

# Gene Advocate

EDITION 45

GENETIC SUPPORT COUNCIL OF WA (INC)

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## Special points of interest:

- *Even Keel Bipolar Support Grp* p4
- *Transition Care Presentation* P11

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## Overview: Mandatory fortification with folic acid

In May 2004, the Australia and New Zealand Food Regulation Ministerial Council asked Food Standards Australia New Zealand (FSANZ) to investigate mandatory fortification with folic acid as a possible means of reducing the incidence of neural tube defects (NTDs) which are serious birth defects.

Internationally, a number of countries have reported successful mandatory folic acid fortification programs as an equitable and sustainable means of increasing the folic acid intake of women of child-bearing age (the target population) to reduce the incidence of NTDs. Wheat flour is the most commonly chosen food vehicle.

FSANZ drew on this international experience and selected bread-making flour as the food vehicle for mandatory folic acid fortification in Australia and New Zealand. From a practical perspective, it considered bread-making flour as a feasible vehicle due to the existing mandatory fortification requirement with thiamin in Australia.

The proposed level of mandatory fortification is 230-280 micrograms of folic acid per 100 grams of bread-making flour, to achieve an average residual level of approximately 200 micrograms folic acid in the flour component of the final food.

The approach maintains current voluntary folic acid permissions except for bread which will be changed from a voluntary permission to a mandatory requirement.

The reasons for the preferred approach are:

- ◆ fortifying flour with folic acid, in this case bread-making flour, is consistent with international experience of mandatory fortification to reduce the incidence of NTDs;

- ◆ bread-making flour (as bread and bread products) is a staple food consumed widely, consistently and regularly by the target population of women of child-bearing age;
- ◆ fortification of bread-making flour will deliver a mean increase in folic acid intake in the target population of 100 micrograms and 131 micrograms in Australia and New Zealand respectively, resulting in an estimated reduction of between 14-49 pregnancies in Australia and 4-14 pregnancies in New Zealand affected by an NTD;
- ◆ on the available evidence, including overseas experience, the proposed level of fortification does not pose a risk to public health and safety.
- ◆ the cost-benefit analysis indicates that the benefits from the projected reduction in NTDs well exceed the costs of mandating fortification: In Australia, the net benefits would be \$23.9 million each year ongoing for live NTDs reduced, or \$124.5 million each year ongoing for all NTDs (including still births and terminations) reduced by fortification; and in New Zealand, the net benefits would be \$4.8 million each year ongoing for live NTDs reduced, or \$41.2 million each year ongoing for all NTDs (including still births and terminations) reduced by fortification.
- ◆ the cost to consumers is likely to be small, probably less than 1% of the price of a loaf of bread; and
- ◆ consumers will be provided with information through ingredient labelling to identify the presence of folic acid in products containing bread-making flour.

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

## Overview: Mandatory fortification with folic acid Cont.

This approach also acknowledges the useful role of current strategies in reducing the incidence of NTDs. These strategies include the promotion of increased folate intakes in women of child-bearing age through education, voluntary fortification and supplement use. Optimal reduction in NTDs depends on these strategies continuing, including a commitment to the ongoing promotion of folic acid supplements.

There are some uncertainties associated with mandatory fortification, particularly chronic exposure to increased folic acid intakes beginning in childhood. As a result, a conservative approach to the level of fortification has been adopted.

Monitoring will form an essential component of implementing this Proposal. It will provide a basis to gauge both the ongoing effectiveness and safety of mandatory folic acid fortification, particularly in further reducing the incidence of NTDs and ongoing need for fortification at the recommended level.

### How mandatory folic acid fortification will work

Following completion of a Final Assessment for the Proposal and approval of the proposed draft variations to the Code by the FSANZ Board, the Ministerial Council will be notified. Subject to any request from the Ministerial Council for a review, the proposed draft variations to the Code are expected to come into effect upon gazettal. Once gazetted, it is proposed that the normal 12-month transitional period for amendments to the Food Standards Code will apply to the proposed mandatory fortification of bread-making flour with folic acid.

FSANZ has prepared a strategy to guide communication and education initiatives to raise awareness and understanding of the proposed standard for mandatory folic acid fortification and its implementation. In implementing this strategy, FSANZ will collaborate with other organisations that play an important role in providing information and education to consumers, industry and other key stakeholders.

