

# Gene Advocate

GENETIC SUPPORT COUNCIL OF WA (INC)

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## Special points of interest:

- *Carers WA Charter*  
p 11
- *Community Resources*  
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## Medical Research: Importance Of Genetic Research

**Research has the potential to enhance our understanding of how genes and environmental factors interact to influence the health of individuals and populations. In turn, this understanding can generate knowledge that has the potential to be used to improve individual and community health. Research can also reveal information about an individual's susceptibility to disease and hence about the individual's future health. Such information may be of interest and benefit to research participants, especially if preventative strategies exist.**

Some genetic research can be conducted without the need for genetic information that can be related to specific persons or communities. However, some forms of genetic research require the use of body samples and/or genetic information that is either identified or potentially identifiable. In these cases there are greater concerns regarding privacy and the ethical standards surrounding the research, and the possible impact on the individual whose samples and/or information are made available for research purposes.

### Ethical Standards For Research

There is a tension between the benefits that can be gained from research and the rights of the participants. Research participants should have their safety protected and be treated with dignity. Modern international standards of ethical conduct of human research stem from the judgement in the medical case at the Nuremberg trials in 1946, referred to as the Nuremberg Code. The principles of the Nuremberg Code were incorporated into the Declaration of Helsinki, made by the World Medical Assembly in 1964. In 1966, the National Health and Medical Research Council

issued an Australian *Statement on Human Experimentation* which was based on the Declaration of Helsinki. This Statement was reviewed and replaced in 1999 with the *National Statement on Ethical Conduct in Research Involving Humans* (the National Statement). The National Statement continues to reflect the principles originally set out in the Nuremberg Code.

The National Statement applies to all research activities involving human participation. It contains general principles to ensure high standards of ethical conduct in research, including that:

- research respects the integrity and human dignity of participants;
- the participants provide consent before taking part in the research;
- where the research involves taking tissue samples, the tissue donor is provided with full information on how the tissue will be used before being asked to provide consent;
- risks of harm or discomfort to participants are minimised;
- research only be carried out where it can be shown to have the potential to contribute to knowledge;
- all research proposals are reviewed and approved before funding is provided and research is commenced;
- research will be suspended if risks become disproportionate to the benefits, or if continuation may be harmful to a participant;
- results of research should normally be published to permit public and peer scrutiny, add to knowledge and be available to participants.

The National Statement includes particular precautions for research involving human

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

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genetics, recognising that such research may affect not only participants but also relatives. Requirements relating to privacy and confidentiality are also more stringent, because of the potential that genetic information can be used to unfairly discriminate against or stigmatise the participants.

## Approval Of Research – Health Research Ethics Committees

The system of review and approval set out in the National Statement requires the establishment of Human Research Ethics Committees (HRECs) in institutions where research is carried out (such as hospitals, universities, and the CSIRO). Each HREC includes as a minimum each of the following:

- chairperson
- community representative
- research expert
- minister of religion or similar person
- lawyer
- person with experience in professional care, counselling or treatment of people.

The primary function of an HREC is to protect the welfare and rights of participants in research. All research projects involving humans must be reviewed by an HREC and must not be undertaken or funded until approval has been granted. The HREC will also ensure that a research project is appropriately monitored through to its completion. Another function of the HREC is to establish mechanisms to receive and handle complaints about any proposed or approved research project.

## Consent Of Participants

For individuals participating in genetic research, one of the important ethical principles is that the researcher disclose all relevant information about the research, including how an individual's information or samples will be used, and then obtain an individual's informed consent before proceeding with the research.

Full information about the research will refer to the purpose, methods, demands, risks, discomforts and expected outcomes of the research. It should also include advice as to whether any remaining tissue samples are to be stored after completion of the research, and any conflicts of interest (for example, if the doctor suggesting participation in the research will receive a benefit from the research company if the research becomes commercially valuable). Consent should be voluntary and not impaired by any coercion, inducement or influence (including monetary payment for participation). The consent should be

specific to the purpose for which the tissue or information is to be used, and can be withdrawn at any time. In relation to genetic information, consent of the participant is also required before the researcher can approach other family members to participate in the research, and before the researcher discloses any information that is relevant to the health of other family members.

Consent is generally obtained through the use of forms and documentation which include information about the research project and require the signature of the participant to confirm his or her understanding and consent. If the participant is not considered competent (such as a child or a person with a mental incapacity), a person with legal authority to act on the participant's behalf must sign (for example, a parent or guardian).

