



# Gene Advocate

## EDITION 12

April 2003

### Special points of interest:

- About Our Members: Lupus Group of WA. Down syndrome amendment of contact details.
- GSCWA News Corner: Update of the directory of support Groups

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## About Our Members

### Down Syndrome Association of WA

The Down Syndrome Association of WA is a Support Group providing 'parent to parent' support and information to families who have a member with Down syndrome. It also assists those working with people who have Down syndrome, and helps raise awareness in the community about people with Down syndrome.

Some of the ways this occurs is through: a parent-run Hospital Visiting Team for new families, a 'new parent' information folder, monthly newsletters, a resource library, the sale of valuable resources, information sessions, seminars, workshops, the availability of telephone support and networking between families, discussion groups, morning teas, social functions and awareness events. The Association receives no ongoing funding, and relies on donations, fund-raising and the payment of membership fees to continue to provide this support to families and to the community.

Source: This article was provided by the Down Syndrome Association of WA

### Amendment of Down Syndrome Association contact details

The publication of the article on Down syndrome, in the March edition of the Gene Advocate stated incorrect contact details for the

Down syndrome support group. 'We apologise' for any inconvenience this may have caused. The correct contact details are:

**PO Box 338, Bentley WA 6982.**

**Phone: 08 9358 3544**

**Freecall: 1800 623 544**

**Fax 08 9358 3533**

**Email: [dsawa@upnaway.com](mailto:dsawa@upnaway.com)**

**Website: [www.dsawa.asn.au](http://www.dsawa.asn.au)**

**Opening hours are on Mondays, Tuesdays and Wednesdays between 9.30am and 12.30pm**

**MEDIA RELEASE 10 April 2003**  
**THE LUPUS GROUP OF W.A.**  
**(Inc.) AWARDED GRANT TO**  
**HELP LOCAL COMMUNITY**

To help you get the best benefit from your medicines, National Prescribing Service has awarded THE LUPUS GROUP OF W.A. (Inc.) grant funding to run an educational seminar on obtaining and using information about medicines.

This seminar is to be held at Royal Perth Hospital, Robin Miller Dicks Seminar Room, Level 3, "M" Block on 29 April 2003 between 7.00pm-8.00pm. This seminar will provide you with information about Consumer Medicine Information (CMI), where to get it and how to use it to take medicines safely and effectively, together with an overview of lupus drug management.

CMI is easy to understand information about medicines written specifically for consumers by the

*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.*

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

### **CHAIR**

Professor Charles Watson  
Executive Dean, Health Sciences Curtin University

### **DEPUTY CHAIR**

Mitch Messer  
Executive Director  
Cystic Fibrosis WA Inc.

### **TREASURER**

Vicki Mort  
Financial Manager  
Holyoake Institute

### **BOARD MEMBERS**

Kerry Gavey  
Convenor  
Klinefelter's Support Group  
Irene Gray  
President  
Western Australian Tourette Syndrome Inc.  
(WATSO)  
Michele Kosky  
Executive Director  
Health Consumers' Council WA Inc.  
Diane Lunt  
Committee Member  
Heart Kids WA Inc  
Dr Peter O'Leary  
Acting Director  
Genomics Branch  
Department of Health  
Del Weston  
Executive Officer  
Australian Huntington's Disease Association WA Inc.  
Carmel Wright  
Client Services Coordinator  
Spina Bifida Association of 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 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*

manufacturing pharmaceutical company. A CMI leaflet is available for each prescribed medicine and companies follow Government guidelines to make sure the information is accurate, unbiased and understandable.

CMI is handy back-up information provided by doctors and pharmacists. It provides important information to consider before, during and after taking your medicine. It includes what the medicine looks like, what it is used for and how it may react with other medicines that you're taking.

CMI also provides information on how to take the medicine, for how long, what to do if you miss a dose or take too much, and possible side effects and what to do if they occur.

CMI leaflets are available from your pharmacist or doctor, although sometimes they are provided inside the packet or box with the medicine. You can also obtain CMI leaflets directly from the pharmaceutical company who made your medicine.