To give industry time to make the required changes to manufacturing and labeling, and to alert consumers to the new rules, we are recommending a **12-month transition period** for implementation after the standard becomes law.

### Commonly Asked Questions

#### What is folate/folic acid?

Folic acid is a B group vitamin that is needed for healthy growth and development. This vitamin is known as **folate** when it is found naturally in food, such as green leafy vegetables, and as **folic acid**

when it is added to food, such as bread and breakfast cereals, or used in dietary supplements.

#### Who needs folic acid and why?

Folic acid is important for everyone but is especially important for women of childbearing age particularly those planning a pregnancy. This vitamin is crucial to the healthy development of babies in early pregnancy. A baby's growth is the most rapid in the first weeks of life, often before a woman knows that she is pregnant. Folic acid taken at least one month before pregnancy and for the first three months of pregnancy will substantially reduce the risk of birth abnormalities called NTDs in babies.

#### What are NTDs?

NTDs are severe congenital malformations of the central nervous system which may occur during early development of the baby in the womb. The two major types of NTDs are anencephaly and spina bifida. There is more information about NTDs on the Australian Spina Bifida & Hydrocephalus Association (ASBHA) website at <http://www.asbha.org.au/SpinaBifidaandHydrocephalus.htm>

#### How much folic acid do women need?

In Australia, women of child bearing age are advised to take folic acid (a synthetic form of folate) as a supplement or consume fortified foods at a level of 400 micrograms a day to minimise the risk of their unborn child being affected by a NTD such as spina bifida. In New Zealand, women are recommended to consume a tablet containing 800 micrograms of folic acid a day. These recommendations are in addition to the normal diet which contains naturally-occurring folate.

#### Why can't women get enough folate in their diet?

A woman needs to consume large quantities of food with high levels of naturally-occurring folate to obtain the recommended daily dose. Foods naturally high in folate include: green leafy vegetables, nuts, orange juice, some fruits and dried beans. Although the naturally-occurring folate in these foods also contributes to protecting against NTDs, naturally-occurring folate is not as easily absorbed by the body as folic acid found in supplements and fortified foods. To obtain the equivalent of 400 micrograms of folic acid, a woman would need to eat daily nearly ½ kilogram of cooked spinach or raw broccoli!

#### Are there education programs in place throughout Australia to encourage women to take folic acid supplements?

Yes. Since the early 1990s, Australian women of

## Overview: Mandatory fortification with folic acid Cont.

child-bearing age have been encouraged to take folic acid supplements at the daily recommended dose of 400 micrograms. Similar health messages have been promoted in New Zealand. However, well-resourced supplement promotion programs encouraging women to take folic acid, such as in WA, have only achieved about 1 in 3 women obtaining an average of 200 micrograms per day or more from supplements. Also, as many pregnancies are unplanned (estimated to be more than 50% of all pregnancies) reliance on supplements alone is not an effective strategy.

### **Voluntary fortification is already in place. Why isn't that enough?**

Voluntary fortification of foods (flour, savoury biscuits, bread, cereal flours, breakfast cereals, pasta, yeast extracts and fruit and vegetable juices) with folic acid has been in place since 1995 but not all of the food industry has taken up this option. Despite this and the fact that not all women are taking sufficient folic acid supplements, some Australian States have reported a fall in NTD rates. So it is possible that there can be further reductions in NTD cases if there is a rise in folic acid intake.

### **What food will folic acid be added to?**

Bread making flour has been recommended as it is a common food that is consumed by most women of childbearing age. Overseas projects, where folic acid has been added to flour, have proven successful in reducing the rate of NTDs. The proposed FSANZ standard balances the need for pregnant women to get sufficient folic acid, while ensuring that some segments of the population, such as small children, do not get too much.

Bread is consumed by over 80% of the target population and surveys conducted in the 1980s and 1990s have shown that this level of consumption has remained stable. Bread products containing bread-making flour that will also be fortified include muffins, buns, crumpets etc.

### **What about women who do not consume bread?**

FSANZ has recognised that some women may not consume bread — they may be gluten intolerant or for cultural or other reasons bread is not a major component of their diet. In this case it will be important for these women to consume folic acid from other sources such as voluntary fortified foods and/or supplements.

### **What about people who may object to mandatory fortification of food?**

Folic acid is a naturally occurring B group vitamin that is essential part of the diet. Based on current

scientific evidence and overseas experience, the levels of folic acid fortification recommended by FSANZ don't pose a risk to public health and safety. The added folic acid will be listed in the ingredient list on the product.