If using human tissue samples, the National Statement requires that the researcher obtain the consent of the donor of the tissue sample, regardless of whether the sample is to be collected specifically for the research, or whether it has been collected and stored after other clinical procedures (such as a surgical procedure to remove a tumour), held in tissue banks or removed for other purposes.

Where human tissue is collected specifically for research purposes (rather than therapeutic purposes), its collection and use will also be regulated by a Human Tissue Act (a version of which applies in each State and Territory, for example the *Human Tissue Act 1983* (NSW)). Children are allowed to donate blood but not other forms of regenerative tissue, providing a limitation on the involvement of children in research projects involving donation of tissue samples. The Act requires that written consent is required for donation of any human regenerative tissue except blood. Thus, the legislative consent requirements will only apply if the genetic analysis is performed on human tissue other than blood.

It is possible for a researcher operating under the National Statement to ask the HREC to waive the consent requirement for a particular research project in certain circumstances. Typically, this might be sought where further research is taking place on samples originally collected and used for a different research purpose (for example, tissue samples originally used in genetic research into breast cancer and are now wanted for research into diabetes). Researchers may argue that it would be too difficult or costly to seek each individual's consent for the secondary research. Each HREC must carefully consider the circumstances, including the justifications for waiving the consent, the risk that the research poses to the privacy or well-being of individuals, and whether the research is related to prior approved research, and weigh the pros and cons in relation to these types of

## Medical Research: Importance Of Genetic Research.

requests. Collection of samples and health information without consent for research purposes must also comply with guidelines issues under sections 95 or 95A of the *Privacy Act 1988* (Cth).

### Commercialisation Of Research

All research receiving public funding in Australia must be conducted in accordance with the National Statement. While the majority of research conducted in Australia receives at least partial public funding, compliance with the National Statement is voluntary where funding is wholly derived from private sources. There are some concerns that privately funded genetic research may become more prevalent in the future as pharmaceutical companies and others try to apply genetic knowledge in new and commercially profitable ways. Some potentially lucrative commercial applications of genetic knowledge include improved genetic testing devices or processes, the refinement of the design of pharmaceutical drugs so that certain drugs will be effective in targeted populations defined by identifiable genetic conditions (known as 'pharmacogenetics'), and applications of novel genetic therapy. Where there is no dependence on public funding of research, there is no formal requirement to conform with existing Australian research standards. However, currently there are requirements in legislation, such as the *Privacy Act 1988* (Cth) and the Human Tissue Acts.

**Information Source:** Australasian Legal Information Institute  
A joint facility of UTS and UNSW Faculties of Law



### HUMAN TISSUE BANKS

Australian pathology laboratories receive many thousands of human tissue samples, including samples of blood, body secretions or tissue, most of which are taken as part of a medical examination or treatment. Once tests are completed by the pathology laboratory, reports are provided to the patient's medical practitioner, but the tissue samples are held by the laboratory in an archive of samples, often for a long period of time. The sample may be retested as part of routine laboratory quality assurance procedures, or on request by the patient's practitioner. In some cases there may be legal reasons for retaining the samples for a certain period of time.

Human tissue banks are also maintained by private and public hospitals and research institutes. Unlike the samples stored in the pathology archives, samples in human tissue banks are stored solely for their possible use in research. Often the tissue in a tissue bank is 'snap frozen' for better preservation.

These pathology archives and human tissue banks are sometimes referred to as human genetic databases. Genetic databases are collections of genetic information about individuals, or may be collections of human tissue from which genetic information might be derived. The information or samples may be identifiable, or may have been de-identified (with a code replacing the individual's name). Their existence raises important questions about informed consent to collect these samples, and the extent of restrictions on the use and disclosure of the information.

One large collection of blood samples is the collection of 'Guthrie cards' in each Australian State and Territory. Since the 1960s, a blood sample has been taken from almost all infants soon after birth, and tested for a number of treatable genetic conditions, including phenylketonuria (PKU), see p 2. The extent of testing varies from State to State and the samples, stored on special absorbent paper, and commonly referred to as Guthrie cards, are stored for a period of time. Depending on the State or Territory, this could range from four years to indefinite storage.

