

## Genetic Support Group Awareness Day 10 August 2004

**EDITION 28**  
**August**  
**2004**

**Special Points of Interest**

- ▶ Link Line
- ▶ Genetic Support Group Awareness Day - 10 August 2004
- ▶ GSCWA AGM

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**Awareness Day 10th of August 2004**

The Genetic Support Council of Western Australia sponsored the first *Genetic Support Group Awareness Day* at the Esplanade Hotel, Fremantle.



The Awareness Day was held in conjunction with the *International Genetics and Population Health Conference* and the *Human Genetics Society of Australasia Scientific Meeting* which ran from the 8th of August until the 13th of August.

Highlights included:

- ▶ The Conference and Scientific Meeting brought together Health Professionals, Genetic Counsellors and Support Group Members from across Australia.
- ▶ Speakers from 23 countries were amongst the wide range of presentations over the two meetings.
- ▶ The 10th of August was titled *Meeting Community Needs* and many of the papers on that day focused on matters of particular interest to Genetic Support Groups and their Members.

In particular, papers from Prof. J.R. Singh, Amritsar India '*Genomics and the role of Genetic Support Groups: an international perspective*',

Dr. V. Collins, Melbourne '*17-year trends in the prevalence of Down syndrome and maternal age in Victoria*',

E. Hughes, Melbourne '*The role of the Genetic Support Groups in the development of Genetic Services in Victoria*',

T. Keating, Perth '*Genetic Support Groups and the developing crisis of care from childhood to late adulthood*'. This session was chaired by Dianne Petri Association of Genetic Support of Australasia Inc (AGSA).



The Genetic Support Council WA maintained a booth in a prominent position through out the 6 days staffed by the GSCWA and assisted by a number of Support Groups.



*The views 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/treatment.*

## GSCWA Members

EDITION 28

### The GSCWA Board of Management

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Dr. Peter O'Leary  
*Director Genomics Directorate, Department of Health. Clinical Senior Lecturer Department of Obstetrics and Gynaecology, The University of Western Australia*  
Del Weston  
*Executive Officer Australian Huntington's Disease Assoc. WA Inc*

### Our Location and contact details:

Level 1, Oasis Lotteries House  
37 Hampden Road  
Nedlands WA 6009  
Telephone: 08 9389 6722  
Mobile: 0411 585 113  
Email: [admin@geneticsupportcouncil.org.au](mailto:admin@geneticsupportcouncil.org.au)  
Web: <http://geneticsupportcouncil.org.au>

#### Office hours:

9.00am to 5.00pm.  
Monday to Friday.

#### Staff:

Terry Keating, *Executive Director*  
Anja Hermann, *Administrative Officer*  
Kristina Johns, *Resource Officer*

- ▶ Information on the Genetic Support Council WA and its Members, *Australasian Genetic Alliance* was provided and well received by conference goers and others.
- ▶ Members of the *Australasian Genetic Alliance* held their Annual General Meeting during this week and further strengthened their network across Australia and New Zealand to better serve Genetic Support Groups, individuals with genetic conditions and their families.

The *Awareness Day* and events during the week where most successful! The Genetic Support Council WA would like to *thank* and *acknowledge* all its Members who assisted to make this day a valuable occasion.

In particular, the Genetic Support Council WA would like to express its appreciation to *Prof. Allan Bittles, Conference Convenor* and *Prof. Nigel Lang, HGSA Local Organisation Committee; the Human Genetics Society Australasia*. Further support in making this possible.



## About Our Members

### MEDIA RELEASE

28<sup>th</sup> July 2004

### Announcement of "HeartKids Australia"

*Every day in Australia 2 babies are born with congenital heart disease.*

The inaugural conference of all Australian Heartkids Associations and Heart Children New Zealand was held last weekend in Melbourne, resulting in the formation of a new alliance. This is an historic moment in the arena of childhood heart disease in this country.

The new alliance formed will be called **HeartKids Australia**. HeartKids Australia aims to address issues on a regional level that face children with heart disease, and their families.

Through a collaborative effort across this region we can drive an agenda to raise community awareness, vital funds for research and address inconsistencies in federal policies activities that will reduce the impact of heart disease on children.

**The objectives of HeartKids Australia are:**

- ▶ To encourage and support research programs through the Australian and New Zealand Children's Heart Research Centre (ANZ CHRC).
- ▶ To coordinate a national approach towards funding of the ANZ CHRC.
- ▶ To raise awareness in the community about heart defects in children, their incidence and continuing consequences.
- ▶ To address national issues of concern with the commonwealth Government.
- ▶ To coordinate a national approach towards securing ongoing funding through sponsorship of each state groups and the alliance itself.
- ▶ To retain the entity of each state group.

