



Genetic Support Council of WA Inc



Gene Advocate

Issue 62

2010

Genetic Research and Gene Patenting

Local and Federal politicians in Australia are working together to prohibit the practice patenting human genes. The issue is whether biotechnology companies such as US firm Myriad Genetics can patent the isolation of genes and gene products identical to those occurring in the human body, and then charge researchers and clinicians for access to the material.

Labor MP Melissa Parke, Liberal senator Bill Heffernan, and independent senator Nick Xenophon will plan to introduce a private member's bill for Australia to prohibit the patenting of human genes and the natural products they produce.

Melissa Parke (Federal Member for Fremantle) introduced the following Notice of Motion on 18th October 2010 in the Lower House to amend the Patents Act 1990 to ensure that patents cannot be granted over any biological materials which are identical or substantially identical to what exists in nature.

Genetic Research

Ms PARKE (9.54 pm)—Last year, the Melbourne company Genetic Technologies ordered Australian hospital laboratories to stop testing for breast cancer as it claimed such testing infringed the licence it had obtained from the US company Myriad in relation to the

breast cancer gene. The company only backed down from its threats to Australian hospitals as a result of the public outcry.

Last month, it was reported in the *New York Times* that a woman seeking a second opinion on a positive genetic test for ovarian cancer, Ms Genae Girard, could not get that opinion because there is only one test, owned by only one company, Myriad Genetics, which owns the rights to the relevant tests for ovarian and breast cancer in the United States. Myriad charges US\$3,000 per test.

With the support of the American council of civil liberties and women's health groups, Ms Girard has launched a lawsuit challenging the US patents office decision to grant a patent on the breast and ovarian cancer genes to Myriad, a decision that has prevented the development of further, possibly better and less expensive diagnostic methods of tests.

These cases show that commercial control or private ownership of human genes may be blocking important health research and development while making scientific innovation, especially in health care, a matter of corporate profit rather than a matter of necessary and common social endeavour. It is no surprise, then, that this issue is beginning to get a lot of attention in the US, Europe and now Australia.

"We are more than the sum of our genes!"

The Senate Community Affairs References Committee is currently undertaking an inquiry into gene patents. This builds upon a review by the Australian Law Reform Commission in 2004 which found:

“ ... overly broad gene patents and aggressive licensing practices might stifle further research and cause problems for governments in providing access to high quality and cost effective healthcare.”

In the view of Dr Luigi Palombi, from the Centre for Governance of Knowledge and Development at the ANU and author of *Gene Cartels: Biotech Patents in the Age of Free Trade*, ‘patents can be and are being used to suppress competition and innovation’.

The simple question is: why are patents being granted over human genes when genes are not inventions or processes but natural phenomena? Gene patents represent a creeping and inappropriate privatisation of knowledge about the human body. We are licensing companies to control the very essence of our commonwealth—the genetic code that belongs to each and all of us.

Professor Guy Maddern of the Royal Australasian College of Surgeons opposes the granting of patents over human genes, stating:

“It is not an invention worthy of a patent but a discovery ... no worthier of a patent than a recently discovered species of animal or plant.”

Inventions must also be new, novel and industrially applicable. In its submission to the Senate inquiry, the New South Wales government submitted that patents on gene

sequences should not be granted because:

“The level of inventiveness in the acquisition of genetic information, most notably sequence data, is increasingly small and the potential negative impact of inappropriately awarded patents increasingly large. The negative impact of such patents is exemplified by those awarded for familial breast cancer genes.”

Those who claim that patents are necessary to encourage investment in research should remember that the most significant discoveries in research and medical history were not achieved in pursuit of a patent — for instance, Pasteur’s work with bacteria and vaccines, Lister’s work on sterilisation, Fleming’s discovery of penicillin, Florey’s development of penicillin as a medicine and Watson and Crick’s development model of the molecular structure of DNA.

Furthermore, much of the medical research and innovation leading to the grant of a patent is publicly funded. As noted by the Country Women’s Association of New South Wales in its submission to the Senate inquiry:

“While the BRCA— or breast cancer— genes are now ‘private property’, their initial discovery was due to the efforts of publicly funded scientists collaborating on an international basis.”

Similarly, Dr Palombi has noted that, while the company Bionomics was granted a wide-ranging patent over the epilepsy gene, most of the research leading to the patent application was in fact carried out in publicly funded institutions such as the University of Melbourne and the University of Adelaide’s Department of Paediatrics at the Women’s and Children’s Hospital.

Professor Ian Frazer, the inventor of the cervical cancer vaccine, has joined other cancer researchers in calling for a revision of patent laws, stating that researchers need to be able to proceed with their work without having to consult the companies whose patents the work might infringe.

Other groups opposed to the granting of gene patents include the Breast Cancer Foundation of Australia, the Royal Australian College of Pathologists, the Human Genetics Society of Australia and the Australian Medical Association.