These newborn screening programs have huge benefits for those identified with the genetic disorders, as treatment can be applied to manage the conditions from the early days of the infants' lives. Guthrie cards are sometimes used for investigations by coroners or the police – usually only if a person is missing or deceased, and the Guthrie card may be the only available sample to assist identification. However, the potential exists for it to be used for other criminal investigatory purposes.

Regulation of the disclosure of information held in genetic databases generally will be covered by privacy legislation, although the extent to which this applies will depend upon whether the database is held by a public or private institution.



## About Our Members

### Australian Cystinosis Support Group

#### What is Cystinosis?

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

#### Is it inherited?

The disease is inherited in an autosomal recessive fashion, meaning that each parent of a child with Cystinosis carries one defective gene and one normal gene. The parents never have any signs of the disease.

#### What causes Cystinosis?

The cystine content of cystinotic cells averages 50-100 times the normal value. The cause is a defect in the transports of cystine out of a cell compartment called the lysosome, in which Cystine accumulates. Because of the cystine's low solubility, this amino acid forms crystals within the lysosomes of cells, and this is probably what destroys the cells.

#### What are the Symptoms?

There are three clinical forms of Cystinosis. Infantile (or nephropathic), Late-onset and Benign Cystinosis. The later form does not produce kidney damage. Infantile and late-onset Cystinosis differ in the age of appearance of the first symptoms and in the rapidity of the clinical course. Infantile Cystinosis is usually diagnosed between 6 and 18 months of age with symptoms of excessive thirst and urination, failure to thrive, rickets and episodes of dehydration. These findings are caused by a disorder called Renal Tubular Fanconi Syndrome, or a failure of the kidney to reabsorb nutrients and minerals.

As a consequence, these important molecules are lost in the urine. Children with Cystinosis also have crystals in their eyes and an increased level of cystine in their white blood cells. Without specific treatment, children with Cystinosis develop end-stage renal kidney failure at approximately 9 years of age.

If Cystinosis patients receive a kidney transplant and reach adulthood, their new kidney will not be affected by the disease. However without Cysteamine treatment (see below) they can develop complications in other organs due to the continued accumulation of Cystine throughout

the body. These complications can include muscle wasting, difficulty swallowing, diabetes, hypothyroidism and blindness. Not all older patients develop these problems, however.

#### Can Cystinosis be Treated?

The symptomatic treatment of the Fanconi syndrome is essential. The urinary losses of water, salts, bicarbonate & minerals must be replaced. Most children receive a solution of sodium and potassium citrate, as well as phosphate. Some also receive extra vitamin D.

The aim of specific treatments for Cystinosis is to reduce Cystine accumulation within the cells. This goal is achieved by cysteamine treatment, which has proven effective in delaying or preventing renal failure. Cysteamine also improves the growth of Cystinosis children. The capsule form of Cysteamine is called CYSTAGON. Kidney transplantation has proven very helpful in patients with Cystinosis and Cysteamine therapy should be considered to try to prevent the late complications of the disease. Cysteamine eye drops can also remove the corneal cystine crystals.

#### What are possible Future Developments?

Much remains to be learned about Cystinosis. Investigators have recently isolated the gene causing Cystinosis and they are now analyzing individual patients mutations. Other investigators are trying to determine the best therapies for each complication.

Some questions which remain include:

- ★ Will children treated with Cysteamine from infancy be spared all of the later complications of Cystinosis?
- ★ Will they avoid kidney transplants entirely?
- ★ Will Cysteamine benefit patients who begin therapy after receiving a kidney transplant?
- ★ Will scientists discover the precise mechanism by which the Cystinosis gene product rids Lysosomes of Cystine?

#### For further information please contact:

Australian Cystinosis Support Group  
1 Clifton Crescent,  
Pinjarra WA 6208  
Phone: (08) 95312135  
Email: [cystinosis.australia@bigpond.com](mailto:cystinosis.australia@bigpond.com)  
Web: <http://australia.cystinosis.com>

(Article Reviewed by Australian Cystinosis Support Group)

## WAVE – Western Australian Volunteering Essentials

***If you are a small organisation run mainly by volunteers with perhaps a few paid staff, with never enough time to do all the things you need to do, WAVE may be just the resource and information program you are looking for.***

Designed as a condensed resource program outlining the most critical information a busy paid or unpaid person running a community organisations needs to know to recruit, screen, protect and acknowledge volunteers, be they Board or service delivery volunteers, this program will bring together a range of relevant resources in an accessible and digestible format.

