



Gene Advocate

Issue 56

2009

WA breakthrough on bowel cancer risks

New WA research that will mean fewer individuals can expect to be diagnosed with or die from bowel cancer. In a world-first, researchers have developed a unique testing regime which identifies those bowel cancers which are the result of a hereditary form of the disease, known as Lynch syndrome.

The study has already found 13 families in WA who were previously unaware that they carried the gene for this potentially deadly condition. The results have been published in the International Journal of Cancer. While only a small proportion of all bowel cancer cases can be linked to Lynch syndrome (less than 2%), this research offers a potential lifesaver for these families, as once they are aware of their risk, they can be closely monitored.

Cancer Council's Director of Education and Research, Terry Slevin, said the work was an important strategy in systematically finding WA families at higher risk of bowel cancer.

"It is the kind of vital local research work the Cancer Council is proud to support because of the many lives that can be saved," said Mr Slevin. Lead researcher, Associate Professor Barry Iacopetta from the UWA School of Surgery, said as a result of the research WA was the only State in Australia where this test was being done routinely.

"By doing a relatively simple test at the time of tumour diagnosis it means there is an almost 100 per cent chance that if the patient has Lynch syndrome, they will be identified," he said.

During the study, over 1,200 tumours from bowel cancer patients aged under 60 were tested for indications of Lynch syndrome. This research would not have been possible anywhere else in Australia as researchers in

WA have access to a unique data collection system.

Professor Jack Goldblatt, Director Familial Cancer Program at Genetic Services WA said the research project had already changed clinical practice in WA.

"Previously the first we'd see of these patients was when they presented with bowel cancer, which was often at a late stage and difficult to treat," said Professor Goldblatt.

"Now we have the capacity to identify virtually all of the bowel cancer patients who have inherited forms of bowel cancer before it becomes a problem."

Professor Goldblatt said these individuals then have the opportunity to refer their family members for genetic testing.

"If a family member tests positive for the gene, which gives them about a 40-80 per cent chance of developing bowel cancer, then they can join a screening program to greatly boost their prospects of preventing or identifying a cancer at an early stage where it is curable," said Professor Goldblatt.

Bowel cancer is the second most common cancer in women in WA and the third most common cancer in men. In 2006, 1,080 Western Australians were diagnosed with bowel cancer and 400 died from the disease.

The work, funded by the National Health and Medical Research Council, has been a Statewide collaborative project between the pathology laboratories in WA (both public and private), Genetic Services WA, the School of Surgery at the University of WA, and supported over the long term by Cancer Council WA.

Source: Tasmanian Broadcasters Pty Ltd. 20/03/2009.
www.7hofm.com.au/news-a-articles/health/935-wa-breakthrough-on-bowel-cancer-risks.pdf

UTAS "proves" genetic discrimination

New Australian research has produced the world's first evidence of genetic discrimination, with the majority of cases relating to life insurance policies. The paper, Verification of consumers' experiences and perceptions of genetic discrimination and its impact on utilization of genetic testing, has just been published in the American journal, Genetics IN Medicine.

The verification study was a key component of the comprehensive five-year Genetic Discrimination Project (GDP), funded by the Australian Research Council (www.gdproject.org). The project was collaboratively undertaken by researchers at the University of Tasmania's Centre for Law & Genetics and School of Sociology & Social Work, and the Centre for Genetics Education (NSW Health), Royal North Shore Hospital.

The verification study examined 14 reported cases of alleged unlawful genetic discrimination in Australia, where it is currently legal for life insurers and employers to utilise a person's genetic information, as long as they are able to justify their actions. Of the 14 claims, two cases were not verified, one case was identified as a fear of genetic discrimination that impacted on the individual accessing testing and 11 cases were verified as actual cases of genetic discrimination. A confirmed case was also identified as involving a fear of genetic discrimination impacting on access to genetic testing.

The confirmed cases of genetic discrimination occurred in various settings:

- Nine cases related to life insurance applications and underwriting (claim risks including income protection and trauma policies (two of which were successfully reversed))
- One involved a worker's compensation claim
- One was in regards to a parole application.

Principal author of the verification study paper, Associate Professor Kristine Barlow-Stewart, Director of the Centre for Genetics Education,

said while the verified numbers may seem small, the process of verification was very complex and time consuming, and required trust from both consumers and the third parties who allegedly discriminated against individuals. "Only reports made by consumers who responded to a comprehensive survey regarding alleged genetic discrimination were verified in this study. However, several other cases of discrimination involving genetic testing for breast cancer were also identified by examining data from the life insurance industry," said A/Prof Barlow Stewart.