Currently, more than 20 per cent of human genes are claimed as intellectual property. It will not be long before knowledge about every part of the human body is controlled by corporations.

I am one of a growing number of people who find this alarming and I am grateful to Dr Luigi Palombi and former Commonwealth public servant Anna George for alerting me to this issue, which has serious implications for Australian medical research, innovation and costs.

I look forward to the recommendations of the Senate inquiry, which is due to report at the end of this sitting year.

Extract from:

**THE PARLIAMENT OF THE
COMMONWEALTH OF AUSTRALIA
HOUSE OF REPRESENTATIVES NOTICE
PAPER**
(www.aph.gov.au/house/info/notpaper)
No. 2 - THURSDAY, 30 SEPTEMBER 2010

NB:

Members may like to support this important Motion by writing a letter of support or speaking to their Local Member

The GSCWA Board
is inviting
nominations
from members to join
the Committee in 2011.

The Committee operates as
an Advisory Board, making
strategic decisions for, and
overseeing the operations of
the Council.

Members interested in
nominating for a position on
the Committee should
contact Mitch Messer or
Sharon Van der Laan on
(08)9485 8999
for further information
or to request a
Nomination Form.

ADHD Genetic, Not Bad Parenting

A team of University scientists have revealed the first direct genetic link to attention deficit/hyperactivity disorder (ADHD). The study, published in *The Lancet*, found that children with ADHD were more likely to have small segments of their DNA duplicated or missing than other children.

It also found significant overlap between these segments, known as copy number variants (CNVs), and genetic variants implicated in autism and schizophrenia, proving strong evidence that ADHD is a neurodevelopmental disorder – in other words, that the brains of children with the disorder differ from those of other children.

"We hope that these findings will help overcome the stigma associated with ADHD," according to Professor of Child and Adolescent Psychiatry Anita Thapar, School of Medicine, who led the study.

"Too often, people dismiss ADHD as being down to bad parenting or poor diet. As a clinician, it was clear to me that this was unlikely to be the case. Now we can say with confidence that ADHD is a genetic disease and that the brains of children with this condition develop differently to those of other children," she added.

ADHD is one of the most common mental health disorders in childhood and Children with ADHD are excessively restless, impulsive and distractible, and experience difficulties at home and in school.

Although no cure exists for the condition, symptoms can be reduced by a combination of medication and behavioural therapy.

The condition is highly heritable – children with ADHD are statistically more likely to also have a parent with the condition and a child with an identical twin with ADHD has a three in four chance of also having the condition.

Until now there has been no direct evidence that the condition is genetic and there has been much controversy surrounding its causes.

The University team analysed the genomes of 366 children, all of whom had been given a clinical diagnosis of ADHD, against over 1,000 control samples in search of variations in their genetic make-up that were more common in children with the condition.

"Children with ADHD have a significantly higher rate of missing or duplicated DNA segments compared to other children and we have seen a clear genetic link between these segments and other brain disorders," explains Dr Nigel Williams, School of Medicine.

"These findings give us tantalising clues to the changes that can lead to ADHD," he added.

The researchers found that rare CNVs were almost twice as common in children with ADHD compared to the control sample – and even higher for children with learning difficulties. CNVs are particularly

common in disorders of the brain.

There was also significant overlap between CNVs identified in children with ADHD and regions of the genome which are known to influence susceptibility to autism and schizophrenia. Whilst these disorders are currently thought to be entirely separate, there is some overlap between ADHD and autism in terms of symptoms and learning difficulties. This new research suggests there may be a shared biological basis to the two conditions.

The most significant overlap was found at a particular region on chromosome 16 which has been previously implicated in schizophrenia and other major psychiatric disorders and spans a number of genes including one known to play a role in the development of the brain .

"ADHD is not caused by a single genetic change, but is likely caused by a number of genetic changes, including CNVs, interacting with a child's environment," explains Dr Kate Langley, School of Medicine.

"Screening children for the CNVs that we have identified will not help diagnose their condition. We already have very rigorous clinical assessments to do just that," she added.

Dr John Williams, Head of Neuroscience and Mental Health at the Wellcome Trust, which has supported Professor Thapar's work for ten years, said: "These findings are testament to the perseverance of Professor Thapar and colleagues to prove the often unfashionable theory that ADHD is a brain disorder with genetic links.

"Using leading-edge technology, they have begun to shed light on the causes of what is a complex and often distressing disorder for both the children and their families."

Source:

Cardiff University News Centre
ADHD's Genetic Link 30/09/2010
<http://www.cardiff.ac.uk/news/articles/adhds-genetic-link.html>

For ADHD Support

LADS— Learning and Attentional Disorders Society



LADS is a support, information and advocacy agency for people with ADHD and associated conditions. LADS supports children and adults with ADHD in their families, as well as supporting those who treat, teach and work with people with ADHD.

