

JULY 2002 EDITION

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

GSCWA First Annual General Meeting

The inaugural AGM of the Council was held at Grace Vaughan House in Shenton Park on the 20 May 2002.

The meeting elected the Council's first Board of Management.

GSCWA Office Bearers

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

Del Weston

Executive Officer
Australian Huntington's Disease Association WA Inc.

Carmel Wright

Client Services Coordinator
Spina Bifida Association of WA Inc.

Dr Peter O'Leary

Acting Director
Genomics Branch
Department of Health

New Members

FULL MEMBERS

Acoustic Neuroma Association of Australia
Alzheimer's Association of WA
Angelman Syndrome Association
Australian Huntington's Disease Association
Australian Tuberous Sclerosis Society Inc.
Coeliac Society of WA
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
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

Carers WA
Health Consumers Council WA
Genomics Branch, Dept. of Health

INDIVIDUAL ASSOCIATE MEMBERS

Professor Charles Watson, Curtin University
Terry Keating, GSCWA

Presentation to the Genetic Support Council Annual general meeting 20 May, 2002

**Clinical Associate Professor Carol Bower
Telethon Institute for Child Health Research**

Whilst looking through the Table of Contents of the Genetic Support Group Directory, I realized that many of the conditions listed were relevant *personally* to me, my family and friends. *Professionally*, I have always been aware that most of these conditions are individually rare, but collectively affect a large number of people, but it really hit home that it would be rare for any one person not to have some fairly close connection with at least one or two of the conditions represented. I guess this means that collectively, almost everyone in the community has some connection with this Council.

I also realized that, although I have had contact with several groups in the course of my work, to my chagrin, there were others listed with which I SHOULD have had contact but have not.

And all that led me to consider the role of the support group in relation to research and the role of the researcher in relation to support groups.

Role of the support group in relation to research

Briefly, the research process involves the following steps:

- Define the research question(s)
- Design the study
- Seek funding – can take time – only 30% successful each round, and only one round of applications each year
- Conduct the study
- Report the findings
- Take action on the findings - Not always the case – and lots of research comes up, not with answers so much as more questions to ask.
- Define the next research question(s)

Research question

How do we decide on the areas to research? We like generally to concentrate on problems that are common or burdensome, or both, we try and keep up to date with what other research has found, both in the published

literature and in discussion with colleagues around the world, and think about whether we in WA can do anything that would add knowledge to the area. Sadly, not often do we ask people or their families affected by the condition about what they would like done, or what their most important question is.

Design

Support groups can be of great assistance in designing studies, for example, advising on how to approach families sensitively, where to refer families who have questions.

Conduct

Support Group members may take part in studies, or assist in recruiting participants. Members of the Spina Bifida Association were very generous volunteers in several research projects we have conducted.

Report

It is important to report the findings of the research to Support Groups, as well as scientific journals, and Support Groups can assist in dissemination of the findings.

Action

Our research and studies overseas in the 1980s and 1990s found that the vitamin folate taken around the time of conception by the mother reduces the risk of spina bifida and related birth defects. We then embarked on a health promotion campaign to inform health professionals and the public, especially women of child-bearing age, about these findings. The Spina Bifida Association was incredibly valuable – designing and wording pamphlets, providing advice regarding the possible effect of this information on families with a child with spina bifida already, and also helping out with many media opportunities. We didn't always get it right, but I am ever so grateful to members of the SBA who let us know where we went wrong, and helped us to do it better.

These are specific ways in which Support Groups help in research – but there is a more general and even more important way. They can give researchers an understanding, insofar as that it is possible, of what it is like to have the condition and its effect on other members of the family. So, whilst we sit in our ivory towers with our heads in the clouds, you can help us to keep our feet rather more firmly on the ground.

Role of the researcher in relation to support groups

Whilst research is not the main aim of Support Groups or the Council, it is ONE of the aims. It may be that a Support Group wants some research done but do not have the expertise or resources – researchers may be able to help out.