WAVE will provide a series of *free* one day training sessions to people who find themselves working with volunteers as one part of their work. As with Employright it will cover such topics as effective recruitment and screening including police checks, equal opportunity legislation, insurance, occupational health and safety issues, confidentiality and discontinuing volunteer involvement.

The training will be supported by a resource manual and website containing resource information that can be drawn upon at any time with links to an even wider range of resources. There will also be a telephone helpline to assist with particular questions or provide referrals to specialists for advice.

If your organisation has a resource, publication or provides a service that is free – or very low cost that you think could be listed on the website as a resource for other organisations or to register your interest in participating in the WAVE program please email Jackie Newbigin at WACOSS - [jackie@wacoss.org.au](mailto:jackie@wacoss.org.au).

More details about the WAVE program, training dates and how to get involved will be posted on the Volunteering Secretariat , WACOSS and VWA websites in the weeks to come.

<http://www.community.wa.gov.au/communities/volunteers>  
<http://www.wacoss.org.au>  
<http://www.volunteer.org.au>

## CommunityGuide.com.au

### **All Community Groups are Welcome !**

CommunityGuide proudly supports and promotes local community groups and offers a range of complimentary (free) services to meet the needs of your organisation.

All local Community Groups and Sporting Clubs may register for a *free website* of up to 10 pages on CommunityGuide to promote their organisation, activities, events, etc.

You will receive your own login and password to the CommunityGuide website builder so that you can update and change your information at anytime

We also provide you with a Free domain name for you to use as your own website address

You may also use any of CommunityGuides

online services at anytime:

- ◆ Promote your events for free in our Community Events Calendar,
- ◆ Place your classified ads in our Community Classifieds
- ◆ Join our Community discussion forum and have your say on issues affecting your local area.

As the CommunityGuide is regularly indexed daily by all the major search engine robots, your organisation will be promoted in all the Major Search Engines just by being a part of CommunityGuide.

This is a Free Service - We do not charge any fees for recognised Community Groups, Sporting Clubs or non profit associations. It takes a few minutes to register your organisation.

Visit: <http://www.communityguide.com.au>

## 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.

- A mother with an eight year old son living with **Hereditary Multiple Exostosis** in the Canberra region would like contact with other families around Australia with a child with the same condition.
- A person living with **Kleinfelters Syndrome XXY** in Canberra/NSW is looking at starting a support group for guys with XXY in Canberra / NSW and would like to get in

contact with any other guys that have KS.

- A family from Western Australia who have a child severely affected with **Lissencephaly** would like to make contact with other families in a similar situation.
- A lady living with **multiple enchondromas** is seeking contact with others living with this condition in Australia.



Please contact Kristina at the Genetic Support Council if seeking contact with these families.  
Phone 08 9389 6722 or email to [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au)

## Hidradenitis Suppurativa Foundation, Inc.

The Hidradenitis Suppurativa Foundation, Inc. (HSF) is a non-profit public benefit corporation dedicated to improving the quality of life for individuals and families affected by Hidradenitis Suppurativa. The HSF is a worldwide charitable organisation of patients and physicians that fosters and encourages research by developing and supporting an interdisciplinary family of scientists and physicians devoted to studying HS and its molecular and cellular basis.

Our aim is to develop and deliver more effective forms of therapy and preventative measures to patients with this common, debilitating, and eminently chronic disease. A summary of genetic research for this condition is presented on the HSF website: <http://www.hs-foundation.org/abouts/genetics.htm>

The first book to specifically deal with HS, appropriately entitled "Hidradenitis Suppurativa," will be available in Europe this

September, and in the United States this October. Written by Drs. Gregor BE Jemec, Jean Revuz, and James J. Leyden, these experts present the best current knowledge about the diagnosis, pathogenesis and complications of HS; comprehensive guidelines on diagnosis and therapy; a description of the patients' perspective, as well as patient information. The book's publisher, Springer, is donating 50 cents from each book sold in support of the Hidradenitis Suppurativa Foundation (HSF).

To read more about the book or order a copy, please visit:  
<http://www.springer.com/3-540-33100-X>

Robert Howes, Vice President (Australia)  
Email: [info@hs-foundation.org](mailto:info@hs-foundation.org)  
Web: <http://www.hs-foundation.org>

(Article was provided by Australian Hidradenitis Suppurativa Foundation, Inc.)

## Interesting Websites



Information accessed through the World Wide Web is of varying levels of quality and accuracy.