The recently established **Australia and New Zealand Children's Heart Research Centre** requires funding to assist with the development of clinical, laboratory, public health and educational advances related to childhood heart disease.

They aim to make a fundamental national and international contribution to the study of cardiovascular disease in children, which is the most common birth abnormality; affecting 1 in every 100 babies.

**HeartKids Australia** and **Heart Children of New Zealand** have also agreed to form an international alliance, which will result in a collaborative association that will benefit the many children who are born with, or acquire, a heart condition.

The conference was generously supported by the **Federal Department of Family and Community Services** and **Qantas Airways**.

***For further information contact:***

Alison Byrne Ph Mobile: 0418 576 448 or our state representative Dianne Lunt  
Ph: 9341 7395



**“AGM REMINDER”**

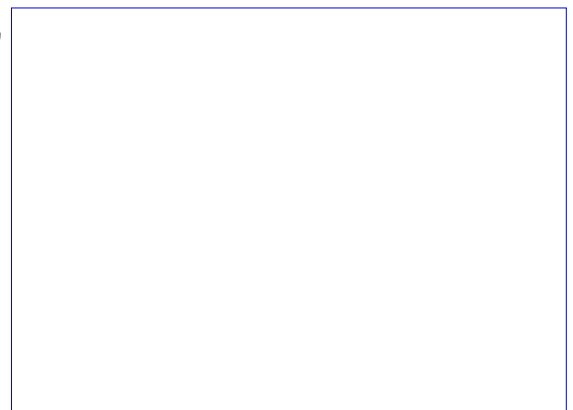
**THE GENETIC SUPPORT GROUP  
COUNCIL WA Inc. IS HOLDING ITS  
ANNUAL GENERAL MEETING**

Date: Tuesday the 7th of  
September 2004

Address: The Conference Room,  
Oasis Lotteries House,  
37 Hampden Rd  
NEDLANDS, WA 6009.

Time: 5.30-6.30

*Followed by Light Refreshments!*



## Coming Events

### Asthma Week

#### Asthma Foundation of WA

Dates: 1- 7 September 2004

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) 9481 1234 Website: [www.asthmawa.org.au](http://www.asthmawa.org.au)

### Spina Bifida Awareness Week

#### Spina Bifida Association of WA

Dates: 1- 7 September 2004

This week helps to promote the awareness of spina bifida within the community. Donations for services will be sought by SBAWA members collecting in Fremantle and the city. Information packs are available for distribution. September is Spina Bifida Awareness Month. Each state holds various fundraising and advocacy events around Australia, to raise awareness of this condition, during this time. Details on what is happening nationally can be found at [www.asbha.org.au](http://www.asbha.org.au) For local details contact: (08) 9346 7520 or [info@sbawa.asn.au](mailto:info@sbawa.asn.au) Website: [www.sbawa.asn.au](http://www.sbawa.asn.au)

### Breakthrough Lecture Series 2004

#### ARAFMI Mental Health Carers & Friends Association

Dates: 6- 20 September 2004

The Breakthrough Lecture Series 2004 is being held each Monday over six consecutive weeks. A brief information exchange about community mental health services is presented at 7pm. Main speakers commence at 7.30pm. Venue for this event is Graylands Hospital, Anderson Hall, Brockway Road, Claremont. Breakthrough lecture series 2004 proudly sponsored by Homecare Services. For more information, call Perth office on 9228 0577 or email [cheryl@arafmi.asn.au](mailto:cheryl@arafmi.asn.au) Contact: (08) 9228 0577 Website: [www.arafmi.asn.au](http://www.arafmi.asn.au)

### What's the Buzz Day

#### Diabetes Australia - WA

Date: 17 September 2004

What's the Buzz Day is Diabetes Australia's annual fundraising day. It involves the sale of Barnaby Bee merchandise. Monies raised from this day help Diabetes Australia in continuing its vital work in the community assisting people living with diabetes.

Contact: 08 9325 7699

Diabetes Information and Advice Line

(Toll Free) 1300 136 588

Email: [info@dawa.asn.au](mailto:info@dawa.asn.au)

<http://www.dawa.asn.au/>

### National Gynaecological Awareness Day

**G.A.I.N Inc. Gynaecological Awareness Information Network** "a community of women and men to work as a team"

Date: 10 September 2004

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* invites you to a night of fun and frivolity - an entertaining, and informative debate featuring some of our funniest 'Perthonalities', as well as some of our most respected and knowledgeable gynaecologic practitioners and health consumers.