For More Information

Location:
The Niche, Suite B
Cnr Aberdare Road and Hospital Avenue
Nedlands Western Australia

Phone: (08) 9346 7544
Fax: (08) 9346 7545
Info/support:
lads.volunteer@cnswa.com
Admin: lads@cnswa.com

Important Breakthrough In Ovarian Cancer Research

A group of international scientists have made an important breakthrough, identifying a handful of important new genetic variants which indicate an increased risk of ovarian cancer. These same variants also reveal important genetic similarities between ovarian and breast cancer.

The research team compared the genes of 10,238 women with ovarian cancer to 13,185 healthy women from all over the world and found five different stretches of DNA containing single-code variations, known as single nucleotide polymorphisms (SNPs) were linked to increased risk of the disease. Four of these five new DNA variations were often found in women who had developed the most common and aggressive form of the disease known as serious ovarian cancer.

DNA base pairs are like letters of words that spell out the genetic code and SNPs are the strips of DNA base pairs, or the "words". Small alterations in the coding of particular SNPs, akin to "spelling errors" in words, link to ovarian cancer risk. This makes the discovery equivalent to finding five individual spelling mistakes in 200,000 pages of text, described Professor Georgia Chenevix-Trench, Head of QIMR's Cancer Genetics Laboratory.

After eight years of searching, the researchers found a SNP on chromosome 9 that was uniquely linked to ovarian cancer. This previously undetected region of DNA when altered can increase a woman's risk of developing ovarian cancer by 40 per cent.

The research follows another recent study by the same team which was also published in the online journal *Nature Genetics* showing that one of these five DNA regions increased the risk of breast cancer in women carrying the faulty copy of the BRCA1 gene. "These

results strengthen the evidence that breast and ovarian cancer share a similar genetic basis," said Professor Chenevix-Trench.

"These latest findings raise the possibility that, in the future, women who are at the greatest risk of developing ovarian cancer because they carry these newly discovered DNA variants, can be identified and given closer surveillance to look for early signs of ovarian cancer when it is most treatable," Chenevix-Trench said.

Ovarian cancer is the fifth most common cancer, and the most common cause of cancer death, of women in the UK where around 4,300 women die every year.

This high mortality rate is due to ovarian cancer's non-specific symptoms, and the absence of an effective screening process which means the cancer often goes undiagnosed, often up until stages III or IV. Having a means by which people can be identified as at risk, then periodically screened therefore has the potential to be of great benefit.



Sources:

Life Scientist: Ovarian Cancer Breakthrough
27/09/2010

[http://www.lifescientist.com.au/
article/362252/
ovarian_cancer_breakthrough/](http://www.lifescientist.com.au/article/362252/ovarian_cancer_breakthrough/)

Med News Today: Gene Variant that increases
Cancer Risk Discovered 03/09/2009
<http://www.medicalnewstoday.com/>

Warning About Genetic Tests From Experts

Medical experts are warning consumers to be cautious about genetic tests that purport to predict various diseases, saying they add little value beyond what consumers already know.

"Studies done for diabetes, heart disease and common cancers have identified a large number of genes associated with increased risk of developing (these diseases)," said lead author Wayne Hall, a professor at the University of Queensland Centre for Clinical Research. "But the liability and increased risk of any one of these genes is often trivially small ... it's not information you can act on."

There have been long-term studies tracking large numbers of people over time to see if those with certain gene mutations go on to develop associated diseases, but Hall said such genetic information was no more superior in predicting disease.

"In general, adding the genetic information doesn't improve on the ability to predict over and above what you know about existing risk factors," he said, which include blood pressure, gender, family history, age and smoking. "They are still good predictors of disease risk and genetic information usually doesn't do as well as those fairly crude predictors of disease risk."

The note of caution comes as consumers are swamped with offers of genetic tests, many of which through the internet, that purport to predict many different kinds of diseases.

"I wouldn't purchase any of these tests myself. They have very limited use and if I have reason to suspect I have some gene that is strongly predictive of disease risk, I will go through a proper genetic testing curriculum because there is very little value in these genome-wide scans that are being marketed," Hall said.

A 31 year old mother from Florida recently had both her breasts removed as a preventative measure after a home DNA test kit revealed that that she has the breast cancer gene mutation BRACA-1. Fortunately in this case the woman and her husband had genetic counselling, had the accuracy of the test double checked and underwent the surgery after developing a plan with doctors. However not everyone is able to afford these extra measures in the US.

Dr. Freya Schnabel of NYU says of the incident, "If they get this information without knowing what their choices are, it can be a really devastating blow."