The material supplied is for information purposes only, and is not to be used for diagnosis or treatment.

### **Kids Are Kids!**

Kids Are Kids! was developed to offer families a holistic service as an alternative to government therapy services. All staff employed at Kids Are Kids are specialised in paediatrics and have had extensive experience working with children who have a range of difficulties and disabilities.

<http://www.kidsarekids.org.au/services.htm>

[Last Reviewed: 6/09/2006]

### **Healthy Community Projects Rural & Remote Health in Australia Human Rights and Equal Opportunity Commission Background**

In 1998 and 1999 Commission members and staff visited regional, rural and remote areas in every State and the Northern Territory as part of the Bush Talks consultations. We invited country people to raise their human rights concerns in public and private meetings and in submissions.

[http://www.hreoc.gov.au/HUMAN\\_RIGHTS/rural\\_health/index.html](http://www.hreoc.gov.au/HUMAN_RIGHTS/rural_health/index.html) [Last Reviewed: 8/09/2006]

### **Crossings: A Manual for Transition of Chronically Ill Youth to Adult Health Care.**

This manual is intended as a guide for health professionals to establish a new health care delivery system for transitioning adolescents with chronic illness to adult health care. DVD coming soon to this site!!

<http://hctransitions.ichp.ufl.edu/crossings.html>

[Last Reviewed: 8/09/2006]

### **About the RCH Transition Project Transition of patients to adult health care**

The information on this web site is designed to assist RCH staff to implement effective Transition processes for their older patients requiring transfer to adult health care.

<http://www.rch.org.au/transition>

[Last Reviewed: 8/09/2006]

### **The protection of genetic information of Indigenous peoples**

Human Rights and Equal Opportunity Commission: [http://www.hreoc.gov.au/social\\_justice/genetic\\_information.html](http://www.hreoc.gov.au/social_justice/genetic_information.html) [Last Reviewed: 8/09/2006]

### **Influence of genetic support groups make to research.**

The importance and influence that genetic support/ advocacy groups can make to the progress and research of genetic conditions is illustrated in a recent article in 'Nature Genetics'. View the full article at <http://www.nature.com/ng/journal/v38/n4/full/ng0406-391.html> [Last Reviewed: 8/09/2006]

### **Surviving the Maze**

Surviving the Maze consists of a fantastic series of 60 information sheets for family carers and service providers on:

- > Starting carer and being a carers
- > Dealing with the hospital system
- > Considering residential care
- > Caring for a family member in residential care

<http://www.survivingthemaze.org.au/BCFC/BCFC.htm>

[Last Reviewed: 4/10/2006]

### **Online community service for individuals and families affected by rare diseases.**

The online community is not meant to be a substitute for professional medical information, but rather a place where those affected by rare diseases can connect with others who have the same interests or medical conditions.

<http://nord.clinicahealth.com> [Last Reviewed: 4/10/2006]

## Australian Jeune Syndrome Association Inc.

Our mission is to raise the awareness and level of understanding of this rare condition throughout the wider community. In the long term, we aim to raise funds to:

- increase research into identifying the Jeune Syndrome gene and the underlying cause of the various symptoms such as renal failure; and
- research various treatments such as rib expansion in order to provide a better quality of life for our children.

### **What is Jeune Syndrome?**

Jeune Syndrome, also known as Asphyxiating Thoracic Dystrophy, is a rare genetic multi-system disorder that primarily affects the growth of the rib cage, thereby restricting

growth of the lungs. Jeune Syndrome may also affects other parts of the skeleton, as well as the eyes, kidneys, liver and pancreas.

### **How common is Jeune Syndrome?**

Jeune Syndrome is very rare. It has been reported to occur with a frequency of between 1/100,000 and 1/130,000. This means that in Australia approximately two babies affected by Jeune Syndrome are born each year.

### **Contact Details**

Claudine Spinner, President  
Australian Jeune Syndrome Association Inc.  
C/- 7 Cathcart St, Maidstone Vic 3012  
Email: [claudinespinner@optusnet.com.au](mailto:claudinespinner@optusnet.com.au)  
Website: <http://home.vicnet.net.au/~jeunesyn>

(Article Reviewed by Australian Jeune Syndrome Association Inc.)

## Coming Events



### **Street Appeal WA Retinitis Pigmentosa Foundation**



Date: 24 November  
Street Appeal to collection funds to support research into Retinitis Pigmentosa.