The verified cases of genetic discrimination occurred against people who were identified by genetic testing, or assumed based on family history, to be carrying a faulty gene that made them more susceptible to particular health conditions including breast and ovarian cancer, Lynch syndrome (a form of colorectal cancer), hereditary haemochromatosis (a genetic condition causing potentially harmful high iron levels), adult-onset polycystic kidney disease and Huntington disease (a debilitating neurological disease affecting adults).

"There is widespread community concern regarding genetic testing and the potential for discrimination, not just against the individual but also their family members," A/Prof Barlow-Stewart said.

"Previous to this paper, only anecdotal reports of genetic discrimination have been available, with some commentators questioning whether or not the phenomenon actually existed. However, we were able to establish verification of genetic discrimination through interviews with people who had participated in earlier aspects of the project and had made claims of genetic discrimination, assessment of their documents and records, or by direct contact with the third parties involved.

"The information coming from genetic testing can be very beneficial and important in terms of prevention and understanding of health problems. However, this verification of genetic discrimination in Australia supports the recommendations of the Australian Law Reform Commission in 2003 for policies and guidelines

UTAS "proves" genetic discrimination

to be developed and implemented to ensure appropriate use of genetic test results in insurance underwriting, as well as the need for education and training in the financial industry, and mechanisms by which consumers and health professionals can challenge adverse decisions."

The verification of genetic discrimination was based on the three key subprojects comprising the GDP:

The Consumer Project, led by Professor Sandra Taylor, University of Tasmania – examined the experiences of people most likely to be affected by genetic discrimination, and the nature and extent of such discrimination.

The Third Party Project, led by Professor Margaret Otlowski, University of Tasmania, and A/Prof Barlow-Stewart – documented the practices and perceptions of relevant third parties like insurers and employers about genetic discrimination.

The Legal System Project, led by Prof Otlowski examined the few cases involving relevant genetic issues or discrimination that have been dealt with in the Australian legal system.

Prof Taylor said most participants reported strong benefit and minimal disadvantage from having genetic test information and had not experienced coercion to undertake testing. However, 85% of respondents said they did not know where to seek assistance if they experienced discrimination.²

"Of the 10 per cent of respondents who did report incidents of alleged genetic discrimination in the survey¹, the cases were significantly influenced by the genetic condition they were at risk for, with the greatest number of reports coming from those at risk of inherited neuro-degenerative disorders and familial cancers," said Prof Taylor.

A sample of cases examined in the verification study included:

- A man underwent genetic testing to identify if he had a faulty gene for breast

and ovarian cancer for the benefit of his family's future health. He was found to have that particular faulty gene, which also made him slightly more susceptible to prostate cancer. Upon disclosure of this information, the man was offered income protection and trauma insurance that excluded him from claims relating to all forms of cancer. Genetic experts ruled that this exclusion was overly broad.

- Two women with a faulty gene (BRCA 1 mutation) that put them at risk of developing breast and ovarian cancer individually applied for income protection with the same insurer, one in 2000 and the other in 2003. Both claims were assessed differently, with one woman being denied any type of income protection and trauma insurance cover, and the latter receiving income protection insurance with an exclusion of breast cancer. The Senior Policy Officer from the Insurance and Financial Services Association explained to the researchers that the difference in decision-making was the availability of updated information in 2003, which the underwriters would have relied upon.

"This case underscores how our understanding and use of genetic information is continually evolving and can consequently be misunderstood. It may be too premature to use test results for such cases of insurance underwriting in such a changing scientific context," said A/Prof Barlow-Stewart.

- A Corrections Board adjudicating a parole application for a man with a family history of Huntington disease requested he undertake testing to establish if he was affected. The man did not wish to have genetic testing in the prison environment but felt pressured to prove that he would not be "a danger to the community" if released early from prison. This illustrates a complete misunderstanding of the nature of Huntington disease, inappropriate use of genetic testing and a lack of understanding of the test results.

Continued...

UTAS "proves" genetic discrimination

According to Prof Otlowski, the use of genetic testing in employment is likely to be an emerging issue in Australia.

"Most Australian employers are not currently using genetic testing or other genetic information in a routine way or in the OH&S domain to monitor present or future employees. However, as will be reported in a forthcoming paper later this year, there were indications that at least some employers would be interested in using genetic testing in the future if it were inexpensive and accessible.

"With regard to the life insurance area, significant challenges lie ahead for life insurers as genetic science rapidly develops and information becomes readily available concerning an individual and their family members. Although the data from the insurance sector revealed largely legitimate and responsible underwriting by life insurers in Australia, we identified a number of cases of concern where genetic test information had been misinterpreted.