Members of Support Groups may have their ideas on causes, prevention, or treatment, that researchers may be interested in, and perhaps address in their studies.

Researchers may be able to help Support Groups in evaluating the literature on the evidence for effectiveness, risks etc of, for example, a new treatment or diagnostic test. Researchers may be able to provide useful information that would help Support Groups in lobbying for more, better, or new services.

How to achieve mutual benefit?

Researchers and Support Groups need to seek each other out.

Researchers need to be mindful of the time commitments of members of Support Groups, especially if they are caring for a person with disability. Similarly, Support Groups need to consider the time frame for research – we may not be able to deliver results quickly.

Support Group members can serve on advisory bodies, management and ethics committees.

This can be very valuable for both parties in gaining further understanding of and respect for each other.

Support Groups may like to invite researchers to share in some of their activities.

Recently, a joint proposal, from the Institute for Child Health Research and the Department of Public Health at the University of WA, was submitted to the National Health and Medical Research Council for a Capacity Building Grant. One of the themes of the Grant was 'Community Participation in Population Health Research'. This proposed theme will include:

- training for PhD and postgraduate students in community partnership concepts
- consultation with consumer groups concerning priorities for health services research
- maintaining a consumer library and
- involving community and consumer groups in the dissemination of and response to research results in major new research developments such as population-based human genome research

The expected outcomes will be:

- Doctoral and masters graduates who will be literate about consumer and community participation in health research
- Increased participation of consumer and community groups in research priority setting & translation of results
- Improved research field performance with higher response rates and fewer complaints

Even if we thought collaboration between Support Groups and researchers was not important or necessary in the past, this position is no longer tenable. With the complete mapping of the human genome upon us, there is now the potential for all sorts of issues arising. I think the very best approach to dealing with them will require well-informed health professionals, well-informed policy makers and a well-informed community being involved in discussion and joint actions at all levels, and from as many perspectives as possible, if we are to avoid problems and take advantage of the benefits.

The Council is well-placed to be leader in this process – I hope you will take up the challenge, and I hope the research community can be a partner in it with you.

About GSCWA

The Genetic Support Council WA (Inc) is a newly formed organisation that will act as a peak body for genetic support groups in Western Australia, in particular those groups who have elected to become members of the Council. The need for this peak body to coordinate and enhance the effectiveness of community genetic support groups was identified in the Review of State Wide Delivery of Genetic Services in Western Australia, conducted in April/May 2000.

Following that review, a number of genetic support groups established a working committee to bring this to fruition.

They proposed the Genetic Support Council WA (Inc) fulfil the following roles:

- Promote awareness of genetic diseases in the community
- Encourage and support effective and efficient management and service delivery practices within genetic support groups
- Assist in the greater participation of consumers in policy, planning, research and service delivery across the genetic services field
- Develop and contribute to policies of common concern to genetic support groups
- Provide genetic support information, resources and referral services to individuals and genetic support groups
- Promote leadership and cooperation between non-government and community organisations within the genetic services field and
- Act as a mentor for the genetic support groups

The Genetic Support Council Western Australia (Inc) has established partnerships with numerous stakeholders. Some key partnerships include:

- Genetic support groups
- Department of Health Western Australia
- Lotteries Commission of Western Australia
- Western Institute for Self Help (Inc)
- Health Consumers' Council (Inc)

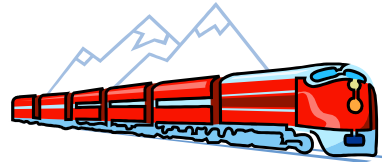
The Public Health Genomics Branch of the Department of Health as been responsible for allocating resources for the development of this initiative.

Lotteries Grant



The GSCWA acknowledges and thanks the Lotteries Commission for its generosity in providing a grant for information technology. This support will further enable the GSCWA to develop worthwhile services to individuals and genetic support groups.

The Link Line



Introducing *The Link Line* which will 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.