### **What will be the expected reduction in NTDs?**

Consuming enough folic acid substantially reduces the risk of NTDs but it won't prevent all cases.

**Australia:** Mandatory fortification of bread-making flour is expected to **increase** the folic acid intake of Australian women of child-bearing age by an average of **100 micrograms a day**. This is estimated to decrease the number of NTDs by 14-49 unborn children. About 300-350 pregnancies in Australia are affected with a NTD each year, with the majority of these (about 70%) terminated.

**New Zealand:** Mandatory fortification of bread-making flour is expected to **increase** the folic acid intake of New Zealand women of child-bearing age by an average of **130 micrograms a day**. This is estimated to decrease the number of NTDs by 4-14 unborn children. In New Zealand, about 70-80 pregnancies are affected with a NTD each year, with the proportion of these terminated similar to Australia.

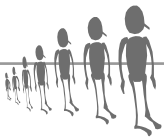
### **Are there other benefits from increasing the population's intake of folic acid?**

The potential positive effect of increased folic acid on several other diseases and conditions (such as cardiovascular disease, cancer and cognitive function) has been investigated. However, the additional adult intake of folic acid from mandatory fortification (averaging 100-130 micrograms a day) is unlikely to produce any other discernible health benefits.

### **Are there any potential adverse effects from taking folic acid?**

High doses of folic acid are not known to have any adverse effects on healthy individuals. The US and Canada have had mandatory fortification of flour with folic acid since 1998 and have found this to be a successful and effective means of reducing the rate of NTDs.

Underpinning this overview is a report that sets out in detail the reasons why new regulations are needed, options that we considered during the development of the standard and a draft standard for incorporating into the Code. You can access this information from the FSANZ website at <http://www.foodstandards.gov.au>.



## About Our Members



### **Even Keel Bi-Polar Support Association**

Even Keel has been operating now for twenty one years. The association offers a network of support groups for people diagnosed with Bipolar affective disorder (also known as manic depression), Depression, schizophrenia and related disorders. Family, friends and other interested members of the community are welcome to attend our groups.

Our group coordinators are caring, supportive and empathic; with many of our employees having a diagnosis of Bipolar disorder themselves.

#### **Support Groups**

Even Keel currently operates twelve support groups. Nine of these are in the Perth metropolitan area, one is held in Rockingham, one is held in Mt Baker and also one in Busselton. Support Group meetings are open to everyone...

#### **Key Benefits**

- Each group operates to meet the needs of its members and the coordinator.
- There is no set formula for group operation. It is not a step program.
- The opportunity to meet new people while relaxing in safe environment.

#### **Where are they located**

##### **Subiaco**

June O'Connor Centre  
2 Nicholson Rd , Subiaco

Every week, Friday 1.30-2.30pm  
Contact John: 08 9388 9869

##### **Online Support Forum**

Go to our home page, Click on "Services", then click on "Support Forum", then register, then you're set to go.

10-11am every Saturday Moderator Julia  
Contact Julia: (08) 93889869 or email  
evenkeel@aapt.net.au or 0438854858

##### **Midland**

The Old Court House  
Helena St Midland  
7-9pm 1st Wed each Month.  
Contact Janice (08) 93889869 or 0419812295

##### **Yokine**

287 McDonald Street, Yokine.  
1-3pm third Saturday of each month.  
*IN RECESS AT PRESENT*

##### **Fremantle**

The June O'Connor Centre  
31 Alma St, Fremantle.  
1-3pm first Tuesday of each month.  
Contact John: (08) 93889869 or 0407793476

##### **Heathridge**

Granny Spiers Community House,  
2A Albatross Court, corner Poseidon Road,  
Heathridge.  
From 7.30pm third Thursday of each month.  
Contact Elizabeth or Maurice: 0439804061

##### **Perth City**

2nd floor, Wesley Arcade,  
William Street, Perth.  
1-2pm Last Wednesday of each month.  
Contact Libby: 04071811591

##### **Rockingham/Kwinana**

June O'Connor Centre,  
8 Baralda St, Rockingham.  
12-3pm second Friday of each month.  
Contact Ingrid: 0412522387

##### **Mount Barker**

Mount Barker Hospital.  
1-2.30pm second Friday of each month.  
Contact Benita: 0418802075