"Researching genetic discrimination in Australia for this project would not have been possible without the valued assistance and counsel of the Insurance and Financial Services Australia and the trust of those who had experienced genetic discrimination," said Prof Otlowski

Source: Tasmanian Broadcasters Pty Ltd. 20/03/2009.
<http://www.7hofm.com.au/news-a-articles/health/936-utas-qprovesq-genetic-discrimination.html>

The GSCWA is interested to hear from any members who feel they have experienced genetic discrimination in any forum.

Please contact GSCWA Executive Director, Sharon Van der Laan, on 9389 6722 or via email to sharon@geneticsupportcouncil.org.au. Confidentiality is assured.

The Bailee Ada Foundation Australia



The Bailee Ada Foundation

Congenital disorders of Glycosylation (CDG)

The foundation was founded by Kevin & Melissa Choate after their 2nd daughter, Bailee passed away from Congenital disorders of Glycosylation (CDG).

They wanted to make Bailee's short life mean something. Some people say that everything happens for a reason and through the foundation she can live on.

The foundation's aim is to raise money for CDG research and raise awareness of the condition. Also, they wanted to be able to offer a support network for other families living with this condition.

Congenital disorders of Glycosylation (CDG) is a group of rare disorders. CDG occurs when the one of the many steps involved in glycolylation goes wrong. There are many types of glycosylation error, and so there are many different types of CDG. There is also great variability in the severity of CDG.

Glycoproteins perform important functions in virtually all parts of the body. This means that CDG can affect any part of the body. The brain is the most complex part of the human body and so the brain is the most common organ affected by CDG. CDG can also affect the liver, intestines, heart, bones, eyes, kidneys and immune system.

For further information visit: www.baf.org.au

Senses Foundation

Dandy-Walker Syndrome

MEDIA RELEASE

5 December 2008

Kezia defies the odds with Senses help
When little Kezia Dias, of Mount Lawley, was born with Dandy-Walker Syndrome doctors gave her a 25 per cent chance of surviving past the age of nine months.

A year-and-a-half down the track, the lively and very determined youngster has defied all the odds and is referred to by her parents, Maria and Aldrin, and doting grandparents as their 'miracle baby'.

With support from Senses Foundation's Early Childhood Intervention program, Kezia is now learning basic life skills that will hopefully see her live a full and independent life.

For over a year Kezia has been enjoying includes regular home visits by a physiotherapist to help her develop muscle strength and balance. Senses' occupational therapist is also helping her hone her fine motor skills and learn ways to communicate.

Maria says doctors discovered a cerebellar cyst on her baby's brain when she was five months pregnant. While this helped her and Aldrin get used to the idea, nothing could prepare them for the challenges ahead.

In Kezia's case, the side effects of Dandy-Walker Syndrome include orofacial syndrome – she has a cleft of the soft palate which means she has to be fed by a tube – and a hearing impairment. In the early days she suffered from regular apnoea and her mobility is delayed.

"There are a lot of unknowns," explains Maria. "I don't know what we would have done without the help from Senses. It would have been very tough.

"If I ever have a question they are always happy to give us advice and they are always finding new toys and pieces of special equipment that will help stimulate Kezia's development.

"The silver lining is that Kezia is very determined, so if she wants to do something she probably will."

Senses' physiotherapist Melissa Evans says her work with the Dias family falls into two categories. In addition to working directly with Kezia to progress her development, a major part of her role is to show Maria and Aldrin how to help their daughter on a day to day basis.

Senses Foundation was formed in 2001 when the Royal WA Institute for the Blind - one of WA's oldest charities - amalgamated with the WA Deafblind Association.

It is now WA's primary advocate and service provider for people who are deafblind or blind with additional disabilities, providing highly specialised programs and services to improve communication, socialisation, mobility and quality of life for both adults and children.

The ECI program provides therapy services to preschool children who have vision impairment with another significant disability, or who are deafblind, in their own home.

More information: Leanne Pitcher,
Media Liaison Officer on 0408 923 249.

Contact Details

11 Kitchener Avenue,

Burswood WA 6100

Ph: (08) 9473-5400

Web: www.senses.asn.au





Member Profile

Acoustic Neuroma Association of Australasia, WA Branch

ANAA WA is a branch of, and supported by, the Acoustic Neuroma Association of Australasia based in Melbourne.

Application forms are available for members of the WA support group to join the ANAA who provide us with stationery items and information material to enable us to function and are available for consultation. Newsletters from Australian support and international support groups are also made available. No other fees are required for membership of the WA support group.