To get CMI leaflets or to find out more about your medicines, ask your pharmacist, doctor or phone the National Prescribing Service's Medicines Line on 1300 888 763.

National Prescribing Service Limited (NPS) is a non-profit, independent, Australian organisation supporting the quality use of medicines.

With a membership base of 33 peak health bodies, the NPS works in partnership with GPs, pharmacists, specialists, other health professionals, Government, industry and consumers to improve the health of all Australians.

The role of NPS is to provide evidence-based services and resources, which ensure that the prescribing of medicines reflects the principles of quality use of medicines (the appropriate, judicious, safe, effective and cost-effective use of medicines). For further information about the seminars, education and support resources offered by The Lupus Group of W.A. (Inc.) please contact on (08) 9224 3144.

Source: This article was provided by the Lupus Support Group of WA.

Reference: National Prescribing Service Limited. Media release. 10th of April 2003

## *Current Issues and Matters of Interest*

### **Helping Individuals with Type 1 Diabetes to Exercise Safely**—Do you know anyone with type 1 diabetes?

The primary aim of this research is to develop guidelines for people with type 1 diabetes to safely participate in all types of activities by maintaining their blood sugar levels within the "normal" range.

If you are interested in learning more or possibly participating in this research please contact: Kym or Vanessa on 9380 1383, e-mail [vbussau@cyllene.uwa.edu.au](mailto:vbussau@cyllene.uwa.edu.au), or alternatively contact Dr Luis Ferreira on 9380 3181.

Source: University of Western Australia. [Notice approved by UWA Human Research Ethics Committee].

### **Assistance for agencies: GST Issues**

A representative of the 'Australian Taxation Office' will be available at WACOSS on Wednesday 30 April 2003, for one-to-one sessions of an hour, to assist agencies with any GST related issues.

If, as a result of the one hour session any larger issues arise, the ATO is happy to arrange a visit to your organisation.

For appointment please contact Faye on phone (08) 9420 7222.

**Health for all**—are community expectations outgrowing our health system? Guest Speaker: Mike Daube, Director-General, Department of Health, Western Australia

Panel: Professor Linda Kristjanson, Associate Professor, Edith Cowan University and 2002 Telstra Australian Businesswoman of the Year. Dr Penny Flett, CEO, Brightwater Care Group and 1998 Telstra Australian Businesswoman of the Year. Chair: Professor Alan Robson, Deputy Vice-Chancellor, UWA

Date: Tuesday, 29 April, 2003 at 5.30-7.00pm  
Venue: Western Australian Museum, James St foyer, Cultural Precinct, Perth  
RSVP: No charge but bookings required  
Ext 7977 or [visionwa@uwa.edu.au](mailto:visionwa@uwa.edu.au)

### **Researching Family History**

<http://www.liswa.wa.gov.au/mrelresearch.html>

A computer terminal for public use is set up at the State Records Office of WA which is linked directly to the database of the National Archives of Australia. The database thousands of records which are held by the National Archives - records dealing with immigration, customs, defence, Commonwealth public buildings, post offices and a whole host of other significant documents created by Commonwealth agencies since federation in 1901.

The computer terminal is situated next to the State Records Office Enquiry Desk. The State Records Office of WA, Ground Floor, Alexander Library Building  
Ph. (08) 9427 3360, email: [sro@liswa.wa.gov.au](mailto:sro@liswa.wa.gov.au)

Source: State Library of WA. Media Release—[Online]. 06 July 2001. Available: <http://www.liswa.wa.gov.au/mrelresearch.html>

## *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 condition *Tegra Collins Facio Cranial syndrome*.

*A Greek mother with an 18 month old child with Tegra Collins Facio Cranial syndrome in the Northern metropolitan region would like contact with another mother with a child with a similar condition.*

Please contact Kristina at the Genetic Support Council if seeking contact with this family, telephone: 08 9389 6722

(see page 2 for GSCWA contact details and location).

