRs explicit in the tax law
- extending the Tax Office's review powers to include DGRs listed by name
- changes to the limits for tax deductible contributions, and
- new tax deductions for gifts of shares valued at \$5,000 or less.

Web: <http://www.ato.gov.au/content/18699.htm>

Phone: 1300 720 092 (quote NAT number 3132)

## Comparing genetics law

The Genetics and Public Policy Center has added a new resource to its site, a searchable database of laws in 11 countries relating to human cloning, human genetic modification, and reproductive genetic modification.

Web: <http://www.dnapolicy.org/policy.international.php>

## Disability building access

The Human Rights and Equal Opportunity Commission recently launched a collection of resources titled "The good, the bad and the ugly: Design and construction for access".

The series includes a free CD, photographs and guidelines aimed at providing information and guidance to designers, builders, planners, certifiers, building managers and access consultants about access to buildings and services for people with disability.

Web: [http://www.humanrights.gov.au/disability\\_rights/buildings/good.htm](http://www.humanrights.gov.au/disability_rights/buildings/good.htm)

## Support for working carers

A new program run by Southern Cross Care has just been announced. The Employed Carers Innovative Pilot (ECIP) is aimed at assisting employed primary family carers to manage their responsibilities of work/study and caring by providing assistance in the form of a Key Worker with tasks that would usually require them to take time off work, such as medical appointments etc.

Phone: 9282 9966

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

## Multilingual resources

Resources in different languages include:

- "Prenatal Testing - Special tests for your baby during pregnancy" available in Arabic, Chinese, English, Farsi, Japanese, Korean, Thai, Vietnamese
- "How can Genetic Counselling Help?" available in Arabic, Chinese, Croatian, English, Italian, Korean, Portuguese, Russian, Spanish, Thai, Turkish, Vietnamese

Web: [www.genetics.com.au/resources/index.html](http://www.genetics.com.au/resources/index.html)

## Human genetics for primary school students

Worksheets for primary schools introducing the fundamental concepts of human genetics to children from an early age.

Web: [www.genetics.com.au/schools/hgps.html](http://www.genetics.com.au/schools/hgps.html)

## Support for siblings

Do you have a brother or a sister with a disability or chronic illness? Then guess what? You are a Sib (Sisters Individuals Brothers), and are eligible to join the fabulous Your Shout online community where Sibs from all over Australia can contribute their thoughts, ideas and feelings.

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

## Siblings Australia web update

The Siblings Australia website has just been updated to include forums for young, teen and adult siblings, as well as service providers. If you are running or intending to run sibling programs the provider forum, Sibservices, could be very useful. Services are also invited to register group details on the directory of services page. The research pages will provide details of activities during 2008 in relation to sibling issue research.

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

## Genetics in family medicine online GP resource

Provides GPs online access to the resource, Genetics in Family Medicine: the Australian Handbook for General Practitioners.

This resource has been developed to support GPs in managing the growing impact of genetic medicine on primary care, to further the knowledge and skills in evaluating family history and in recognising clinical findings that indicate genetic risk.

Web: <http://www.gpgenetics.edu.au>



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

## Dreamworld Sponsorship

Funder: Dreamworld  
Closes: Ongoing

Dreamworld supports charity, arts, community or sporting activities. Proposals must be submitted with a minimum of six weeks lead time for your planning purposes. Dreamworld's sponsorship team evaluates all proposals to assess their feasibility, suitability, and resources required. Proposals are considered based on Dreamworld's Sponsorship Charter.

Dreamworld is a place where dreams come true for children of all ages. As such, Dreamworld supports charities and initiatives that help dreams come true for children experiencing hardship, disabilities or sickness, who would benefit from visiting such a place.

### Contact

Website: [http://www.dreamworld.com.au/content/tpgc\\_standard.asp?name=TPGC\\_CharitySponsorships](http://www.dreamworld.com.au/content/tpgc_standard.asp?name=TPGC_CharitySponsorships)

## St George Foundation

Funder: The St.George Foundation  
Closing Date: Ongoing

The Foundation supports innovative projects that enable disadvantaged and disabled children to reach their potential.

When to apply

The Governors of the Foundation meet twice a year to consider applications for financial assistance from \$5,000-\$50,000. The cut off dates for applications are 22 February 2008 and 13 June 2008 and must be made online.

Applications for financial assistance for less than \$5000 are given discretionary consideration once a month.

Examples of projects we support:

- Early intervention services
- Educational equipment and assistance
- Youth workers
- Recreational and respite programs
- Counselling and therapy
- New technologies
- Medical equipment

To be eligible for funding, an organisation will:

- assist children under the age of 18 years of age
- focus its efforts on Australian children
- be a registered Australian charity endorsed as a deductible gift recipient (but not another ancillary fund).