Source:
ABC News/Technology 13/10/2010
<http://abcnews.go.com/Technology/wireStory?id=11868818>

WSTP.com 10 News 19/10/2010
<http://www.wtsp.com/news/health/story.aspx?storyid=151612&catid=12>

New Contact Details



The Genetic Support Council of Western Australia Inc. have moved back into Oasis House.

Address:
Suite 7, Oasis Lotteries House
37 Hampden Road, Nedlands WA
6009

New Phone Number:
(08) 9485 8999

European Society of Human Genetics: direct-to-consumer genetic testing for health-related purposes

Statement of the European Society of Human Genetics (ESHG) on direct-to-consumer genetic testing for health-related purposes:

Many private companies offer direct-to-consumer (DTC) genetic testing services. Some tests may detect severe and highly penetrant monogenic disorders, while other tests are for genetic variants found associated with increased susceptibility for common and complex diseases in large-scale population studies.

Through its Public and Professional Policy committee followed by member and expert consultation, the European Society of Human Genetics has developed the following policy on advertising and provision of predictive genetic tests by such DTC companies:

- (1) clinical utility of a genetic test shall be an essential criterion for deciding to offer this test to a person or a group of persons;
- (2) laboratories providing genetic tests should comply with accepted quality standards, including those regarding laboratory personnel qualifications;
- (3) information about the purpose and appropriateness of testing should be given before the test is done;
- (4) genetic counselling appropriate to the type of test and disease should be offered; and for some tests psychosocial evaluation and follow-up should be available;
- (5) privacy and confidentiality of sensitive genetic information should be secured and the data safely guarded;
- (6) special measures should be taken to avoid inappropriate testing of minors and other legally incapacitated persons;

(7) all claims regarding genetic tests should be transparent; advertisement should be unbiased and marketing of genetic tests should be fair;

(8) in biomedical research, health care and marketing, respect should be given to relevant ethical principles, as well as international treaties and recommendations regarding genetic testing; and

(9) nationally approved guidelines considering all the above-mentioned aspects should be made and followed.

European Journal of Human Genetics advance online publication, 25 August 2010;
doi:10.1038/ejhg.2010.129

Information Source: <https://www.eshg.org/fileadmin/www.eshg.org/documents/PPPC/2010-ejhg2010129a.pdf>

Additional Information

International Principles for direct-to-consumer genetic tests - produced by the Human Genetics Commission.

The Human Genetics Commission, the UK Government's advisory body on developments in genetics and their ethical, legal, social and economic implications, has launched today a 'Common Framework of Principles' for direct-to-consumer genetic testing services.

The Principles can also be downloaded from the HGC website: <http://www.hgc.gov.uk/Client/document.asp?DocId=280&CAtegorId=10>.

Communicating Research

Communicating research for evidence-based policymaking: A practical guide for researchers in socio-economic sciences and humanities.

Evidence-based policymaking depends, first of all, on the existence and availability of reliable evidence. No less importantly, it requires that researchers and policymakers communicate with each other effectively. Both parties stand to benefit from this interaction.

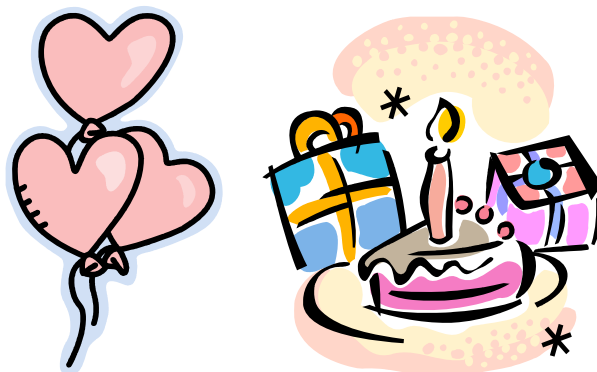
Tackling socio-economic challenges is definitely a cooperative enterprise. Cooperation between policymakers and researchers, however, does not always come naturally. A familiar set of obstacles – cultural, linguistic and institutional – can make interaction difficult.

This publication is designed to offer an easy-to-read guide which identifies the most important stages in the development of a dynamic communication strategy and which will ensure that the projects funded under the Framework Programs make a real difference in enabling policymakers to respond to the significant challenges we face.

Divided into three parts – Concept, Policy Briefs and Practical Means – this guide is intended to help exploit research concepts into genuine policy action.

See: http://ec.europa.eu/research/social-sciences/pdf/guide-communicating-research_en.pdf

HFWA 25th Anniversary



The Haemophilia Foundation of WA Inc. (HFWA) are this year celebrating their 25th Anniversary, after being formed on July 8 1985. Over this time HFWA have successfully provided support, information and advocacy to individuals with Haemophilia, von Willebrand disease and other bleeding disorders throughout Western Australia. Their aims also include promoting a better lifestyle for individuals with these conditions, raising awareness in the community.

HFWA continue to be praised for the support and advocacy they offer to their members, people with these conditions and their family. This milestone was celebrated with an afternoon tea on Saturday 16th October.