## Coming Events

### Genetic Support Council of WA Stem Cell Research Forum

Date: Wednesday 21st of May 2003

A programme of talks and lectures will be held at the Subiaco Theatre. Please refer to the enclosed *flyer* in this newsletter or refer to our website:

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

### Neurofibromatosis Awareness Month Neurofibromatosis Association of WA (Inc.)

Dates: 1 – 31 May

A month of activities to raise awareness of neurofibromatosis disorder.

Contact: (08) 9346 7488

### Addison's Disease Awareness Week Australian Addison's Disease Association

Dates: 6 – 10 May

An health promotion week with activities to raise awareness of Addison's Disease.

Contact: (08) 9335 5661

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

### Autism Week Autism Association of Western Australia (Inc.)

Dates: 10 – 17 May

A week of seminars and other events to educate the community about autism spectrum disorders and provide support to carers and professionals working with people with autism.

Contact: (08) 9489 8900

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

### ME/Chronic Fatigue Syndrome Awareness ME/Chronic Fatigue Syndrome Society of WA (Inc.)

Dates: 12 – 18 May

Activities throughout this time raise awareness of ME/Chronic Fatigue Syndrome in society.

Contact: (08) 9346 7477

### Coin for a Cord Day Inner Wheel Australia

Date: 16 May

Inner Wheel Australia (one of the largest women's organisations in the world) is holding a nationwide fundraising day on Friday 16th May to support the national project Cord Blood Bank Research. This research is into blood disorders in children, especially acute leukaemia. There will be shopping centre displays around Perth to promote the cause.

Contact: (08) 9401 6509

### Bearing Point Central Park Tower Stair Climb Activ Foundation

Date: 17 May

54 flights of stairs! 1,236 individual steps! Start training now. Team or Individual entries accepted.

Contact: (08) 9387 0555

Website: [www.stairclimb.activ.asn.au](http://www.stairclimb.activ.asn.au)

### Schizophrenia Awareness Week Schizophrenia Fellowship of WA Inc.

Dates: 19 - 25 May

To raise awareness in the community about schizophrenia and the resources available to those affected and their carers.

Contact: (08) 9380 6688

### Tourette Syndrome Awareness Week WA Tourette Syndrome Organisation Inc.

Dates: 26 - 31 May

Activities coordinated to raise awareness of Tourette Syndrome.

Contact: (08) 9346 7399

### APRIL Lupus Seminar

**Title:** "Medication and Patient Education"

**Details:** It is important to have access to good information on medications used to treat lupus. This seminar will provide an overview of lupus drug management, along with how to access medicine information effectively.

**Date:** 29<sup>th</sup> April 2003

**Time:** 6.30-7.00pm coffee/tea. 7.00-8.00pm Seminar with expert medical and health professionals facilitating

**Venue:** Robin Miller Dicks Seminar Room, Royal Perth Hospital, Level 3, "M" Block

**Cost:** Gold coin donation

**Recommended for:** People who are affected by a diagnosis of lupus

**Contact:** The Lupus Group of W.A. ph/fax: (08) 9224 3144

### MAY Lupus Seminar

**Title:** "Fatigue and Pain"

**Details:** This seminar will overview practical ways to 'pace your day' in relation to fatigue and pain, and understanding their association with lupus.

**Date:** 26<sup>th</sup> May 2003

**Time:** 1000-1100am-support group; 1100am-1200pm Seminar with expert health professional facilitating

**Venue:** Robin Miller Dicks Seminar Room, Royal Perth Hospital, Level 3, "M" Block

**Cost:** Gold coin donation

**Recommended for:** People who are affected by a diagnosis of lupus

**Contact:** The Lupus Group of W.A. ph/fax: (08) 9224 3144

### JULY Lupus Seminar

**Title:** "Workshop/Seminar for Supporters/Carers of a person with Lupus"

**Details:** Are you someone who provides support and is interested in the well-being of someone with lupus. Then, this one-day event will provide "Information, Interaction and Inspiration" for family, friends and partners of people with lupus.

**Date:** 5<sup>th</sup> July 2003

**Time:** 9.00am-4.00pm with expert medical and health professionals facilitating

**Venue:** CWA House, 1174 Hay Street, West Perth

**Cost:** \$15.00 bond-refundable upon attendance. Refreshments, lunch provided with comprehensive take-home information.

