

**AUGUST 2002**  
**EDITION 4**

## ***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 August 2002 edition of the Genetic Support Council Western Australia (Inc) newsletter.

## ***Current Issues and matters of interest***

### **Response to the ALRC and AHEC Issue Paper 26: Protection of Human Genetic Information**

The Genetic Support Council Western Australia (Inc) as the peak body for genetic support groups in Western Australia, held a round table discussion in March 2002 with representatives from the genetic support groups in order to gain an appreciation and understanding for their opinions of the issues covered in the Issue Paper 26 entitled "Protection of Human Genetic Information". These views provided an important indication of the opinions of genetic support groups in Western Australia.

A submission was forwarded to the ALRC and AHEC by the Genetic Support Council WA. The complete paper you can find on our website under "Publications".

A follow up forum has been planned following the release of DP66, details in "Coming Events".

### **Privacy Debate goes on**

In August The Age Newspaper published two articles titled "Let us warn patients of gene mutation, say doctors" and "A test to know and the devil you don't". Following this Federal Privacy Commissioner Malcolm Crompton, made comments regarding the Privacy Act. For details of the articles and media release of Federal Privacy Commissioner, Malcolm Crompton, please see our website under "Publications".

### **Disability & Discrimination**

For some interesting information on the relevant sections of the Disability & Discrimination Act, see our website under "Current Issues".

### **Directory of Genetic Support Groups in Western Australia**

We are continuing to update the current edition of the *Directory of Genetic Support Groups in WA*. The current edition is dated March 2001. Kristina Johns, Social Work Student on placement at the GSCWA has been carrying out this as a placement project. She will no doubt be contacting you if she has not already.

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Monday to Friday.  
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Monday to Friday.

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Anja Hermann, *Administrative Officer*

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**Dr Peter O'Leary**

Acting Director  
Genomics Branch  
Department of Health

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.

## Coming Events

Date: 23 September 2002

### Have your say about protecting human genetic information

A public meeting will take place to consider the following issue:

The Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee (AHEC) are conducting a joint inquiry into the protection of human genetic information at the request of the federal government. The ALRC and AHEC have been asked to consider what type of regulation may be needed in relation to human genetic samples and information to:

- Protect privacy;
- Provide protection from unfair discrimination; and
- Ensure high ethical standards of conduct.

Discussion Paper 66 was released 28 August 2002 and the Genetic Support Council would like to invite you to a follow up public meeting to gather comment on the discussion paper. The resulting submission will represent the collective views of genetic support groups in Western Australia. Your views are important and a presence is needed to address the requirements of those whose lives are affected by a genetic condition. For more information log on to [www.alrc.gov.au](http://www.alrc.gov.au) and view Discussion Paper 66.

A meeting has been scheduled for 23 September at Grace Vaughan House 227 Stubbs Terrace Shenton Park at 10am until 12 noon.

Should you be able to attend, please reply to the following e-mail-address: [admin@geneticsupportcouncil.org.au](mailto:admin@geneticsupportcouncil.org.au)

## **WACOSS Events**

### **FUND RAISER MOVIE: "About a Boy" for WA Deaf Society Inc**

Date: 4 September 2002

Time: 6.45pm

Place: Hoyts in the city

Cost: \$10 per ticket.

Roz from WA Deaf Society in her email to me says that they need lots of people to attend this film which is helping to raise funds for deaf education. Roz has requested that you put off seeing this film until then.

**Source:** WACOSS E-News 50 (19 August 2002)

### **Inaugural Art Exhibition - Citizen Advocacy Perth West Inc**

Citizen Advocacy - Perth West (Inc) is proud to announce its inaugural art exhibition featuring the work of artists with intellectual disability to be held 7-11 October 2002 during Citizen Advocacy Week in the foyer of QV1. At this point we are extending an invitation to people with intellectual disability, who are interested in expressing themselves through art, to submit their work for selection to our offices by 12 September 2002.

Entries must be submitted with Entry Form which can be obtained from Rosalind Lewis email [capw@smartchat.net.au](mailto:capw@smartchat.net.au)

Enquiries: Rosalind Lewis - Citizen Advocacy

Tel: 08 9322 5999

**Source:** WACOSS E-News 50 (19 August 2002)



## **Past Events**

The Australian Huntington Disease Association (Inc) WA in conjunction with the Genetic Support Council WA presented a forum on:

### ***Genetics, Insurance and Employment.***

Approximately 45 people attended the forum. Presenting at the forum were:

#### **Dr. Ian Walpole**

*Senior Consultant Clinical Geneticist  
with Genetic Services of WA*

Ian outlined the general best practice guidelines which enable access by and delivery of such genetic tests to the community. 'The expanding knowledge of the genetic basis of disease in humans opens extraordinary possibilities for new approaches to disease prevention and treatment.' However, as Ian explained, many such exciting developments realistically still remain in a research phase. The ready availability of community based gene tests for disease predisposition, offers great potential to strongly influence public health policy and priorities.

#### **Ms. Moira Rayner**

*Acting Commissioner, Equal  
Opportunities Commission*

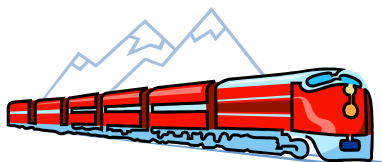
Moira spoke on genetic testing and discrimination. See her paper on our website under "Publications".

#### **Fran Mc Grath**

*Senior Social Worker and Co-ordinator  
of the Predictive Testing Programme at  
the Neuroscience Unit in Mount  
Claremont*

Fran gave an overview of some of the issues that have arisen in the area of genetics, predictive testing and the consequences for gene positive people in the area of insurance and employment.

## ***The 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.

To make confidential contact with anyone using *The Link Line*, or for further information regarding this service, please call Terry Keating at GSCWA.

### ***New Members are always welcome***

Are you or is your organisation already a member of the GSCWA? If not, just fill in an application form and send it to us. There is no registration fee and by joining you will ensure that you and your organisation are kept up to date with the Council's activities and benefit from services provided. **There are several categories of membership to enable you to choose the most appropriate for your organisation.** Application forms can be requested at the abovementioned address or downloaded from our website under section "Publications".

## **GSCWA Members**

### **FULL MEMBERS**

Acoustic Neuroma Association of Australia  
Alzheimer's Association of WA  
Angelman Syndrome Association  
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  
Epilepsy Association of WA  
Haemophilia Foundation WA Inc.  
Heart Kids WA  
Klinefelters Support Group  
Mucopolysaccharide & Related Diseases Society (MPS)  
Neurofibromatosis Association of WA.  
Parents of Children with Disabilities  
Short Statured People's Association WA Branch  
Spina Bifida Association of WA  
Thalassaemia Association of WA  
The Periodic Paralysis Society of Australia  
Trisomy and Related Disorders  
WA Tourette Syndrome Organisation (WATSO)

### **CORPORATE ASSOCIATE MEMBERS**

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Health Consumers Council WA  
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Professor Charles Watson, Curtin University  
Terry Keating, GSCWA