CONGRATULATIONS TO HFWA ON 25 YEARS!



Contact:

City West Lotteries House
2 Dehli St, West Perth WA 6005
Ph: (08) 9240 7294 Fax: (08) 9486 8966
www.hfwa.org
email: office@hfwa.org



Member Profile

Charcot-Marie-Tooth Association Australia Inc.

The CMT Association in Australia (CMTAA) began as a Support Group in 1988, and was incorporated in 1990 as a registered charity. It is run by a group of volunteers who have personal experience of CMT, either as an individual or family member.

Aims

- Provide support through contact with people with CMT
- Distribute information related to the welfare of people with CMT
- Promote the development of facilities and services for people with CMT
- Actively support CMT research
- Conduct information seminars
- Provide an informative website
- Send regular newsletters to members
- Provide videos of seminars
- Provide additional information regarding CMT
- Establish support groups throughout Australia

What is Charcot-Marie-Tooth disease?

CMT or Charcot-Marie-Tooth disease is a common but frequently undiagnosed condition, it is estimated that in Australia as many as 1 in 2,500 people in Australia could have CMT. There are several types, Type 1A being the most common, and is an autosomal dominant condition which means there is a 50% chance of being passed on to other generations in some families.

CMT causes slow degeneration of the nerves in the extremities including feet, legs, arms and hands. Typically muscles are weakened due to the loss of stimulation by affected nerves. The severity of the disease can vary a great deal from person to person. The symptoms are also varied.

CMT is also known as Hereditary Motor and Sensory Neuropathy (HMSN) and Peroneal Muscular Atrophy

Symptoms of CMT

Weakness in leg muscles due to CMT can affect co-ordination and balance in such things as walking, running, walking up or down stairs, walking on uneven ground or just standing still or standing for long periods of time. Other symptoms which may affect CMT patients include tremors, fatigue

and fine motor skills. Foot abnormalities such as high arched feet, weak ankles and tendon tightening pose the most serious problems. Sometimes patients may need to wear foot orthoses or braces or undergo surgery.

Even the simplest things like unscrewing a bottle top, fastening buttons, turning on a tap or opening a door handle can pose problems. These are all things that we take for granted. Untidy hand writing due to not having control over the muscles and nerves in the hands and fingers can pose a big problem for both children and adults.

Other activities such as sport may pose a problem for those with CMT. One of the best activities for CMT is swimming as there is low impact upon the ankles. People with CMT should be encouraged to participate in as many regular daily activities as possible.

Research

There is no known cure for CMT, however, continual research is being done both in Australia and overseas to find one. Some promising results from mouse studies did allude to the benefits of vitamin C for improving the symptoms of CMT, however a clinical trial at Westmead Hospital did not report significant differences in nerve function or quality of life in those treated with high levels of ascorbic acid (vitamin C).

CMT is one of the most commonly inherited neurological disorders and many research efforts are aimed towards finding a treatment and cure. Attempts are being made to treat CMT at the earliest stages of life possible

before permanent nerve damage is done. The Institute of Neuroscience and Muscle Research (INMR) through Westmead Children's Hospital are also running studies into the effects of exercise and strength therapy for CMT.

For further information

WA Co-ordinators

Chris

Phone: 0414 316 729

Email: chrism@quantia.com.au

Angela

Phone: 0414 905 013

Email: angelacorfe@hotmail.com

National Office

Ph: (02) 9767 5105

Fax: (02) 9767 5167

Email: cmtaa@email.cs.nsw.gov.au

Website: www.cmt.org.au

CMTAA encourages people with CMT to develop skills in areas that they can excel in. People with CMT can fulfil a happy, long and healthy life.



[Article reviewed by Charcot-Marie-Tooth Association Australia Inc. - WA Division]



Coming Events

CONSUMERS REFORMING HEALTH 2011 CONFERENCE

Health Issues Centre will host the inaugural international conference for community engagement in health care.

Date: 18-20 July 2011 with a Public Forum on Sunday, 17 July 2011 at the Melbourne Convention and Exhibition Centre.

Consumers Reforming Health 2011 is a forum developed specifically for those with interest in involving consumers in health policy and process. The conference upholds the essential principle that consumer participation is fundamental for health development, clinical governance, community capacity building and health outcomes.

The program aims to demonstrate and enhance this proposition by exploring the experiences, frameworks and practical strategies of participation in a number of health sectors among a diverse range of relevant stakeholders. It intends to broker some new learning on core principles for future change.

✓ Abstract submissions for the conference are now open.

Key dates:

- Abstract submission is now open
- Abstract submission closes: March 18th 2011
- Earlybird Registration deadline: April 1st 2011

For further information available: <http://consumersreformhealth.asnevents.com.au>

KALPARRIN CENTRE

The Kalparrin Centre is holding the following event:

Siblings Programme

A one-day camp during school holidays is being run through Kalparrin for those aged 9 – 15 years who are the sibling of a child with disabilities and other special needs. A variety of different activities are being offered.