GSCWA has a new home

On the 25 June 2002 the GSCWA opens its offices at:

**Level 1, Oasis Lotteries House
37 Hampden Road
Nedlands WA 6009**

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.

Telephone: 08 9389 6722

Mobile: 0411 585 113

Email: admin@geneticsupportcouncil.org.au

The task of establishing the Council and setting up the office is well in hand. Work will commence at the end of July on developing our resource centre. It is hoped that the Resource Centre will be functioning at least in a basic sense, by the end of October 2002.

The Council appointed Anja Hermann to the position of Administrative Officer on the 10 June 2002. Anja has played a valuable role in assisting establish the Council's new office.

New Members

Attached is an application for membership. The Council is keen to obtain the widest possible input into its activities. 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.

Members News

Members are encouraged keep the GSCWA informed of new developments in their area and of any issue that they would like others in the community to know about. These can be included on your behalf in this newsletter.

Community Awareness project

One of the most common issues that has been raised with the Council by member groups and others, is lack of community awareness of genetic conditions and in particular the various support groups. Furthermore, the more rare a condition is and the smaller the support group, the more evident this becomes.

The GSCWA is considering the development of a poster that it hopes it could display in Doctors' surgeries throughout Western Australia. The Council will be canvassing this idea with the various member groups in the near future.

The intention is to draw attention to the GSCWA and its members who will be listed (with their consent) on the poster.

By providing a single telephone number to the GSCWA for individuals to ring, a referral service to the member groups listed can be provided by the GSCWA. The information provided by the GSCWA in these circumstances would be limited to whatever the support group member organisation had requested. It may for example be merely to pass on the contact details of the particular support group. It is not intended that the GSCWA would become an alternate source of support to individuals with a genetic condition or predisposition if there is an existing support group.

Any feedback or suggestions by member groups would be most welcome, please contact Terry Keating at the GSCWA.

GSCWA Web Site

Its official, the GSCWA has its own web site. Although it will no doubt undergo some changes over time the structure

is essentially set and some initial information has been imputed, including this newsletter.

Links to member genetic support groups have been listed and current and past newsletters added.

Opportunity for members and other associated groups to have news and upcoming events included is another feature of the web site.

Let the Council know if you have suggestions or require anything about your organisation displayed.

You can find us at:

<http://geneticsupportcouncil.org.au>

General

The council extends a warm invitation to members or interested individuals to visit us at Oasis Lotteries House here in Nedlands.

The frequency of newsletters is yet to undecided, however, future editions will include a member support group profile.

Coming events

Advertise here. Let us know what events are coming up in your organisation so we can let others know.

The GSCWA is in the process of joining a number of organisations that provide a range of significant information for not for profit organisations. It is intended that members will be kept informed of any information that may be of benefit to them. This should be particularly helpful for smaller support groups who do not normally have the resources to join the organisations.

We will be contacting all GSCWA member groups and other organisations who may have some association with this area in the near

future. The purpose of this contact will be to:

- update our contact records
- revise and reprint the Directory of Genetic Support Groups
- Obtain feedback from members as to which GSCWA services they may find of benefit to them

The Genetic Support Council WA and the Australian Huntington's Disease Association are conducting an education forum on

“Genetics, Employment, Insurance and Superannuation”

Wednesday, 21 August 2002 from 10.00 am to 12.00 noon

Panel members include

Moira Raynor, Commissioner, Equal Opportunities Commission
Terry Keating, Executive Director, Genetic Support Council WA
Brendon Durrant, Hammond Insurance Broking Pty Ltd
Fran McGrath, Senior Social Worker Predictive Testing, Neuroscience Unit
Dr. Ian Walpole, Consultant, Genetic Services of WA

Address: The Niche, cnr Aberdare Rd and Hospital Avenue, Nedlands.

Cost: \$10.00
(includes morning tea at **9.30** am)

Bookings by 16 August
to GSCWA – 9389 6722
or AHDA 9346 7599