## About Our Members

### **Busselton "Caring Friends"**

Meets at the Uniting Church\*  
47 Kent St Busselton 6280.  
Wednesdays 1-3pm.  
Office open 10-4pm. Ph:97515866

### **Mandurah**

Meets at Baptist Church\*  
Cnr Rio Grand & Pinjarra Rds Mandurah,  
Upstairs in the Ross Chatfield Room,  
12-2pm on the third Tuesday of each Month.  
Contact Glenys on 0418828387

\* *Groups are not affiliated with any church*

### **Inpatient Information Sessions**

#### **SCGH**

Ward D20  
First Tues each month 10.30-11.30am  
Contact Janice 0419812295 or 93889869

#### **Fremantle Hospital**

Ward 51  
Alma St Centre  
Bimonthly  
Contact Janice 0419812295 or 93889869

#### **ROYAL PERTH Hospital**

Ward 2k  
Meets Bi monthly  
Contact Libby 0407181591 or 39889869

### **Even Keel Contact Details**

Ph: (08) 93889869  
Email: [evenkeel@aapt.net.au](mailto:evenkeel@aapt.net.au)  
Web:  
<http://www.evenkeel.org.au>  
Mail: PO Box 1584 MIDLAND,  
WA 6936



*(Article Reviewed by Even Keel  
Bi-Polar Support Association)*

### **First Bipolar Disorder Risk Gene Found**

A study led by scientists at the Garvan Institute of Medical Research and the University of New South Wales, which has discovered the first risk gene specifically for bipolar disorder, also known as manic-depressive illness. The discovery has shown that people who have a particular form of this gene are twice as likely to develop the disease.

Dr Ian Blair, lead investigator of the study, says: "We are the first group in the world to take a multi-faceted approach to identify a bipolar risk gene. We used a number of families, unrelated patients, and therapeutic drug mouse models. Each of these three lines of investigation led us to a gene called FAT." We know that the FAT gene codes for a protein that is involved in connecting brain cells together, what we need to do now is find out exactly how it contributes to the increased risk of bipolar disorder," explained Dr Blair.

Bipolar disorder is a major psychiatric illness affecting around one person in every 50. Tragically, around one in six people suffering from the condition will suicide. Mood-stabilising medications are typically prescribed to help control bipolar disorder. Lithium, the first mood-stabilising medication approved by the U.S. Food and Drug Administration (FDA) for treatment of mania has been widely prescribed for treatment of bipolar disorder, yet no one knows for sure why it works.

Dr Blair's research has raised the possibility that lithium alters FAT gene expression, as well as the expression of genes encoding FAT's protein partners. However Lithium has a number of severe side effects that include tremor and weight gain. Kidney dysfunction may develop in a small proportion of patients when it is administered for long periods of time.

"Once we understand exactly what the FAT gene does, we will be able to develop better diagnostic tests for bipolar disorder. We hope our research will lead to new, targeted medicines specifically for bipolar disorder that don't have the unpleasant side effects that lithium has", said Dr Blair.

Information Source: Neuroscience Institute of Schizophrenia and Allied Disorders. Newsletter May 2006. [Online]. Available: [http://www.nisad.org.au/newsEvents/headlines/headlines\\_May06.pdf](http://www.nisad.org.au/newsEvents/headlines/headlines_May06.pdf)

## 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.
- **Chromosome 6q27 deletion** Rita and Arthur have two sons with this rare deletion and would love to hear from other families with the same condition. They can be contacted through the *Genetic Support Network of Victoria*.  
E-mail: [info@gsnv.org.au](mailto:info@gsnv.org.au)  
or phone: (03) 8341-6315

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)

## Whats' in a name?

### Marinesco-Sjogren Syndrome

Marinesco-Sjogren Syndrome is a very rare genetic disorder characterized by ataxia (balance and coordination), juvenile cataracts, generally some degree of cognitive delay, and small stature. About 100-200 cases of MSS have been diagnosed worldwide.

**The MSS website has been developed to provide information and support to families affected by MSS and to encourage communication between doctors and researchers interested in this disorder.**

This is a site run by a small number of MSS families, and dedicated to our very special children.

<http://www.marinesco-sjogren.org>

### Sjogren's syndrome

Sjögren's ("SHOW-grins") syndrome is a chronic disease in which white blood cells attack the moisture-producing glands. The hallmark symptoms are dry eyes and dry mouth, but it is a systemic disease, affecting many organs and may cause fatigue. It is one of the most prevalent autoimmune disorders.