Contact: (08) 9227 7585  
Website: <http://www.retinitispigmentosa.com.au>

### **Men's Advisory Network (MAN) Conference "From Babies to Blokes: The Making of Men"**

Date: 29 October to 1 November 2006.  
Location: Esplanade Hotel, Fremantle, WA.  
Program and registration details are available at:  
<http://www.promaco.com.au/conference/2006/man>

Register your interest so that the program can be posted directly to you. You can do this through the website or by email to:  
[romaco@promaco.com.au](mailto:romaco@promaco.com.au)  
Website: <http://www.man.org.au>

### **The Australian Huntington Disease Association National Conference.**

#### **"Melbourne 2006: Another Piece of the Puzzle".**

Date: 15 - 17 November 2006  
Location: Hotel Y, Elizabeth Street, Melbourne.  
The conference will be held at the Hotel Y in Elizabeth Street, Melbourne, and will be an exciting opportunity for families and professionals with an interest in HD to learn about latest advances in research and in care for people affected by HD.

Contact AHDA (Vic) office on 03 9563 3922 or by email on  
[NationalConference@ahda.com.au](mailto:NationalConference@ahda.com.au)

### **Relationships, Sexuality & Disability Awareness Day secca (Sexuality Education Counselling and Consultancy Agency)**

Date: 16 November  
An awareness raising event to increase knowledge and capacity to access services for people with disabilities. This event targets service providers, agencies, carers, families and health professionals in the disability field in relation to sexuality, sexual health and relationships.

Contact: (08) 9420 7226  
Website: <http://www.secca.org.au>



### **Transcultural Mental Health Conference & Convention of Carers of the Mentally Ill Office of Mental Health**

Date: 16 - 17 November  
The theme for this conference is 'Broadening the Horizon'. There will be international keynote speakers who have been invited to address the conference.

Contact: (08) 9224 1760  
Website: <http://www.broadeninghorizon.health.wa.gov.au>

### **Mental Health End of Year Art Exhibition Sale The Creative Expression Unit**

Date: 8 - 22 December  
The Creative Expression Unit hosts our annual Mental Health week Art Exhibition and sale of art works by artists with a mental illness who currently participate in CEU's programmes using art/art therapy for mental health recovery. All public are welcome. See CEU website

Contact: (08) 9347 6579  
Website: <http://www.ceu.health.wa.gov.au>

**Promote your coming events in the 'Gene Advocate' or on our website!!!**

*Contact Kristina on (08) 9389 6722 [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au)*

## Coming Events

### **Westcare Presents an International Day of People with a Disability Event Breakfast with Jack Cowin**

Come and join Jack Cowin for the International Day of People with Disability event. A day of uniting disability organisations, people with disabilities, businesses, governments and communities in celebrating the achievements of people with a disability

Date: Tuesday, 28th November 2006

Time: 7am for 7.30am - 9am

Venue: Hyatt Regency Hotel, 99 Adelaide Tce, Perth 6000

Prices: Tickets - \$55 (inc gst), Tables of 10 - \$500 (inc gst)

Bookings to Jan Bryson & Rebecca Taplin

Phone: (08) 9246 5622

Email: [events@redhorizonevents.com.au](mailto:events@redhorizonevents.com.au)

### **2006 Conference "From Babies to Blokes: The Making of Men" - M.A.N.**

The Conference will be of interest to all people working in areas associated with men and boys.

The program for the 2006 National Conference of the Men's Advisory Network Inc., titled "From Babies to Blokes: the Making of Men", is fantastic, involving 80 speakers and workshop leaders.

The program and registration brochure is available for download at:  
[www.promaco.com.au/conference/2006/man](http://www.promaco.com.au/conference/2006/man)



## Community consultation and participation

Community consultation and participation resource kit for area health service managers and project leaders.

*Publication Date: June, 1999, Pages: 112 ,*

*Author/Source: NSW Health.*

### **Summary**

A resource kit designed to assist Area Health Service Managers and project leaders in establishing and maintaining community and consumer input into planning, policy development and service monitoring.

### **Abstract/Review**

This kit explores the meaning of consultation and participation, benefits of consultation for service providers and consumers, benefits, techniques, a checklist to assist evaluation.

Case studies highlight some challenges, techniques, outcomes and key lessons learnt. References included in the kit are listed in Section 9 and contacts are listed in Section 10.

