

October 2002
EDITION 6

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 October 2002 edition of the Genetic Support Council Western Australia (Inc) newsletter.

Current Issues and matters of interest

HeartKids WA Inc

Proudly announces the release of Precious Hearts

The new Rose named to honour all Heart Children

The unique function of HeartKids WA is to provide support & hope to children and the families of children with congenital and/or acquired heart disorders. Sales of Precious Hearts will assist HeartKids WA continue to provide services to Western Australian heart kids, such as family camps, kids camps, quarterly newsletters, hospital support services, kids club activities and a resource centre at Princess Margaret Hospital for Children.

HeartKids WA have great pleasure in being associated with Bob Melville of Melville

Nurseries and English rose breeder, Colin Horner, in the release of their rose Precious Hearts. Colin Horner has kindly donated the rights for this new variety to HeartKids WA & Bob Melville has undertaken all propagation & distribution of the rose.

Precious Hearts is a unique & distinctive rose, having large clusters of single blooms. The blooms are cream with red edge, a moderate perfume & the variety will flower all season.

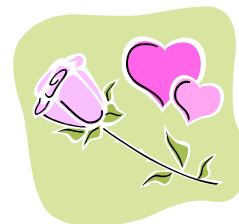
The growth habit of Precious Hearts is as a ground cover, but it also makes an ideal standard. As a ground cover it will grow to approximately 0.75m high with a spread of approximately 1m.

Precious Hearts is water wise & has a high level of resistance to all common rose diseases. It is ideally suited to Western Australian conditions.

Provisional PBR protection has been granted & the variety will be available from 23rd October 2002 through Melville Nurseries in Carmel, as both a ground cover & a standard.

The official morning tea launch will be hosted by Christina Morrisy.

The mornings proceedings will include auctioning the first Precious Hearts Rose, a 15th anniversary Swarovski crystal rose and a handmade quilt (made especially for this occasion), followed by a presentation to PMH Cardiology Dept and finishing with entertainment from heart kid Victoria Denn with her school choir from St Brigids, Lesmurdie.



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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:

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Anja Hermann, *Administrative Officer*

The GSCWA Board of Management

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Inc.

Carmel Wright

Client Services Coordinator
Spina Bifida Association of WA Inc.

Dr Peter O'Leary

Acting Director
Genomics Branch
Department of Health

Heart Kids continued:

A Story

.....**Denise & Phil Rigg**

On 19th May 1993 weighing 7.2 pounds, Stephen Jack Rigg entered the world. He was a normal beautiful bouncing baby with many of the predictable baby health issues. Stephen suffered from colic & croup.

It was because of the latter, we discovered Stephen was a heart kid. We had never suspected.

On the night of 20th June 1994, Stephen suffered his worst croup attack & stopped breathing. He was resuscitated by his Dad as we waited for the ambulance to arrive. To our horror, not only was Stephen an asthmatic who suffered from croup, but our 13 month old baby was diagnosed with a heart condition that needed a pace maker.

With the continued support of family, friends and the Heart Kids of WA, we all cope just that little bit better. Stephen has had many admissions & operations in PMH, the longest & no question the toughest was in 1999, when he stayed for 3 weeks after contracting viral meningitis & encephalitis, due to a complication with chickenpox.

Stephen's future was uncertain. If he survived his ordeal, we didn't know if he would ever walk, talk or hear again. We left hospital with a very weak but determined little boy. His very strong & gutsy nature makes him fight & fight and overcome challenges life has handed him. To his eternal credit, he never gives up.

Now nine, Stephen is our inspiration & strength. He is unconditionally supported & loved by us his parents & especially his hero in life, his 12 year old brother Benjamin.



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.

What do genes have to do with me?

(As stated by Justice Michael Kirby)

"Perhaps from the perspective of history, the most important scientific breakthrough of this century may be seen in time, to be neither nuclear fission, nor interplanetary flight, nor even informatics, but the fundamental building and basal molecular biology which permits the human species to look into itself and find, at last, the basic building blocks of human and other life. Who knows where this discovery will lead the imaginative human mind? Lawyers, and indeed citizens everywhere, should begin thinking about the issue. In its resolution may lie the very future of our species."

Ref E-Law; Permission by Mathew Stulic

published in the newsletter of the Genetic Support Network of Victoria,
<http://www.gsnv.org.au>

International Perspectives:

Universal Declaration on the Human Genome and Human Rights, 1997 – United Nations

Article 13

“The responsibilities inherent in the activities of researchers, including meticulousness, caution, intellectual honesty and integrity in carrying out their research as well as in the presentation and utilization of their findings, should be the subject of particular attention in the framework of research on the human genome, because of its ethical and social implications. Public and private science policy-makers also have particular responsibilities in this respect.”

http://www.unesco.org/human_rights/hrbc.htm

published in the newsletter of the Genetic Support Network of Victoria,
<http://www.gsnv.org.au>

If you are looking for fund raising opportunities, we may be able to provide you with some further information.