Nine out of ten patients are women. The average age of onset is late 40's although Sjögren's occurs in all age groups in both women and men.

**Information about Sjogren's syndrome  
Sjögren's Syndrome Support Group WA  
on (08) 9447-9922**

## 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.

### **Diversity Health Institute Clearinghouse**

A gateway to multicultural health information in Australia, the website is funded by the NSW Government. It aims to bring together the large amount of work conducted nationally in the area.  
<http://www.dhi.gov.au/clearinghouse>  
[Last Reviewed: 10/07/2006]

### **Physical Disability Council of N.S.W. - Information for Students page**

This section of the website provides information for high school and university students studying the issues faced by people with physical disabilities. It includes definitions, statistics and answers to frequently asked questions about people with disability in N.S.W.  
<http://www.pdcnsw.org.au/students.html>  
[Last Reviewed: 10/07/2006]

### **The Defence Special Needs Support Group (DSNSG)**

This group is the only Australian charity dedicated to providing support, information and assistance to Australian Defence Force families who have someone with special needs. This site contains links to regional and local DSNSG Support Groups and to special needs information at a Local, State, National and International level.  
<http://www.dsnsng.org.au>  
[Last Reviewed: 10/07/2006]

### **WE MOVE**

A resource for movement disorder information and education and the only organisation of its kind. Since 1991, this 501(c) 3 not-for-profit organisation has

been educating and informing patients, healthcare professionals, and the public about the latest clinical advances, management, and treatment options for neurologic movement disorders.

<http://www.wemove.org>  
[Last Reviewed: 10/07/2006]

### **Genetic Interest Group (GIG): Human Rights, Privacy and Medical Research: Analysing UK Policy on Tissue and Data**

London - May 19, 2006  
<http://www.gig.org.uk/docs/hrprivacypdf190506.pdf>  
[Last Reviewed: 11/07/2006]

### **Review of Assistive Technology funding and equipment for disability and its application in the West Australian community.**

<http://www.ilc.com.au>  
[Last Reviewed: 11/07/2006]

### **Online article: Disabilities complicate adolescence ?**

Social issues as children with disabilities enter their teens.  
<http://www.post-gazette.com/pg/05271/578693.stm>  
[Last Reviewed: 17/07/2006]

### **Quilts 4 Kids project**

This project is based on volunteers who cross stitch squares that are sewn together into quilts. These quilts are then given as gifts to Australian kids up to age nineteen with life-long or life-threatening illnesses. Accepting 'Kids of 2007' registrations.  
<http://www.quilts4kids.com>  
[Last Reviewed: 17/07/2006]

## Continence Management and Support Scheme WA

The State Government has established a new continence management and support scheme for seniors and adults with disabilities.

The scheme, which will start in early 2007, will be coordinated jointly by the Department of Health and the Disability Services Commission.

The scheme is targeted to those seniors and adults with a disability who:

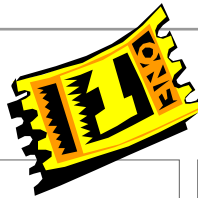
- have permanent incontinence;
- receive a health care card or pensioner concession card; and
- are not eligible for the Continence Aid Assistance Scheme (CAAS) administered by the Commonwealth Government.

The scheme will introduce a continence product subsidy of up to \$470 per annum and a continence management and advisory support service. Access to the product subsidy will require a professional continence assessment and management plan developed by an approved continence advisor.

An implementation committee with representatives from the Disability Services Commission, the Department of Health and Office of Seniors Interests and Volunteering will oversee the development of policies and procedures, including the specification of eligibility criteria.

For further information, please contact the Disability Services Commission on telephone 08 9426 9200 or 1800 998 214.

## Coming Events



### **Climb to the Top — Heart Foundation**

Date: 1 - 31 August

Climb to the Top is a month long physical activity program encouraging participants to climb the equivalent of Mt Everest by the end of August, by using the stairs, walking, cycling, swimming or running.

Contact: (08) 9388 3343 or email  
melissa.sulcs@heartfoundation.com.au



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



### **Continenence Awareness Week Continenence Advisory Service**

Date: 6 - 12 August

Continenence Awareness Week is a national week which highlights the prevalence and impact of bladder and bowel control problems on Australians of all ages. There will be a public seminar, a range of health promotion activities and displays throughout the week.