To celebrate National Gynaecological Day 2004, the Great Gynae Debate will be a fun night about a very serious subject and is aimed at anyone involved in gynaecology in any way (which means just about everyone)!

Great Gynae Debate: SUBIACO THEATRE CENTRE, 180 Hamersley RD, SUBIACO

9<sup>th</sup> of September 2004

Time: 6. 0 0 p m - 8. 3 0 p m

Download Flyer:

[http://www.gynsupport.com/newsite/downloads/flyers/gyn\\_day\\_invite.pdf](http://www.gynsupport.com/newsite/downloads/flyers/gyn_day_invite.pdf)

For ticket enquiries please email [mazzella@bigpond.com](mailto:mazzella@bigpond.com) or call 9279 7773.

Contact: (08) 9279 7773

Website: [www.gynsupport.com](http://www.gynsupport.com)

### Community Health Nurses Week

#### Community Health Nurses Western Australia

Dates: 13- 19 September 2004

A celebration of Community Health Nursing in WA. The events will include professional development, networking and social events in country and metro areas.

Contact: (08) 9391 2283

Website: [www.chnwa.org.au](http://www.chnwa.org.au)

### International Physiotherapy Day

#### Australian Physiotherapy Association

Date: 8 September 2004

This day promotes physiotherapy and the role of the practitioner.

'Hampden House' 174 Hampden Rd, NEDLANDS WA 6009

Ph: (08) 9389 9211

Fax: (08) 9389 9221

[wa.branch@physiotherapy.asn.au](mailto:wa.branch@physiotherapy.asn.au)

Website: <http://apa.advsol.com.au>

### Eczema Awareness Week

#### Eczema Association of Australasia Inc

Dates: 19 - 25 September 2004

This is a week of media coverage to promote awareness of the condition of eczema and its impact on sufferers, carers and their families.

Contact: 1300 300 182

Website: [www.eczema.org.au](http://www.eczema.org.au)

**Leukaemia Week****"AUSSIES GO "OUT TO LUNCH - FOR LEUKAEMIA" Leukaemia Foundation**

Dates: 13 - 19 September 2004

This week is designed to raise the awareness of leukaemia and other related blood disorders in the community. Australians are invited to go OUT TO LUNCH "en masse" across the country, in the Leukaemia Foundation's *World's Greatest Grill* and the *World's Largest Lunch* to be held as part of the Foundation's Leukaemia Week activities during September.

Contact: 1800 620 420.

Website: [www.leukaemia.com](http://www.leukaemia.com)

**Community Health Nurses National Conference  
Community Health Nurses Western Australia**

Dates: 16 - 18 September 2004

A national conference for Community Health Nurses and other Health Professionals. This is a great networking opportunity. The WA conference will be held in Margaret River.

Contact: (08) 9391 2283

Website: [www.chnwa.org.au](http://www.chnwa.org.au)

**ADHD Awareness Week****Learning and Attentional Disorders Society of WA**

Dates: 20 - 26 September 2004

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

Ste B/11 Aberdare Rd

Nedlands, WA 6009

Website: [www.ladswa.com.au](http://www.ladswa.com.au)

**World Retina Week****WA Retinitis Pigmentosa Foundation Inc.**

Dates: 25 September - 2 October 2004

Retinitis Pigmentosa organisations worldwide will hold public awareness and fundraising events. Australian groups will be selling "Owl Badges" for \$2.00 each from selected outlets.

Contact: (08) 9227 7585

2/251-255 Stirling Street

PERTH, WA 6000

Website: [www.retinitispigmentosa.com.au](http://www.retinitispigmentosa.com.au)

**Thyroid Awareness Week****The Australian Thyroid Foundation Limited**

1- 7 September 2004

Week designed to promote the understanding of Thyroid disease within the community.

Thyroid Awareness Week Co-ordinator

Phone: (02) 9890 6962 (answering service)

Fax: (02) 9845 7287

Email: [thyroid@icpmr.wsahs.nsw.gov.au](mailto:thyroid@icpmr.wsahs.nsw.gov.au)

<http://www.thyroidfoundation.com.au>

**First Western Australian Transcultural  
Mental Health Conference: "Similarities and  
Differences - Working Together"**

Date: 21st October 2004

Perth, Western Australia - CALL FOR PAPERS and registration. This conference is for anyone working in the area of mental health. It aims to involve all stakeholders including clinicians, service providers, policy makers, educators, researchers, consumers and carers from a culturally and linguistically diverse background. Please contact: Dr Bernadette Wright

Ph: 08 9224 1760 for details.