The next one day camp will be held on Friday 14 January 2011 at Point Water Recreation Centre, Biction – Bookings are open from 18 October, and are essential.

For further information visit

www.kalparrin.org.au, call 9340 8094. or email kalparrinwa@health.wa.gov.au



INTERNATIONAL DAY OF PERSONS WITH DISABILITIES

3rd December— United Nations



Dignity and justice for all of us is the theme of this year's International Day for Persons with Disabilities, as well as for the 60th anniversary of the Universal Declaration of Human Rights. Dignity and justice for all persons are established universal principles. Since its inception, the United Nations has recognized that the inherent dignity and the equal and inalienable rights of all members of the human family are the foundations of freedom, justice and peace in the world.

Website: www.un.org/disabilities/

TELETHON INSTITUTE OF CHILD HEALTH RESEARCH

How does your child's diet affect their DNA?



A new research project is investigating the role that diet plays in maintaining healthy DNA in children. They are looking for healthy volunteers aged 3, 6 and 9 whose parents are happy to provide information about their child's diet and provide one blood test and two saliva tests. Information about your child's micronutrient levels and dietary advice if needed will be provided.

You will be helping to gather vital information on how diet affects children's DNA so attempts can be made to prevent diseases in later life.

For more information please contact the study team:

Email: dietgenome@ichr.uwa.edu.au

Phone: (08) 9489 7784

AN INTRODUCTION TO ENDURING POWERS OF GUARDIANSHIP

Huntington's WA



Date: Thursday, 9 December 2010

Time: 1:30 to 3:30pm

Where:

The Niche Conference Room, 11 Aberdare Road Nedlands 6009

RSVP: admin@ncwa.com.au by 19 Nov

Phone (08) 9346 7533.

GLUTEN FREE FOOD & HEALTHY LIVING EXPO

This event will be held again on March 12 and 13, 2011 at the Convention Centre.

In response to the demographics having attended the event for the last 3 years, the 2011 expo will have a broader health focus.

If you wish to receive more information about the expo, or are interested in reserving a stand

Visit: www.glutenfreeinwa.com.au

Email:

richard@cmsevents.com.au

katherine@cmsevents.com.au

Or Call: (08) 9228 9766

HOLDING AN EVENT?

Ourcommunity.com.au have helpful tips on how to advertise your event.



A fact sheet entitled "25 Ways to advertise your event for FREE" contains tips including:

- Add a paragraph to your email signature to let people know about your upcoming event
- Include your event in the newsletter of related organisations
- Try public interest on your community radio
- Community announcements on TV

For more information or to view the fact sheet visit: ourcommunity.com.au and search for "25 ways to advertise" .

For an even easier option: Advertise Here!

Promote your event here and on our website at no cost! Contact us on

(08) 9389 6722 or e-mail

info@geneticsupportcouncil.org.au





Resources

NHMRC Research Funding Facts Book 2010

The NHMRC Research Funding Facts book 2010 contains key statistics related to NHMRC's research funding and research activity over the last ten years. It reflects NHMRC's substantial commitment to collecting, reporting and increasing the understanding of health and medical research funding in Australia.

NHMRC research funding to each of the Australian Government's National Health Priority Areas (Arthritis, Asthma, Cancer, Cardiovascular disease, Diabetes, Mental health and Obesity) has increased at least three fold since 2001.

More of the latest research funding statistics and facts can be found on the NHMRC research funding statistics and data page.

<http://www.nhmrc.gov.au/grants/dataset/index.htm>

Medicare Schedule November 2010

The 1 November 2010 Medicare Benefits Schedule files are now available to download from the following site:

<http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/Downloads-201011>

For a summary of changes for this November's release, please visit:

http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/News-20101015-November_2010_MBS

Australian Indigenous Health InfoNet - Yarning places

Yarning places (formerly called communities of practice) are electronic networks that enable people with an interest in Indigenous health to share information, knowledge and experience - even when they live in different States, Territories and regions, come from different sectors (such as health, education and justice), and work for different organisations.

By combining quality, up-to-date web-based information resources with yarning places we aim to create 'one stop info-shops' for people working, studying or interested in various Indigenous health issues. When you join a yarning place - membership is free - you will have access to electronic services that assist members to network, yarn and share information and experiences online:

- ✓ The e-mob list provides members' contact details (permission to display the details is obtained beforehand).
- ✓ The e-yarning board is an electronic board for discussion and debate about relevant issues.
- ✓ The e-message stick is an email list which enables a member to reach all members with one email.