This document is from:

<http://www.health.nsw.gov.au/public-health/crcp/hib/publications/community.html>



### **GSCWA EVENTS ONLINE:**

<http://geneticsupportcouncil.org.au/pages/events.asp>

## Access to Health Services for People who are Blind or Vision Impaired

### **This document acts as both an advocacy and information document.**

Blind Citizens Australia encourages members, and others, to use this document to help educate health professionals on the specific issues faced by people who are blind or vision impaired when accessing the health care system.

There is a download facility on the web version so you can obtain a large print plain text Word version of the document.

The contents includes:

- \* General information on blindness, vision impairment and health care services
- \* Access to Information
- \* Access to Premises and Services
- \* Hospitals and Public Health settings
- \* Principles of good practice for the General Practice (GP) setting
- \* Suggestions for Change

The web address to access the document is:

[http://www.bca.org.au/natpol/Blind\\_Citizens\\_Australia\\_Access\\_to\\_health\\_services.htm#\\_Toc145215273](http://www.bca.org.au/natpol/Blind_Citizens_Australia_Access_to_health_services.htm#_Toc145215273)

## Grants

### **Grant Information Seminars**

Our Grant information seminars provide an opportunity for groups or organisations to get up to date information about Lotterywest Grants and the Application process. The seminars also give organisations the opportunity to hear first hand how the grants process works and to have their questions answered.

Members of our Lotterywest grants team regularly visit Western Australia's major regional centres to run information seminars and when doing so take the opportunity to visit smaller surrounding communities wherever possible. Our grants team may also be available to meet organisations in the location they are visiting to discuss specific grant proposals.

In addition, the Lotterywest grants team schedule information seminars

in venues within the Perth metropolitan area.

### **Metropolitan Grant Information Seminar Diary:**

<http://www.lotterywest.wa.gov.au/asp/index.asp?pgid=518>

### **Regional Grant Information Seminar Diary:**

<http://www.lotterywest.wa.gov.au/asp/index.asp?pgid=455>

### **Disability Projects**

Lotterywest supports time-limited community development projects that involve individuals or communities working together with people with a disability to improve opportunities for people with a disability. Go to Enhancing Community Development Initiatives for more information.

<http://www.lotterywest.wa.gov.au/asp/index.asp?pgid=423>



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

# Have you used The WA Carers Charter

It states:

- Carers must be treated with respect and dignity.
- The role of carers must be recognised by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers.

- The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.

- Complaints made by carers in relation to services that impact on them and the role of carers

must be given due attention and consideration.

Are you aware of your rights as a family carer under the Carer Recognition Act?

For further information ask Ellen 9583 3372 or phone the Carers Secretariat 6217 8500.



## Biobank

**A biobank is not a fridge with specimens in it or a pathology lab, and it is not a study that some geneticist has done. A biobank is a database that can be searched, and it is organized in a systematic way.**

Source: Knoppers B.M., (2006) "Biobanks: New Challenges for Bioethics and Biolaw". GenInfo newsletter September-October 2006

## Members of the GSCWA

### 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  
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  
Mental Illness Fellowship WA (Formerly: Schizophrenia Fellowship of Western Australia)  
Motor Neurone Disease Association of WA Inc.  
Mucopolysaccharide & Related Diseases Society (MPS)  
Muscular Dystrophy Association of WA  
Neurofibromatosis Association of WA.  
Parents of Children with Disabilities  
Periodic Paralysis Society of Australia  
PXE Support WA  
Raynaud's Syndrome Support Group  
Rett Syndrome Association of WA  
Senses Foundation Inc.  
Short Statured People's Association WA Branch  
SIDS and Kids Western Australia  
Sjögren's Syndrome Support Group  
Spina Bifida Association of WA  
Thalassaemia Association of WA  
Turner Syndrome Association of Australia (WA Branch)  
Support Organisation for Trisomy and Related Disorders of WA (SOFTWA)  
Western Australian Retinitis Pigmentosa Foundation

WA Tourette Syndrome Organisation (WATSO)

### CORPORATE ASSOCIATE MEMBERS

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

### INDIVIDUAL ASSOCIATE MEMBERS

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



*Membership Forms are available on the Web!*

<http://geneticsupportcouncil.org.au>

## ***The GSCWA Board of Management***

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Executive Director  
Cystic Fibrosis WA Inc.

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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.

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