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

Website: <http://www.stgeorgefoundation.com.au/stgeorgefoundation/gift.asp>

## Community Health Services

Funder: Lotterywest  
Closing date: Ongoing

Strengthening Community Service Delivery grants have been developed to add value to the various not-for-profit community services available to the Western Australian Community.

Priority for these grants is given to:

- Organisations that provide support to disadvantaged people or groups
- Proposals that will provide a broad community benefit

Lotterywest may support health-related services which are an initiative of the community, rather than a core government service.

### *Targeted Community Health Strategies*

Grants will be considered for community health services for medical equipment for services that:

- Are delivered within a community setting
- Involve preventative and educational elements
- Are of a high quality and use professional, qualified personnel and
- Are financially viable

### *Community Health Centres*

Lotterywest may support general preventative and educative health services provided by Community Health Centres through a grant towards the cost of medical equipment where:

- the service is of a high quality and delivered by appropriate medical professionals
- the service is complementary to the Centre's core services
- the service is financially viable and is supported by medical practitioners
- services complement rather than duplicate private or public services in the area
- the equipment being purchased is not the responsibility of another agency and
- the service is available to all of the key target groups, women, Aboriginal people, youth

### **Contact**

Website: <http://www.lotterywest.wa.gov.au/asp/index.asp?pgid=431>  
Phone: 9340 5270

## IOOF Foundation

Funder: IOOF Foundation  
Closing Date: Ongoing

The IOOF Foundation is committed to making an ongoing contribution to the community in which we live. By providing grants that support Australian not-for-profit organisations working with disadvantaged families, disadvantaged children and youth and aged care, the IOOF Foundation is making a difference to those in need.

The Foundation will support the following areas:

- Disadvantaged families;
- Aged care; and
- Disadvantaged children and youth.
- Grants will be considered for organisations represented in any Australian State or Territory.

### Applications for funding

Applications for funding that meet the Foundation's broad criteria, as established by the Foundation Board from time to time, will be placed before the Board at its regular meetings.

### Requirements for applications

There are no standard application forms. However, the Requirements for the application are listed under the tab "apply for a grant" on the website.

**Contact:** Ms Nicole Wright  
Foundation Manager  
**Address:** Level 29, 303 Collins Street  
Melbourne VIC 3000  
**Phone:** 03 8614 4560  
**Email:** [n.wright@iooffoundation.org.au](mailto:n.wright@iooffoundation.org.au)  
**Website:** <http://iooffoundation.org.au>



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



# 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.

## Parent to Parent New Zealand

If you want to make contact with another parent whose child has similar needs. This service is both free and confidential to families.

Currently Parent to Parent NZ are looking for contacts for the following conditions:

- DUPLEX KIDNEY
- ARTIFICIAL EYE & BRAIN HAEMORRHAGE
- MACROCEPHALY
- SACROCOCCYGEAL TERATOMA:
- SPONDYLOEPIMETAPHYSEAL DYSPLASIA
- LONG-SEGMENT HIRSCHSPRUNG'S DISEASE
- CHROMOSOME 22q.11 DELETION
- DYSTONIA
- NEONATAL HYPOGLYCEMIA
- ATAXIA TELANGIECTASIA
- PTEN HAMARTOMA TUMOR SYNDROME
- SEPTIC ARTHRITIS
- ISOLATED CONGENITAL ACTH DEFICIENCY
- OCCULAR MOTOR APRAXIA
- 17q21.3 MICRODELETION SYNDROME
- NASAL-FRONTO-FACIODYSPLASIA
- TEMPORAL SCLEROSIS
- UNILATERAL LINEA MORPHEA

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

## New Support Group for Hereditary Hemorrhagic Telangiectasia (HHT)

HHT is a genetic disorder that causes abnormalities of blood vessels and involves nosebleeds and characteristic red spots that are distinctly different from haemophilia. Most blood vessels in the body of someone with HHT are normal, however, a small percentage of the blood vessels have a specific type of abnormality.

**Contact:** Christine  
**Phone:** 9228 4488  
**Email:** [cdo@connectgroups.org.au](mailto:cdo@connectgroups.org.au)

## New Online Support Group for Hemihypertrophy

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

**Website:** <http://au.msnusers.com/AussieHemihypertrophySupportGroup>

## Support for rare conditions

The Genetic Support Council (GSCWA) is starting a genetic support group for families affected by rare disorders and for whom there is no specific support group available. Any families or individuals interested in finding out more please contact Kristina.

**Phone:** 9389 6722  
**Email:** [kristina@geneticsupportcouncil.org.au](mailto:kristina@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  
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!  
[www.geneticsupportcouncil.org.au](http://www.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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Executive Director  
Cystic Fibrosis WA Inc.

### TREASURER

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Senior Policy Advocate  
Disability First Stop

### DEPUTY CHAIR

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