To find out more, go to: <http://www.healthinfonet.ecu.edu.au/health-resources/yarning-places>

National Health Data Dictionary, Version 15

The July 2010 revision to the National Health Data Dictionary (NHDD) including national minimum data sets (NMDS) has now been released and is available on the Australian Institute of Health and Welfare (AIHW) website.

As part of the METeOR metadata online registry, the dictionary's purpose is to provide national standards on the health reporting framework for both statistical and clinical analysis which provides meaningful input to community discussion and public policy debate on health issues in Australia. This version conforms to international standard ISO/IEC 11179 Information Technology Metadata Registries (MDR), 2003.

Report Available:

<http://www.aihw.gov.au/publications/index.cfm/title/11793>

Supporting Women With Secondary Breast Cancer

A booklet which provides guidance on how to conduct important and often difficult conversations around palliative care for women whose breast cancer has spread is now available.

Finding the words - starting a conversation when your cancer has progressed has been produced by the National Breast and Ovarian Cancer Centre (NBOCC), a national coordination centre funded by the Australian government to improve breast cancer outcomes through the translation of research evidence into policy and practice.

The booklet is designed to help women with secondary cancer talk about how palliative care might help them to live as well as possible when their cancer has spread.

NBOCC resources are available free of charge within Australia.

To order, Phone: 1800 624 973

Or visit: www.nbocc.org.au/resources

Assistive Equipment and Technology Services - Independent Living Centre of Western Australia

The service areas in this section provide specialised equipment assistance to meet the needs of West Australians of all ages experiencing reduced independence or mobility resulting from a disability, aging or health related condition. Each service model has been adapted to deliver information, advice and trial to consumers across the State.

Understanding there are people within the community who are unable to travel or use telephones effectively we have developed a Community Based Outreach and Information Service. This service provides information sessions related to assistive equipment and technology to staff and individuals attending community based groups. The service is not available to provide individual home visits.

For further information please visit:

<http://www.ilc.com.au/pages/assistive-equipment>

Or Phone: 1300 885 886



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

Disability Equipment Grants Independent Learning Centre

Closing Date: Ongoing

The Disability Equipment Grants program (DEG) assist 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.

The grants are income assessed, and not available where another government agency has a policy and funding responsibility for equipment.

What Equipment is Eligible?

- ✓ Vehicle Modifications (maximum grant \$7,500): Equipment such as wheelchair hoists, wheelchair / scooter carriers, modified driving controls and specially modified wheelchair accessible vehicles.
- ✓ Assistive Technology for people with a vision impairment (maximum grant \$5,000): Hardware or software that magnifies, produces spoken output or presents information as Braille for other tactile formats.
- ✓ Assistive Technology for people with a communication impairment (maximum grant \$5,000): Covers equipment such as communication devices for personal safety or specialised computer hardware or software.

- ✓ Air Conditioners (maximum grant \$1,500) Air conditioners for one area of respite, for individuals whose disabilities are significantly increased or functionality is decreased because of their inability to regulate their body temperature.

Further Information

For application forms and fact sheets visit: [http:// www.ilc.com.au](http://www.ilc.com.au)

Or contact the Independent Living Centre Project Officer on 9381 0600 or 1300 885 886.

Inclusion Support Subsidy (ISS)

Department of Education, Employment and Workplace Relations

Closing Date: Ongoing

Aim: To assist eligible child care services to improve their capacity to include children with ongoing high support needs in quality child care.

Children with ongoing high support needs include:

- ✓ children with a diagnosed physical, sensory, neurological or intellectual disability
- ✓ children that are undergoing continuing assessment of a disability

- ✓ children from a refugee or humanitarian intervention background who demonstrate behaviours symptomatic with having experienced or having been subject to torture or trauma in their country of origin or during their refugee experience.

Who is eligible for Inclusion Support Subsidy (ISS)?

Child care services that are eligible to access Inclusion Support Subsidy (ISS) include:

Australian Government child care services approved for Child Care Benefit, including Long Day Care, Outside School Hours Care including Vacation Care, Family Day Care, Occasional Care, and In Home Care.

Government child care services funded under the Budget Based Funding Program, including flexible/innovative services, mobile child care services, Multifunctional Aboriginal Children's Services (MACS), Indigenous Playgroups, Indigenous outside school hours care and enrichment programs, crèches and innovative child care service centres.

Further Information

Freecall: 1300 363 079

Visit: <http://www.deewr.gov.au/Earlychildhood/Programs/ChildCareforServices/SupportFamilyCCS/Pages/home.aspx>

Accommodation Support Disability Services Commission (WA)

Closing Date: Ongoing

For many people support will come from family, friends, neighbours and other people. Sometimes people need more support and may apply for Accommodation Support Funding (ASF).

The Commission provides Accommodation Services in over 100 purpose designed facilities across Perth. 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.