At least five informal meetings are held at Oasis Lotteries House, 37 Hampden Road Nedlands, the third Saturday of every second month, unless otherwise advised.

The first meeting of the year is held in March, the last in November, commencing at 1.30 p.m, ending around 4-4.30 p.m. Members are requested to bring a small plate of something for afternoon tea during or following the meeting.

At most meetings there is a 'round the table' update from everyone present, and when possible, we have a Guest Speaker. During 2008, Guest speakers included:

Geraldine O'Brien, from Murdoch University student doing her thesis on 'The Psycho-physio Correlates of Relaxation' under supervision Professor Peter Drummond, particularly interested in recruiting research subjects who'd had the AN experience and dry eye as a result – those of us who fitted the criteria took part in her research programme.

Brett Robinson, WA Manager of the Ear Science Institute of Australia (formerly Lions) re the new building under way in Perth as a centre of research, information and clinical services provided by a multi-

disciplinary team for people with ear, hearing and balance disorders.

We were fortunate in 2008 to have Gunesh Rajan MD, FM, FRACS – Associate Professor of Otolaryngology, Head & Neck Surgery, Head of Clinical Research, Ear Science Institute Australia, Ear Sciences Centre, Depts. Of Otolaryngology, Head & Neck Surgery, University of W.A. and Alexander Ring, Neurological Physiotherapist, in a 'double act' as Guest Speakers.

As well as meetings we are available by phone, mail or email at any time to those in need of support or information, whether it be post diagnosis of Acoustic Neuroma, or head tumours with similar affects, or post treatment. We can offer the kind of information, often 'survival tips', and understanding only possible from those who are travelling the same journey!

2009 Meetings and Activities

VENUE: Oasis Lotteries House
37 Hampden Road
NEDLANDS WA 6009
Phone 9389 6722

TIME: 1.30 p.m. to 4.30 p.m.

DATES: Saturday	21st March
Saturday	16th May
Saturday	18th July
Saturday	19th September
Saturday	21st November

Welcome to our 2009 schedule – I trust the recess since our last meeting in 2008 has been all you'd hoped it would be and more. At that meeting it was agreed to experiment with a regular day of the month for our 2009 meetings and the third Saturday of every second month was chosen, from the March meeting onwards. Now it's time to get our show on the road again!

Our March meeting will be one of catching up with

everyone, having a good cleanout of all our pamphlets etc. as some of them are well beyond their use-by date, and general planning for meetings during the year.

We've been contacted by Chris Broadbent of Cochlear Limited, Perth. They are now providers of BAHA (Bone Anchored Hearing Aid). Christ said that originally BAHA was considered most suitable for people unable to have a normal hearing aid fitted (such as children with 'glue' ear). It has been discovered that BAHA could be of benefit in other situations, such as post-Acoustic Neuroma (Vestibular Schwannoma) removal. Chris has agreed to be Guest Speaker in May.

Since our last meeting, we sent, on her request, 50 ANAA pamphlets to Kim McAuley, Physiotherapist at the Shenton Park Campus of RPH – she intended passing some on to a work colleague.

We looking forward to welcoming you at our meetings this year. As usual a small plate of 'goodies' for afternoon tea would be appreciated.

All suggestions welcome!

Tea and Coffee are provided by the Centre.

Barb Wolff, Co-ordinator

What is Acoustic Neuroma?

An Acoustic Neuroma (or Vestibular Schwannoma) is a benign encapsulated tumour which arises from the 8th cranial nerve. The 8th cranial nerve is actually two separate nerves, one associated with balance and the other with hearing and it is here that this tumour usually arises from either one of these nerves in the bony internal auditory canal between the inner ear and brain. The 7th nerve which services facial movement also passes through this canal as do important blood vessels.

These tumours are usually slow growing but as they expand they begin to press on the hearing, balance, and other nerves. They can then extend into the area at the base of the brain and press on the vital structures of the brain, which can be life threatening.

Cause

Until recently the cause was unknown except for a small group of patients who have Neurofibromatosis type 2 which is genetically determined. Recent

research has discovered the following:- Neurofibromatosis type 2 (NF-2) is a dominantly inherited disease characterized by the formation of bilateral acoustic schwannomas and other benign tumours associated with the central nervous system.

The NF-2 protein, also known as merlin or schwannomin is a tumour-suppressor protein whose loss of absence is clearly linked to the development of certain types of brain tumours, in particular, acoustic neuromas.