For registration: 02 9840 3333 or email [admin@mmha.org.au](mailto:admin@mmha.org.au). Registration brochure at [www.mmha.org.au](http://www.mmha.org.au)

**Men's Health Week**

The launch of Men's Health Week will be held from 12noon to 4 pm on Sunday 29 August.

Location: The Esplanade Reserve, Marine Terrace, Fremantle.

The flyer is available online at the GSCWA "Publications Page", it provides details of the free family entertainment. There will also be a wide range of information and displays, plus Pit Stop, which provides free men's health risk factors screening. Other activities are being conducted throughout the state during the week.

Contact details:

Phone/Fax: (08) 9218 8044

Email: [admin@man.org.au](mailto:admin@man.org.au)

Website: [www.man.org.au](http://www.man.org.au)

**Healing Hands - Indigenous Health Rights  
Campaign 2004**

Healing Hands is a new initiative by ANTaR and led by a core group of eminent Australians including Patrick Dodson, Prof. Lowitja O'Donohue and Dr. Bill Jonas.

It aims to turn the tide of the worsening crisis in Indigenous Health in Australia, and lead a resurgence of the prominence of Indigenous issues on the national political agenda. The ANTaR website contains a library of downloadable resources about Indigenous Health, the campaign and what YOU can do to help turn things around.

ANTaR WA—Contact: Lesley Hart

Tel/Fax: 08 9371 7116

Email: [antarwa@antar.org.au](mailto:antarwa@antar.org.au)

[www.antar.org.au](http://www.antar.org.au)

## *Current Issues and Matters of Interest*

### **CONGENITAL ADRENAL HYPERPLASIA SYMPOSIUM**

**Sunday 4<sup>th</sup> July 2004**

*About the Symposium!*

The annual symposium of the Congenital Adrenal Hyperplasia (CAH) Support Group of Australia was held in Perth for the *first time* in July. Approximately 40 local and interstate families and supporters attended the symposium at Princess Margaret Hospital.

Dr Tony Lafferty, a pediatric endocrinologist from Perth, opened the symposium with a description of the condition, how it occurs and he discussed the latest treatments. Dr Lafferty noted that CAH is a condition that requires medication from early childhood throughout their lives, and that the medication needs changed as children progressed through their teenage years and into adulthood.

He proposed that parents could carry a special certificate that he had designed to give to Emergency Centre doctors with information about CAH and what treatment was required.

After his presentation, Dr Lafferty spent some time answering questions from the audience and discussing any issues raised by the audience. After morning tea, Michael Green, a family counsellor from Victoria and partner of a CAH sufferer, talked about some of the social issues that parents experience when their child is diagnosed with CAH.

He described how counsellors could assist through the life stages of CAH where parents and children may need support. Helen described the process of genetic testing, the techniques that were used and

He also showed a list of questions to ask to determine whether outside assistance could be of value and gave some practical suggestions for self-help strategies. His main message was that you need to '*look after yourself to be able to help others*'. In the afternoon, Helen Mountain, a genetic counsellor from Genetic Services of Western

Australia, spoke about the genetics of CAH and how some changes to a person's DNA (mutations) result in the condition. Helen described the process of genetic testing, the techniques that were used and also about the limitations of genetic testing.

Helen also outlined the process of prenatal diagnosis for mothers who are at risk of having a child with a genetic disease like CAH. This is important because CAH is one of the few genetic conditions that can be treated during pregnancy to reduce the risk of some of the more serious consequences. In the future, preimplantation genetic diagnosis (PGD) might also offer an option for some women.

Finally, Joanna Delaney, a senior social worker at Princess Margaret Hospital spoke about the counselling and support that is available within the public health system for children with special needs and their families. Joanna highlighted the changing needs of children as they grow and the different issues that they and their families need to deal with, such as maintaining a positive self-image and discipline. In addition, Joanna explained the conditions that need to be met to receive the Carers Allowance and recommended that families seek advice from social workers when completing the Department of Family and Community Services forms.

It was clear that everyone attending the symposium thought the day was a great success. Many of the local participants had not known about the CAH Support group and were not members, but intended to become members after the experiencing how valuable these group can be for parents of children with serious illnesses like CAH.

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For further information please contact the Genetic Support Council of WA (Inc).