### **Join the Continenence Advisory Service for their first ever Continenence Symposium**

7th August 2006

There are many great speakers to be heard and lots of information to be gained.

Contact: (08) 9386 9777 Country 1800 814 925

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

Website: <http://www.continenencewa.org.au>

### **International Physiotherapy Day Australian Physiotherapy Association**

Date: 8th September

This day promotes physiotherapy and the role of the practitioner.

Contact: (08) 9389 9211

Website: <http://www.physiotherapy.asn.au>



### **Eye Health Week Lions Eye Institute**

Date: 13 - 19 August

Eye Health Week aims to inform the community of the risks to eye health posed by diet, lifestyle, hereditary conditions and eye injuries, as well as treatments minimising the risk of blindness.

Contact: Development Office on (08) 9381 0777

Website: <http://www.lei.org.au>

### **Community Health Nurses Week**

#### **Community Health Nurses Western Australia**

Date: 21 - 27 August

A celebration of Community Health Nursing in WA. The events will include professional development, networking and social events in country and metro areas. Highlight of 2006 will be the Biennial Conference held this year in Kalgoorlie from 24th to 26th August.

Contact: (08) 9391 2283

Website: <http://www.chnwa.org.au>

### **Asthma Week**

#### **Asthma Foundation of WA**



Date: 1 - 7 September

This is the national week for promoting asthma awareness, education and self management. A range of education and support activities will be held throughout the state.

Contact: (08) 9289 3600

Website: <http://www.asthmawa.org.au>

### **Spina Bifida Awareness Month**

#### **Spina Bifida Association of WA**



Date: 1 - 30 September

This National Awareness month helps to raise awareness of spina bifida and hydrocephalus within the community, and raise funds for services and research.

Contact: (08) 9346 7520

Website: <http://www.asbha.org.au>

### **Blood Donor Week**

#### **Australian Red Cross Blood Service**

Date: 10 - 17 September

Blood Donor Week recognises Blood Donors and the enormous contribution they make to our community. Over 1 000 000 donations are made each year by just under 500 000 Australian Donors.

Contact: (08) 9421 2803

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

### **Carers WA is planning another Practical Matters & Planning Ahead Forum this time in the City for family carers on Tuesday 29th August 2006**

Details available: <http://www.carerswa.asn.au>

## Coming Events

### ADHD Awareness Week

#### Learning and Attentional Disorders Society of WA

Date: 16 - 22 September

This week is designed to raise the awareness of Attention Deficit Hyperactivity Disorder and to inform the public of advances in the diagnosis and treatment of ADHD via media releases and community events.

Contact: (08) 9346 7544

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



### National Gynaecological Awareness Day

Date: 10th September

This week promotes gynaecological awareness, with gynaecological displays at hospitals, and joining medical professionals and community women to work as a team in raising the profile and access to information.

**GAIN**

### The Fifth National Gynaecological Awareness Day "The Great Gynae Day Out"

This event will be held on Sunday, 10 September 2006 at the Hyatt Regency, Perth from 10 – 4pm. This year we will go one step further by bringing research, fact and real life case studies together to promote gynecological awareness through our key message Beyond the Research. It will be a stunning day full of information sessions, workshops, natural therapies, Playback Theatre, cooking demonstrations, multicultural entertainment and displays.

Bookings for both events are with BOCS Ticketing 9483 1133 or <http://www.bocsticketing.com.au>

Contact: (08) 9279 7773

Website: <http://www.gynsupport.com>

### World Retina Day

#### WA Retinitis Pigmentosa Foundation

Date: 30th September

Sale and promotion of Owl lapel pins for research into retinal dystrophies.

Contact: (08) 9227 7585

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



### The Chromosome 18 Registry & Research Society

(Aust) are holding their Annual Family Meeting in Auckland, New Zealand, on Saturday 30th September and Sunday 1st October 2006. Health professionals will discuss topics including bipolar/depression as well as family/sibling issues. For more information please contact: Marlene by phone on (02) 9580-5707 or email [chromosome18@optusnet.com.au](mailto:chromosome18@optusnet.com.au) or contact Ruth by email at [drmcrae@xtra.co.nz](mailto:drmcrae@xtra.co.nz)

### 49th Annual RACGP Scientific Convention Be the future. land Faculty

Date: 5-8 Oct 2006, Brisbane QLD

The overarching theme of the convention is Be the future. Many Australian GPs and researchers are at the forefront of family medicine in the world. Planned keynote presentations on cutting edge research in evidence based medicine, new advances in malignant skin disorders, and research into genetic diseases will complement exciting panel discussions on where general practice is heading in the future.