Symptoms

The early symptoms are reduced hearing in one ear, ear noise (tinnitus) and poor balance. Large tumours may produce additional symptoms including headache, facial pain, numbness or twitching, double vision, speech difficulties, and swallowing problems.

How is it Found?

If you have any of the symptoms previously mentioned, request a referral from your local doctor to an Ear, Nose and Throat Specialist who will carry out the appropriate hearing and balance tests followed by either a C.A.T. Scan or preferably an M.R.I. Scan that will show the presence or absence of the tumour. A diagnosis of Acoustic Neuroma should always be considered with unilateral (single side) ear symptoms

Contact Details

Barb Wolff, Co-ordinator
Phone: (08) 9453 3338
Mobile: 0418 734 814
Email: barbwolff@bigpond.com

Nancy Verco
Phone: (08) 9476 2444 (Work)
(08) 9447 3069 (Home)

Web: www.anaa.org.au



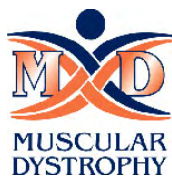
(This article has been reviewed by the Acoustic Neuroma Association of Australasia, WA Branch)



Coming Events

Muscular Dystrophy Awareness Month Muscular Dystrophy Association of WA (Inc.)

Date: 1 - 31 March



This month is devoted to raising awareness about various muscular dystrophies.

Contact: (08) 9382 2700

Website: www.mdawa.asn.au

Great Australian Bite Diabetes WA

Date: 1 - 30 April

The Great Australian Bite is a community participation event involving people and groups getting together throughout the month of April to share a bite to eat and support Diabetes WA by making a tax deductible donation.

Contact: 0893257699

Website: www.diabeteswa.com.au



World Parkinson's Day Parkinson's Western Australia

Date: 11 April

This day aims to raise awareness of Parkinson's disease.

Contact: (08) 9346 7373

Website: www.parkinsonswa.org.au

World Haemophilia Day Haemophilia Foundation WA

Date: 17 April



To raise awareness of Haemophilia in the worldwide community.

Contact: 08 9420 7294

Website: www.hfwa.org

The Learning and Attentional Disorders Society of WA Inc

The Society are holding a series of coffee mornings for parents of children who are living with AD/HD.

When: 1st Wednesday of every month, 9.30am to 11.30am

Where: The Niche

Cnr Aberdare Road & Hospital Ave, Nedlands

Contact: Please call LADS on (08) 9346 7544

Website: www.ladswa.com.au

Arthritis Awareness Week Arthritis Foundation of WA

Date: 29 - 4 April

Arthritis Awareness Week is held every April to highlight the impact of Arthritis on the lives of everyday people of all ages and backgrounds and to draw attention to what can be done to help improve their quality of life. Arthritis WA will be holding a variety of events this year.

Contact: 9388 2199

Website: www.arthritiswa.org.au

Equal Opportunity Commission Training Session.

Date: Friday 15th May 2009

Time: 9:30 to 1:00

Who should attend: Any person interested in developing their knowledge of Equal Opportunity Law. The training session is designed to focus on a range of human rights issues affecting people with disabilities.

Cost: Free

Location: Equal Opportunity Commission
Level 2, 141 St George's Terrace PERTH WA 6000

RSVP: Friday 8th of May 2009

Contact Kristina at the Genetic Support Council
(08) 9389 6722 or e-mail
kristina@geneticsupportcouncil.org.au

Disability Discrimination in Employment and Education Seminar

Date: Thursday, 21st May 2009

Time: 10am to 12.30pm

Facilitator: Rebecca Tedder — Solicitor
Disability Discrimination Unit WA. Sussex Street
Community Law Service Inc.

The Unit engages in community legal education by informing people about their rights so that they can address issues relating to their or another's disability.

** Limited Places Available: RSVP Essential**

Cost: Free

Location: The NICHE Board Room, 11 Aberdare Rd Nedlands WA 6009

RSVP: Monday 4th of May 2009

Contact Kristina at the Genetic Support Council
(08) 9389 6722 or e-mail
kristina@geneticsupportcouncil.org.au



Promote your event here and on our website at no cost! Contact us on
(08) 9389 6722 or e-mail
info@geneticsupportcouncil.org.au

Tourette Syndrome 20th Anniversary Conference



*** Don't get cross... ✓ Because I tic!**

A rare opportunity to learn how to understand and manage this far from rare condition and access otherwise hard to come by resources.

- ☉ Did you know Tourette Syndrome (TS) affects 1 in 100 boys and 1 in 300 girls? TS is now recognised to be relatively common but under recognised and a major cause of hidden disability.
- ☉ TSAA offers telephone and email support, and where possible we are happy to visit and talk at your school.