Telephone: 08 9389 6722

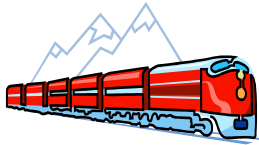
Email: [admin@geneticsupportcouncil.org.au](mailto:admin@geneticsupportcouncil.org.au)

**Or**

Visit The Congenital Adrenal Hyperplasia (CAH) Support Group of Australia Inc. Online, Available:

<http://home.vicnet.net.au/~cahsga>

## Link Line



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.

Genetic support groups are an important resource for families or people in a similar situation. To date, there appears to be no specific support group for the following conditions/syndrome:

*A mother with a 16 month old child living with Bilateral periventricular nodular heterotopia in the VIC region would like contact with other families in any part of Australia with a child with a similar condition*

*A mother with a 4 yr old child with Dandy Walker syndrome in the WA region would like contact with other families in Western Australia with a child with a similar condition.*

*A Perth family would like contact with other families living with XYY Syndrome in the expectation of forming a support group, online & or in person. Health professionals with an interest or knowledge are welcome to contact us also.*

☞ Please contact Kristina at the Genetic Support Council if seeking contact with this family, telephone: 08 9389 6722 or [info@geneticsupportcouncil.org.au](mailto:info@geneticsupportcouncil.org.au)

## Interesting Websites



### Australian Physiotherapy Association PHYSIO INFO CARDS

<http://apa.advsol.com.au>

(last Reviewed: 11/08/04)

**Are you a doctor or carer?** You are invited to print the information cards and give them to the person being treated:

- [Ankle Sprain](#)
- [Back Pain](#)
- [Your Infant's Feet and Legs](#)
- [Sports](#)
- [Arthritis](#)
- [Your Child's Feet and Legs](#)
- [Neck Pain](#)

### Who Owns My Disease?

<http://www.motherjones.com>

(Last Reviewed: 18/08/04)

In the scramble to patent human genes, companies have put profits ahead of patients' needs. Now some families with congenital diseases are staking a claim on the genetics revolution-and their own DNA.

Full article available Online:

<http://www.motherjones.com/news/feature/2001/11/gene.html>

### What is the Care & Counselling Program?

<http://www.phdgp.com.au/healthy-minds.html>

(Last Reviewed: 18/08/04)

The Care & Counselling Program is a pilot program being run through the Perth and Hills Division of General Practice and funded by the Commonwealth Department of Health and Ageing. It is one of the *Access to Allied Health Services* programs that forms part of the Commonwealth Government's *Better Outcomes in Mental Health Care Initiative*.

**For further information on the Care & Counselling Program please contact Judith, The Care and Counselling Program Coordinator, on 9376 9200.**

Information Source:

<http://www.phdgp.com.au/healthy-minds.html>

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.

## *GSCWA Members*

### **FULL MEMBERS**

Acoustic Neuroma Association of Australia  
 Alzheimer's Association of WA  
 Angelman Syndrome Association  
 Arthrogyrosis Support Group  
 Australian Huntington Disease Association  
 Australian Pituitary Foundation WA Branch  
 Australian Tuberous Sclerosis Society Inc.  
 Coeliac Society of WA  
 Cornelia De Lange Syndrome Support Group  
 Cushings 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 Inc.)  
 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  
 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  
 Thalassemia 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  
 Genomics Directorate, Dept. of Health  
 Health Consumers Council WA  
 Lone Parent Family Support Service (LPFSS)  
 The Kalparrin Centre  
 The Neurological Council of WA Inc  
 Western Australian Deaf Society Inc.

### **INDIVIDUAL ASSOCIATE MEMBERS**

Anja Hermann, GSCWA  
 Bonita Anne Eaton, LPFSS  
 Darren Webb, ECU – Human Biology Student  
 Kristina Johns, GSCWA  
 Linda Bovill  
 Mark Bovill  
 Professor Charles Watson, Curtin University  
 Terry Keating, GSCWA

## *Grants*

### **Extending the Capacity of Not-For-Profit Organisations. LotteryWest**

**Closes:** Ongoing

**Aim:** Community Services & Development.  
 To extend the capacity of the not-for-profit sector by promoting and supporting your organisation's or sector's development.

Contact details:

Freecall: 1800 655 270

Telephone: (08) 9340 5270

Fax: (08) 9340 5274

TTY: (08) 9340 5236

Email: [grants@lotterywest.wa.gov.au](mailto:grants@lotterywest.wa.gov.au)

Further information available at the following website:

<http://www.lottery.wa.gov.au/asp/index.asp?pgid=288>

▶ **GSCWA can assist members with grant applications & further resources!**