**Recommended for:** Family, Friends and Partners of people with lupus

**Register Today:** Limited places Funding available (travel/accommodation) for limited country participants.  
**Contact:** The Lupus Group of W.A. ph/fax: (08) 9224 3144

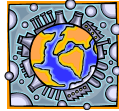
**People With Disabilities (WA) Inc.  
 Welfare Reform Forum**

Examines impact of the proposals and the cost for people with disabilities, families, friends & carers for people with disabilities.

Date: 7 May 2003, RSVP: 30 April 2003  
 Time: 9am-1pm, Location: Technology Park, 2 Brodie-Hall Drive, Bentley. For further information contact:  
 Ph: 9386 6477, TTY 9386 6451 Email: info@pwdwa.org

**Muscular Dystrophy Association of WA  
 Perth Conference**

Date: 9th and 10th of May 2003  
 For further information please contact the Association  
 ph: (08) 9382 2700 fax: (08) 9346 3487



### Interesting Websites

**Parent to Parent New Zealand**  
<http://www.parent2parent.org.nz>

Parent to Parent is a support and information network for parents of children with special needs. The website contains a page called 'Syndromes and Conditions' which contains listings of people who are seeking linkage with others.

**Assistive Media**  
<http://www.assistivemedia.org/>

Assistive Media provide free-of-charge, copyright-approved, high calibre audio literary works to the world-wide disability community via the Internet effectively, inexpensively and efficiently.

### Grants

Several relevant grants this month are:

**ANZ Charitable Trusts:** *Sylvia and Charles Viertel Charitable Foundation - General Program.*

Provide grants to charitable organisations and for charitable purposes. Categories: older people and frail people, children and young people, disadvantaged, cancer and sight impairment.  
 Closes: 15 June 2003

Contact details:  
 Email: [charitabletrusts@anz.com](mailto:charitabletrusts@anz.com)  
 Website:  
[www.anz.com.au/australia/charitabletrusts/Guidelines.asp](http://www.anz.com.au/australia/charitabletrusts/Guidelines.asp)

**Department for Community Development -  
 Office for Women's Policy: Women's Grants  
 2003**

A grants program to acknowledge and encourage the participation of women in the community. Categories: Community organisations, key interest groups and other not-for-profit organisations. Closes: No closing date.

Contact details:  
 Telephone: 9264 1900 Freecall STD: 1800 199 174  
 Email: [wpo@dcd.wa.gov.au](mailto:wpo@dcd.wa.gov.au)  
 Website:  
[www.womenwa.communitydevelopment.wa.gov.au](http://www.womenwa.communitydevelopment.wa.gov.au)

\* GSCWA can assist members with grant applications.

### GSCWA SPECIAL PROJECT FUND GRANT

The Genetic Support Council WA has a limited one off fund that is available to members for grants of up to \$1000 to assist with special projects such as:

- Assisting with publications
- Conducting seminars and forums
- Compilation of information base for consumers
- Attendance at conferences
- Assistance in engaging expert speakers at conferences, seminars and forums.
- Other projects that have a direct benefit to Genetic Support Groups and their members may be considered.

\* Contact GSCWA for further information and criteria

### GSCWA Grants

The Muscular Dystrophy Association received a grant from GSCWA. The grant to provide funds for hire of equipment for the Muscular Dystrophy conference held in Perth on the 9th and 10th of May 2003.

## **GSCWA Members**

### **FULL MEMBERS**

Acoustic Neuroma Association of Australia  
 Alzheimer's Association of WA  
 Angelman Syndrome Association  
 Arthrogyrosis 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**

ARAFMI Western Australia  
 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

## **GSCWA News Corner**

*The Genetic Support Council is currently updating the 'Directory of Genetic Support Groups'.*

*Our student Sophie is undertaking this project and has mailed out the details to organisations. We are hoping to complete the draft of the 'new' directory by the end of April 2003, your response by then would be greatly appreciated.*

*Please feel free to contact us for further information.*

\* *So far we have had 37 responses out of 88, thank you*

*Please keep them coming in!*



**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.

(see page 2 for GSCWA contact details).