Take advantage of our Education Awareness Program and order your school's FREE DVD 'What is Tourette Syndrome?.' Contact TSAA and one will be sent FREE!

Date: Saturday 13th June 2009

Time: Registration 9.30am for 10am to 5pm

Venue: The Niche, 11 Aberdare Road
Nedlands WA 6009

Cost: \$40 individuals, \$35 TSAA Members, Includes an Education Pack:

- DVD "What is Tourette Syndrome?"
- Brochures "What is Tourette Syndrome?"
- Classroom strategies
- Educator's Guide to TS
- Behavioural Problems & TS
- Certificate of Attendance

\$55 Professionals (includes Doctor's Pack)

Morning, afternoon tea & light lunch provided

SPEAKERS:

Professor Perminder Sachdev

Professor of Neuropsychiatry at University of NSW and Clinical Director of the Neuropsychiatric Institute at Prince of Wales Hospital, Randwick, Sydney NSW & TSAA Medical Adviser

Robyn Latimer, President TSAA

Psychosocial perspectives, educational and management strategies for Tourette Syndrome

* Register online at www.tourette.org.au

☎ Phone enquiries (02) 9382 3726.



Resources

High Functioning Aspergers Video

Lecture delivered by Dr Temple Grandin, a noted expert and author on early intervention, educational strategies, visual thinking, social skills, and mentoring.

Visit:

<http://au.youtube.com/watch?v=bgEAhMEgGOQ>

Genetic Science Learning Center

General information on genetics and disorders including animated activities aimed at students. Also provides resources for teachers.

Visit: <http://learn.genetics.utah.edu>

New National Disability Agreement

A new National Disability Agreement between the Australian Government and State and Territory Governments will improve and increase services for people with disability, their families and carers. The agreement reflects a strong commitment from both levels of government to provide more opportunities for people with disability to participate in and enjoy Australia's economic and social life.

The agreement comes into effect from 1 January 2009 and will replace the existing Commonwealth State Territory Disability Agreement.

Document Available: www.facs.gov.au/internet/facsinternet.nsf/disabilities/policy-disability_agreement.htm

My Family Health Portrait

In using My Family Health Portrait you can:

- Enter your family health history.
- Create drawings of your family health history to share with family or health care worker.
- Use the health history of your family to create your own.

Privacy

The Surgeon Generals family health history tool does NOT make your health information available to the government or to anyone else but you. It only provides the software for organizing your information.

My Family Health Portrait
A tool from the Surgeon General

Visit: <https://familyhistory.hhs.gov/fhh-web/home.action>

Multilingual Resources

The Centre for Genetics Education has been involved in the production of several resources that have been translated in to a variety of languages.

Visit: www.genetics.com.au/resources/index.html



Fremantle Headspace

A place where young people can receive free or low cost help and support for a range of issues including mental health, general physical health, education, work, drug and alcohol problems, sexuality issues and family and relationship issues.



Visit: www.fremantleheadspace.com.au

Free Interpreting Services

The Australian Government, through TIS National, provides free interpreting services to non-English speaking Australian citizens or permanent residents communicating with the following approved groups and individuals:

- ✓ private medical practitioners providing Medicare-rebateable services and their reception staff to arrange appointments and provide results of medical tests
- ✓ non-profit, non-government, community-based organisations for case work and emergency services where the organisation does not receive funding to provide these services
- ✓ Members of Parliament for constituency purposes
- ✓ local government authorities to communicate with non-English speaking residents on issues such as rates, garbage collection and urban services
- ✓ trade unions to respond to members' enquiries or requests
- ✓ Emergency Management Australia
- ✓ pharmacies for the purpose of dispensing Pharmaceutical Benefits Scheme (PBS) medications.

Visit: www.immi.gov.au/living-in-australia/help-with-english/help_with_translating/free-services.htm

Sexual Health Helpline

The Sexual Health Helpline covers all aspects of sexual and reproductive health and is operated by FPWA Sexual Health Services' Advanced Practice Nurses who are available to discuss the following in a confidential and anonymous manner:

- ✓ emergency contraception
- ✓ contraception including new and emerging
- ✓ contraception options
- ✓ unplanned pregnancy, including the law in WA on the issues of termination of pregnancy
- ✓ planning a pregnancy
- ✓ post natal depression
- ✓ fertility issues
- ✓ safe sex information
- ✓ sexually transmissible infections (STIs)
- ✓ sexual health checks and screenings
- ✓ HIV/AIDS
- ✓ hepatitis
- ✓ relationships and sexuality
- ✓ sexual difficulties

Perth metropolitan area callers can phone 9227 6178 on weekdays between 8.30am to 5pm.