Web: <http://www.racgp.org.au/asc2006>

### Australian Disease Management Association (ADMA) 2nd Annual National Conference. Evidence-based disease management in the 21st century

Date: 7-8 Sep 2006, Melbourne VIC

The focus of the conference is on programs/services which have demonstrated outcomes in disease management, self-management, population health management, behaviour change, remote monitoring, technology and health coaching for people with chronic disease.

Phone 03 9276 3535

Email [K.Fiddes@alfred.org.au](mailto:K.Fiddes@alfred.org.au)

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

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



*Contact Kristina via e-mail or phone and we can arrange it for ou.*

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

☎ (08) 9389 6722

## Making your event more accessible

**Any groups involved in holding fetes, conferences, festivals, fundraisers or events of any kind should take note of a great new guide on making events more accessible.**



Accessible Events – A Guide for Organisers, has been developed by Meetings and Events Industry of Australia in partnership with the Human Rights and Equal Opportunity Commission.

The guide takes you through all aspects of event preparation, from selecting a venue, to transport considerations, promotion, bookings, catering and accommodation.

It also provides a range of practical tips on how to make events more accessible to people with disabilities, including how you can make written, visual and audio information accessible, as well as the legal responsibilities events organisers have under antidiscrimination law. The guide points out that it's easier and cheaper

to think about access at the very earliest planning stages of your event than to address them as an afterthought.

"The most effective way of ensuring access for everyone is to think about access at the very earliest planning stages of your event. This means thinking about the access requirements of attendees, staff, speakers, performers and exhibitors who may have a disability," the guide says.

"It will often be more expensive and more time consuming to address the requirements of people with disabilities if you treat access as something you add at a later stage."

The guide can be downloaded free at <http://www.meetingsevents.com.au/research>

Information courtesy of  
"www.ourcommunity.com.au"

## Grants

### Independent Living Grants Lotterywest

Lotterywest will consider grants for eligible organisations managing Independent Living properties. Assistance may be provided with furniture and equipment to support people with a mental illness moving to supported accommodation for the first time, as follows:

- ➔ One-off grants of up to \$4,000 per property towards essential household furniture and equipment
- ➔ In recognition that a person living with their family may need a larger fridge, washing machine, dining table etc. an additional amount of up to \$1,000 will be considered for properties accommodating an individual and their family.
- ➔ The organisation must make provision for the maintenance and replacement of the furniture and equipment items.

For specific information about this grant area and access to an Application Form, please visit:

<http://www.lotterywest.wa.gov.au>

### Tye Estate Fund Deaf Children Australia

Closes: Ongoing

Aim: To assist with financial assistance towards the costs of holidays, rest and recreation and/or convalescence for deaf people.

Applications are invited from organisations on behalf of individuals requiring financial assistance towards the costs of holidays, rest and recreation and/or convalescence for deaf people.

For further details please contact:  
Chief Executive Officer VSDC Services

**Freecall: 1800 645 916**

**Or visit their website at:**  
<http://www.deafchildreinaustralia.org.au>



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

# GSCWA ANNUAL GENERAL MEETING

Will be held on  
**Wednesday 27th September 2006**

**Guest Speaker: Penny Shannon**

Health Department WA

## Transition Care

Moving from paediatric to adult healthcare.  
Why has it become so important? What are the issues young people have identified  
and how do we address some of these issues.

**6.30 - 7.30 pm**  
**at Grace Vaughan House**  
**Shenton Park**

**A light supper and refreshments will be provided.**

**All members welcome. Phone 9389 6722 to register your attendance.**

## 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**

### CHAIR

Professor Charles Watson  
Executive Dean  
Health Sciences Curtin University

### TREASURER

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Executive Director  
Cystic Fibrosis WA Inc.

### DEPUTY CHAIR

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Meredith Doyle  
President  
Huntington's Disease Association of WA

Steve Sandilands  
President  
Cornelia De Lange Syndrome Support Group

▶ 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.

## Our Contact Details

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### **Office hours:**

9.00am to 4.00pm.  
Monday to Friday.

### **Staff:**

Sharon Van der Laan, *Executive Director*  
Anja Hermann, *Administrative Officer*  
Kristina Johns, *Resource Officer*

