

**January 2003**  
**EDITION 9**

## ***Our Mission***

To promote and develop awareness of genetic conditions within the community, provide information and advocacy to individuals and families, foster research, encourage and support service delivery by genetic support groups.

Welcome to the January 2003 edition of the Genetic Support Council Western Australia (Inc) newsletter.



## ***About Our Members***

### **Haemophilia Foundation Western Australia (Inc.)**

Haemophilia Foundation Western Australia Inc. (HFWA) is committed to the improvement of treatment for haemophilia and related bleeding disorders, and the complications arising from such treatment. HFWA is run by a Management Committee of volunteers from the bleeding disorders community.

Haemophilia is a blood clotting disorder in which one of the essential clotting factors is deficient. There is no cure for haemophilia but the development of clotting factor concentrate has meant that it can be managed effectively.

Bleeding is mostly internal. The deficiency in clotting factor produces a wide range of bleeding episodes, usually into the joints or muscles. These bleeding episodes may be caused by injury, but in severe haemophilia can begin spontaneously. Bleeding into joints produces damage, and joints may develop arthritis and have reduced range of motion as a consequence.

Haemophilia is hereditary. It affects males almost exclusively, and is passed on by females who carry the defective gene. However, almost one third of all occurrences appear in families with no previous family history of the disorder.

Von Willebrand Disorder is a related bleeding condition, characterised by the inability of the blood's platelets to form an effective clot. It is also hereditary but affects both males and females. It is thought that von Willebrand Disorder affects about one percent of the general population.

Haemophilia Foundation Western Australia Inc. works for, and represents all people with haemophilia and related bleeding disorders and their families, improving care, support

### **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 12.00pm and 1.00pm to 5.00pm.  
Monday to Friday.  
12.00pm to 1.00pm by appt.  
Monday to Friday.

#### **Staff:**

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

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

#### CHAIR

Professor Charles Watson  
Executive Dean, Health Sciences Curtin University

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Mitch Messer  
Executive Director  
Cystic Fibrosis WA Inc.

#### TREASURER

Vicki Mort  
Financial Manager  
Holyoake Institute

#### BOARD MEMBERS

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Australian Huntington's Disease Association WA Inc.  
Carmel Wright  
Client Services Coordinator  
Spina Bifida Association of WA Inc.

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.

and quality of life through advocacy, education and the promotion of research.

The Foundation's activities include:

✚ *The provision of information about bleeding disorders to members and the general public.*

HFWA issues regular newsletters and bulletins to members, and holds occasional public meetings and seminars on issues relevant to our community. HFWA also distributes publications and information produced by the Haemophilia Foundation Australia.

✚ *Representation and lobbying*

HFWA is able to represent or advocate on behalf of members when requested. This may be in relation to medical services or any other issue relevant to haemophilia.

✚ *Financial assistance*

HFWA provides limited financial support in a range of areas including subsidising or meeting the cost of essential services or aids for care, transport from remote areas or any worthwhile purpose. Supporting research and development of new and improved therapy.

✚ *The provision of a counselling service for people with bleeding disorders and their families.*

The Haemophilia Counsellor - Coordinator is a full time worker funded by HFWA to provide a range of services to people affected by haemophilia and related bleeding disorders and their families.

✚ *Peer support*

HFWA organises a number of social events and groups designed to encourage peer support, information sharing or informal contact. Camps are held for people with a bleeding

disorder and their families, or special needs groups.

If you would like more information about haemophilia, von Willebrand's disorder or the Haemophilia Foundation Western Australia (Inc), please feel free to call Ruth Heady, Counsellor/Coordinator on 9224 2330.