Country area callers can phone 1800 198 205 Monday to Friday between 8.30am to 5pm and on Saturday's between 9am to 5pm.

Alternatively, you can seek confidential answers to your questions by emailing sexhelp@fpwa.org.au

Visit: www.fpwa.org.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

DonorTec



Via the DonorTec

Program eligible Australian charities and nonprofits can request donated technology products from partners such as Microsoft, and Cisco. Criteria for eligibility can be seen at www.donorotec.com.au/eligibility while full details of all our current partners can be found at www.donorotec.com.au/Donor-Partners

Eligible organisations are required to pay a small Administrative Fee to cover the costs of the program. Whilst the Administrative Fees vary, nonprofit organisations stand to make savings of between 92-96% on typical retail prices.

- To gain access to this program you will firstly need to register your organisation via our online registration form www.donorotec.com.au/user/register

DonorTec is very proud to start the new year with the announcement of our newest donor partner, B-Free. B-free Small Business has been tailored towards small organisations to help them prepare accounts and budget their income more efficiently.

- Eligible organisations need only have access to Internet banking and the easily-followed B-free software. Say goodbye to double entry bookkeeping, confusing accounting jargon or continual sorting through receipts to manually enter data.
- Organisations with an operating budget of over \$15,000,000 are ineligible to receive donations from B-free.

Please be advised pricing and available products are subject to change so please visit www.donorotec.com.au/directory for the most up to date and available products from all current donors.

Intensive Family Support Disability Services Commission WA

Closing Date: 1 April 2009

Aim: To provide respite opportunities to families who care for a family member with a disability who has complex and/or high support needs in the family home and who are in need of crucial support.

Respite opportunities may include a range of activities, services or supports that could have a 'respite effect', that is, results in a break for the carer from their carer role.

Funding is allocated to people who have been given the highest priority by an independent panel, and is allocated specifically to the person with a disability.

- To be eligible to apply for funding, the person with a disability must qualify for level two or three services from the Commission.

Contact Details:

Manager Community Support Program Disability Services Commission

Email: cap@dsc.wa.gov.au Freecall: 1800 998 214
Telephone: (08) 9426 9200 TTY: (08) 9426 9315

Further Information:

Web: <http://www.disability.wa.gov.au>



WorkVentures Connect IT Low Cost Computer Systems

To be eligible to purchase a computer system, our customers must be holders of a current Centre Link Health Care Card, Aged Pension Card, Disability Card or some other form of documentation relating to low-income or disadvantage.

For an organization to be eligible it must be a non-profit organization, educational institutions, church, charity or community group.

Payment

WorkVentures has developed a Purchase Plan to assist customers who cannot afford to pay up front. There are no up front deposits, fees, charges or interest involved - you simply receive a Westpac deposit book and can deposit money at any Westpac branch. We will build and ship the computer once you have paid off your Purchase Plan.

To find out more about the WorkVentures Purchase Plan please talk to our Call Centre on 1800 112 205, or email connect.support@workventures.com.au

Schools and community groups - options exist to fundraise to pay for PCs; apply to a local Apex, Lions, Rotary or Zonta club; seek a donation from a major local employer or a registered club through the funds they must give to charity from their poker machine profits; ask a bank or other major corporation where people involved from your organization live.

Low-income individuals

Centre link has an Advance Loan option for recipients of a benefit for 3 months or more. You should discuss this carefully with your local Centre link office.

Charitable and community organizations

Some charitable and community organizations run No Interest Loan Schemes NILS. To help people buy things they need and pay it back over time. Locate your local NILS

For further information visit: <http://connectit.workventures.net.au/wv/new/terms.aspx>

Disability Equipment Grants

The Independent Living Centre of Western Australia—No Closing Date

The grant assists West Australian individuals with permanent disabilities. Grants are available for specific items of equipment for people who would not otherwise be able to afford this equipment.

Equipment supported by the Grants scheme are:

- Vehicle Hoists and Modifications
- Assistive Technology for people with a vision and or communication impairment
- Air Conditioners

Not-for-Profit Organisations or Local Government Authorities can apply for Disability Equipment Grants on behalf of individuals.

Contact Details: Program Coordinator
The Lotteries Commission of Western Australia

Email: lwgrants@ilc.com.au

Freecall: 1300 885 886

Telephone: (08) 9381 0600



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.