Applying for funding

Before applying for Accommodation Support Funding, contact a Local Area Coordinator or one of the service providers funded by the Disability Services Commission. You can find a Local Area Coordinator using the directory available in Your local support.

They will help you to clarify if you are eligible and need to sign any application forms. They can also explain the current availability of accommodation support and discuss alternative solutions.

The organisations that can provide services to people who have received funding under the ASF program can be found in the Directory of service providers by selecting the Service type - Accommodation Support Program.

Applications for this program are made through the Combined Application Process.

Further Information

Freecall: 1800 998 214

TTY: (08) 9426 9315

Visit: <http://www.disability.wa.gov.au/forindividuals/disabilityservices/accommodationsupport.html>



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'.

Opitz G/BBB syndrome

A Western Australian family living with Opitz G/BBB syndrome are seeking contacts with others living with this condition.

Synonyms of Opitz G/BBB syndrome:

- BBBG Syndrome
- Hypertelorism with Esophageal Abnormalities and Hypospadias
- Hypertelorism-Hypospadias Syndrome
- Hypospadias-Dysphagia Syndrome
- Opitz BBB Syndrome
- Opitz BBB/G Compound Syndrome
- Opitz BBBG Syndrome
- Opitz G Syndrome
- Opitz Hypertelorism-Hypospadias Syndrome
- Opitz Oculogenitolaryngeal Syndrome
- Opitz-Frias Syndrome
- Telecanthus-Hypospadias 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: of Monomelic Amyotrophy:

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

If you would like to contact with one of these families or individuals, please call Kristina at the Genetic Support Council for further details on 08 9389 6722 or email: info@geneticsupportcouncil.org.au

Expressions of Interest: Dyspraxia WA Support Group

The Australian Dyspraxia Association are wishing to commence a new support group in WA but unfortunately do not have a person to train as the volunteer mentor. If you are a member of the ADA and have a few hours spare each month, have a child with Dyspraxia and would like to meet with and support others in the same boat, please contact Christine to discuss this matter further. Training will be provided. If you would like to join this support group, please contact Christine at Head Office.

For further information, please email: information@dyspraxia.com.au



GSC Members

Full Members

Acoustic Neuroma Association of Australia, WA Branch
Alzheimer's Association of WA
Angelman Syndrome Association
Arthritis Foundation of WA
Arthrogryposis Support Group
Australian Cystinosis Support group
Australian Dyspraxia Association
Australian Leukodystrophy Support Group
Australian Mitochondrial Disorder Foundation
Australian Pituitary Foundation WA Branch
Australian Tuberous Sclerosis Society Inc.
Cardio Facio-Cutaneous Syndrome Support
Charcot-Marie-Tooth Association Australia
CHARGE Syndrome Association of Australasia
Chiari & Syringomyelia Australia
Chromosome 18 Registry & Research Australia Inc
CleftPALS WA
Coeliac Society of WA, Inc
Cornelia De Lange Syndrome Support Group
Cushing's Disease Support Group
Cystic Fibrosis WA
Diabetes Western Australia
Down Syndrome Association of WA Inc
Dyslexia SPELD Foundation WA Inc
Epilepsy Association of WA
Even-Keel Bi-Polar Support Association (Inc)
Familial Hypercholesterolaemia Support Group WA
Fragile X Support Group WA Inc
Haemophilia Foundation WA Inc.
Heart Kids WA
Huntington's WA Inc
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 Group of WA
Retina Australia (WA)
Rett Syndrome Association of WA
Senses Foundation Inc.

Short Statured People's Association WA Branch
SIDS and Kids Western Australia
Spina Bifida Association of WA
Thalassaemia Association of WA
Tourette Syndrome Support Group, Perth
Turner Syndrome Association of Australia (WA Branch)
Support Organisation for Trisomy and Related Disorders of WA (SOFTWA)
Usher Syndrome Support Group

Corporate Associate Members

ARAFMI Western Australia
Androgen Insensitivity Syndrome Support Group Australia
Association of Genetic Support of Australasia
Carers Association of WA Inc
ConnectGroups
Ectodermal Dysplasia Support Group - OzED
Genetic Support Network of Victoria
Health Consumers Council WA
Kidney Health Australia
Meniere's Australia WA Branch
Myasthenia Gravis WA Friends and Support Group
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
Anja Hermann
Terry Keating
Sindhu Kurup
Amanda Samanek
Kristina Sengotta
Professor Charles Watson
Robyn Hendriks
Darren Webb

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



Our Location and Mailing Address:

Unit 7, Oasis Lotteries House
37 Hampden Rd, Nedlands WA 6009

Attach mailing
address label here

Contact Us

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Phone: (08) 9485 8999

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Staff: Sharon Van der Laan - Executive Director
Kristina Sengotta - Resource Officer
Joan Ryder - Book Keeper
Lynley Liddle - Community Officer



GSCWA

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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.