#### **Contact details:**

Haemophilia Foundation Western Australia  
City West Lotteries House  
2 Delhi Street  
West Perth WA 6005  
Ph: (08) 9420 7294

### **Current Issues and Matters of Interest**

#### **The December 21<sup>st</sup> Deadline for Compliance with the Privacy Act**

The Privacy Legislation came into full on the 21st of December 2002. For more information about understanding how to apply privacy to your organization or for further information, please contact GSCWA. Further Information can be obtained at: <http://privacy.gov.au>

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#### **SPECIAL PRICES: Telstra Special Pricing Offer for ITECs**

Some non-profit organisations may benefit from following up on Telstra's special pricing offer for ITECs. A substantial line rental reduction can be obtained by applying to Telstra for a "Business Line Charity Tag" to be placed on your billing account. All that is required is a fax to Telstra requesting the tag, providing a brief description of your activities and a copy of your ITEC endorsement from

the ATO. The Telstra fax number to send the request to is 1800 899 001.

SOURCE:

<http://www.wacoss.org.au/enews/61/enews61.html#6>

### **Interesting Articles**

#### **What the world needs.**

*A little more kindness and a little less creed,  
A little more giving and a little less greed;  
A little more smile and a little less frown,  
A little less kicking a man when he's down;  
A little more "we" and a little less "i",  
A little more laugh and a little less cry;  
A few more flowers on the pathway of life,  
and fewer on graves at the end of the strife.*

*Author unknown*

Provided by: Even Keel Bipolar Disorder Support Association (Inc) WA

### **Coming Events**

#### **The Tuberos Sclerosis Society Inc.**

Dr Lawrence Lai is headed for WA and is available to provide up to date information on the latest research into Tuberos Sclerosis complex on the 7<sup>th</sup> – 14<sup>th</sup> of February.

Dr Lai has widespread training in Genetics and teaches the subject to Medical and Biological Science students as well as Human and Biochemical genetics to science students. He has conducted research into the molecular and family studies of tuberous sclerosis and corroborated

with a group at the University of California, Irvine.

Please forward expressions of interest to:

Sue Williamson: President of WA

PH: 9367 7458

E: [williamson@brightonline.com.au](mailto:williamson@brightonline.com.au)

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### **The Lupus Group of WA (Inc)**

The Victoria Park Library: *Lupus Awareness Display*

Date: Tuesday to Thursday - 14<sup>th</sup> 30<sup>th</sup> January

Time: 9.30 am – 6pm, 8pm

The Subiaco City Library: *Lupus Awareness Display*

Date: Tuesday to Thursday – 6<sup>th</sup> -20<sup>th</sup> of February

Time: 9.30 am – 6pm, 8pm

The Royal Perth Hospital: Robin Miller-Dick Seminar Room:

“*Getting the Most out of you Doctor*”, the guest speaker is Dr. Jean Foster.

Date: Tuesday the 18<sup>th</sup> of February

Time: 7pm to 8pm

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### **Congenital Heart Disease Awareness Heart Kids WA Inc.**

Date: 14 February

This day is designated worldwide as Congenital Heart Disease Awareness Day and happen together with Valentines Day. Heart Kids WA arrange pictorial promotions at shopping centres, through schools and medical centres, with the aim of raising awareness and funds.

Funds are raised through the sale of our series Barnard Bear Badges

available at displays or from Heart kids; and the sale of our Precious Hearts Rose, also available at displays or from Melville Nurseries.

Contact: (08) 9388 9238

Email: [heartkid@iinet.net.au](mailto:heartkid@iinet.net.au)

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### **Me No Hair**

#### **Cancer Foundation of WA**

Date: 18 February

The fundraising focus is for men's cancer research.

Contact: 1300 656 585

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### **The Walk Against Want**

#### **Oxfam Community Aid Abroad**

Date: 23 February

*The Walk Against Want* raises money for *Oxfam Community Aid Abroad's* programs in some of the world's poorest countries.

Contact: (08) 9381 3144

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

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### **Grants**

The GSCWA maintains a list of grants that can be applied for by community organisations such as genetic support groups. Members can contact our office for further information. Several relevant grants this month are:

- ★ Volunteer Equipment.
  - ★ Wheelchairs for Kids.
  - ★ Boeing Contributions (Cash or donation of goods or services).
- ✓ GSCWA can assist members with grant applications.