Coming Events

Monday December 2nd
until Tuesday December 3rd

NEUROLOGICAL EXPO – PUBLIC LECTURES – LIMITED PLACES

CHAIR: Sarah Dunlop & Giles Plant, WAIMR,
University of Western Australia
Conference Room, Centre for Neurological Support,
Niche house, QE II medical centre
11 Aberdare Road, Nedlands, WA 6009

Tuesday December 3rd
until Friday December 6th

3RD ASIA PACIFIC SYMPOSIUM ON NEURAL REGENERATION **SHERATON PERTH HOTEL**

Tuesday December 3rd

WELCOME RECEPTION
The Perth Mint

Wednesday December 3rd

Stem Cells

Thursday December 5th

Spinal Cord Injury & Repair
In Association with The Neurotrauma Research Program,
Road Safety Council, WA

Friday December 6th

Spinal Cord Injury DISCUSSION workshop – Limited Places

Source:

<http://neuro.zoology.uwa.edu.au/sympprogram.htm> - please check this website also for detailed program

More events:

October 2002

01.10. – 31.10.2002

Lupus Awareness Month

The Lupus Group of WA
for more information, call 9224 3144

20.10. – 26.10.2002

National Carers Week

Carers WA
for more information, call 9424 5210

About our members

In our October Gene Advocate we profiled the **Periodic Paralysis Society Of Australia**.

Periodic Paralysis is a generic name given to a family of rare genetic disorders causing temporary episodes of muscle weakness or paralysis. Episodes can be brief or last for several days depending on the type of periodic paralysis. Symptoms usually manifest in first or second decade but some people may not be aware of any abnormality till later in life.

Periodic Paralysis has an autosomal dominant pattern of inheritance but mutation can occur spontaneously. It is found in most races and both sexes.

Periodic paralysis and myotonia congenita are caused by ion channel dysfunction in muscle membranes and are known as channelopathies. There is a disruption of the chemo-electrical functioning of the muscle cell.

Many of the mutations have only been identified in the last decade and it is likely that more mutations will be located in the future. While those who are directly involved in the research are familiar with the current concepts, much of the last decade of insight has not filtered out to the general medical community. Genetic researchers are still in the early stages of matching specific clinical symptoms to the different mutations.

Periodic Paralysis Society Of Australia

www.e-wire.net.au/~eb_grtyl

The Periodic Paralysis Society of Australia (PPSA) is a non-profit organisation. We provide accurate and up to date information about periodic paralysis and associated conditions to sufferers, their families, health care professionals, and the community. We provide practical support for the management and treatment of these diseases. By working together we can all contribute to improving the quality of life of people with periodic paralysis and associated conditions. These conditions include:

- Hypokalemic Periodic Paralysis
- Thyrotoxic Periodic Paralysis
- Hyperkalemic Periodic Paralysis
- Normokalemic Periodic Paralysis
- Andersen's Syndrome
- Paramyotonia Congenita
- Myotonia Congenita

Contact:

Sue Fraser: 9248 3252
Gillian Tyler: 9297 1185
Bruce Connor: 9322 4441
Email: grtyler@ellenbrook.net

For on-line general and detailed information about Periodic Paralysis see:

Periodic Paralysis Association at

<http://www.periodicparalysis.org>

Periodic Paralysis News Desk

<http://www.hkpp.org>

Neuromuscular Disease Center

<http://www.neuro.wustl.edu/neuromuscular/mother/chan.html>

eMedicine—Periodic Paralysis

<http://www.emedicine.com/neuro/topic308.htm>

Internet Handbook of Neurology

<http://www.neuropat.dote.hu/nmd.htm>

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.

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 Ehler Danlos (connective tissue disorders) in Western Australia. A family living in the southwest region of Western Australia is seeking linkage with other people and families living with this condition.

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

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.

Outside WA

There are two organisations, one in New South Wales and the other one in Victoria, who are quite similar to the GSCWA.

We would like to publish their contact details, in case you need them some day.

They are:

Dianne Petrie
Association of Genetic Support of
Australasia (AGSA)
66 Albion Street,
Surry Hills, **NSW** 2010

e-mail: agsa@ozemail.com.au
web: www.agsa-geneticsupport.org.au

and

Eilis Hughes
Co-ordinator
Victorian Clinical Genetics Services
10th Floor Royal Children's Hospital
Flemington Road
Parkville, VIC 3052
e-mail: gsvn@murdoch.rch.unimelb.edu.au
web: www.gsvn.org.au

Interesting Websites



KidNeeds.com is a worldwide resource that provides children with special needs, families and other caregivers with access to comprehensive information and resources. KidNeeds.com is affiliated with St. Mary's Healthcare System for Children in New York

<http://www.kidneeds.com/>

Child Dreams This site is dedicated to children whose lives are made difficult because they have some form of developmental disorder - whether these disorders are obvious or subtle. The information provided is for families, health and education professionals, and any others involved.

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

Department of Education: Government of Western Australia. This site contains many resources for use with students at educational risk.

<http://www.eddept.wa.edu.au/saer/resource/index.htm>

MEDLINEplus is designed to help you find appropriate, authoritative health information. This will access information produced by the National Library of Medicine and the National Institutes of Health in the USA.

- Special features
 - The site contains special features such as graphics/diagrams, glossary, or other unique information.
 - The content of the site is accessible to persons with disabilities.

<http://medlineplus.gov/>

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.
Celiac Society of WA
Cushings Disease Support Group
Cystic Fibrosis WA
Dyslexia SPELD Foundation WA Inc
Epilepsy Association of WA
Haemophilia Foundation WA Inc.
Heart Kids WA
Klinefelters Support Group
Learning and Attention Disorders Society of WA (LADS)
Mucopolysaccharide & Related Diseases Society (MPS)
Neurofibromatosis Association of WA.
Parents of Children with Disabilities
Short Statured People's Association WA Branch
SIDS and Kids Western Australia
Spina Bifida Association of WA
Thalassaemia Association of WA
The Periodic Paralysis Society of Australia
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

INDIVIDUAL ASSOCIATE MEMBERS

Professor Charles Watson, Curtin University
Terry Keating, GSCWA