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

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:

- Cerebro-Oculorenal Dystrophy
- LS
- Lowe's Disease
- Lowe-Bickel Syndrome
- Lowe-Terry-MacLachlan Syndrome
- OCRL
- OCRL 1
- Oculocerebrorenal Dystrophy
- Oculocerebrorenal Syndrome
- Renal-Oculocerebrodystrophy
- oculocerebrorenal syndrome
- oculocerebrorenal syndrome of Lowe.

47XYY

A family in outer Perth (south) area with a 4 year old son with 47XYY would like to make contact with anyone else in a similar situation.

Synonyms: Male Chromosomal Karyotype 47XYY; Hypermasculine Syndrome.

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:

- Benign Focal Amyotrophy
- Hirayama syndrome
- O'Sullivan-McLeod syndrome
- Sobue disease and Single limb atrophy.

If you would like to get in contact with one of these families or individuals, please contact Kristina at the Genetic Support Council of WA for further details:

Ph: 08 9389 6722

Email: info@geneticsupportcouncil.org.au

NEW Perth Tourette Syndrome Support Group

For further details contact:

Melinda Diemar, TSAA Perth Co-ordinator

Ph: 0422768235 or 08 9272 3727

Email: md606806@gmail.com

Web: www.tourette.org.au

NEW Klinefelters Support Group of Victoria

Ph: 0419-556-825

PO Box 652 Templestowe Vic 3106

Email: kieran215@hotmail.com

Web: www.klinefeltersupportgroupvic.websytc.com.au



GSC Members

Full Members

Acoustic Neuroma Association of Australia, WA Branch
Alzheimer's Association of WA
Angelman Syndrome Association
Arthrogryposis Support Group
Australian Cystinosis Support group
Australian Huntington Disease Association
Australian Leukodystrophy Support Group
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
Perth Tourette Syndrome Support Group
PXE Support Group of 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)
Usher Syndrome Support Group
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
ConnectGroups
Ectodermal Dysplasia Support Group - OzED
Genetic Support Network of Victoria
Health Consumers Council WA
Office of Population Health Genomics
People with Disabilities WA
The Chromosome18 Registry & Research Society
The Kalparrin Centre
The Neurological Council of WA Inc
Western Australian Deaf Society Inc.

Individual Associate Members

Linda Bovill
Mark Bovill
Anja Hermann
Terry Keating
Amanda Samanek
Kristina Sengotta
Professor Charles Watson
Darren Webb



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



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

Attach mailing
 address label here

Contact Us

Genetic Support Council WA Inc. (GSCWA)
 ABN: 63 614 315 270

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

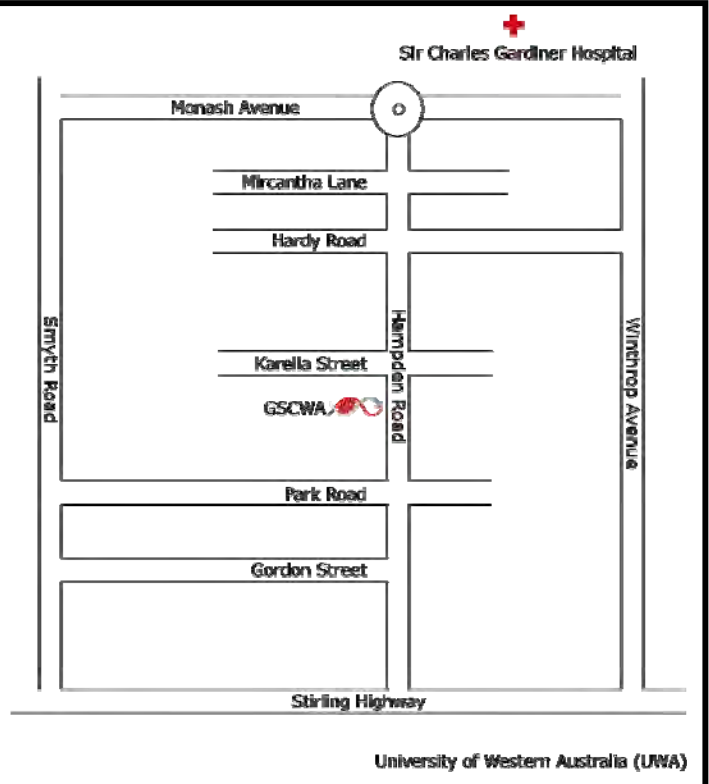
Phone: (08) 9389 6722

Email: info@geneticsupportcouncil.org.au

Web: www.geneticsupportcouncil.org.au

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

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 Kristina Sengotta - Resource Officer
 Joan Ryder - Book Keeper



GSCWA

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