## **Interesting Websites**

### **HealthInsite**

<http://www.healthinsite.gov.au>

HealthInsite provides a gateway to up-to-date information on important health topics through links to over 50 information partner web sites. Expert views are also available on particular subjects, including asthma, cancer, Aboriginal and Torres Strait Islander mental health, diabetes and immunisation. Users may also choose to enroll with HealthInsite enabling persons to subscribe to information meeting their personal requirements. Developed by the Commonwealth Department of Health and Aged Care

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### **The National Human Genome Research Institute (NHGRI) Glossary**

<http://www.genome.gov/glossary.cfm>

The NHGRI created the *Talking Glossary* of Genetic Terms to help people without scientific backgrounds understand the terms and concepts used in genetic research. Simply click on the term of interest to open a page with a wealth of information, including the term's pronunciation, audio information, images and additional links to related terms. Students, teachers and parents will find the glossary an easy-to-use, always available learning source on genetics.

### **Managing a Non-Profit Organisation or Group Online**

<http://www.makingthenetwork.org>

Making the Net Work is a joint UK-US initiative led by David Wilcox, Drew Mackie and Terry Grunwald.

- ❖ The aim is to develop 'how to' guidance for those aiming to get their organisation or neighbourhood online, or to create community technology or learning access centres.

## **Organisations of Interest**

### **St.George Foundation Limited**

<http://www.stgeorge.com.au/about/foundation/gifts/default.asp?orc=about>

Provide support to charitable organisations throughout Australia to help them to assist children and young people up to 18 years of age, who are living with a 'disability' and or are 'disadvantaged'.

In addition, the St.George Foundation welcomes groups/persons to get involved and is always looking for auction items. You can find out more by contacting:

A list of donors and volunteers who have been involved can also be viewed online:

<http://www.stgeorge.com.au/about/foundation/thanks/default.asp?orc=about>

### **Contact details:**

Selina Wisdom

Ph: (02) 9952 2298

Email: [wisdoms@stgeorge.com.au](mailto:wisdoms@stgeorge.com.au)

## GSCWA Members



### Advertise in 'Gene Advocate' or on our website!!!

Have you got anything you want to be published? Either our newsletter or our website can be the place to display your information. So contact us via e-mail or phone and we can arrange it for you.

#### FULL MEMBERS

Acoustic Neuroma Association of Australia  
Alzheimer's Association of WA  
Angelman Syndrome Association  
Arthrogryposis Support Group  
Australian Huntington's Disease Association  
Australian Pituitary Foundation WA Branch  
Australian Tuberous Sclerosis Society Inc.  
Coeliac Society of WA  
Cushings Disease Support Group  
Cystic Fibrosis WA  
Down Syndrome Association of WA  
Dyslexia SPELD Foundation WA Inc  
Epilepsy Association of WA  
Even-Keel Bi-Polar Support Association (Inc)  
Haemophilia Foundation WA Inc.  
Heart Kids WA  
Klinefelters Support Group  
Learning and Attention Disorders Society of WA (LADS)  
Lupus Group of WA  
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  
Schizophrenia Fellowship of Western Australia 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  
Trisomy and Related Disorders  
Western Australian Retinitis Pigmentosa Foundation  
WA Tourette Syndrome Organisation (WATSO)

#### CORPORATE ASSOCIATE MEMBERS

Australian Kidney Foundation  
Carers WA  
Health Consumers Council WA  
Genomics Branch, Dept. of Health  
The Kalparrin Centre  
The Neurological Council of WA Inc  
Western Australian Deaf Society Inc.

#### INDIVIDUAL ASSOCIATE MEMBERS

Professor Charles Watson, Curtin University  
Terry Keating, GSCWA

