

GSNV September Update

Decision Making Processes for Families Affected by a Genetic Condition

This two-part seminar will be held on Tuesday 18th and Tuesday 25th of September, from 6pm-9pm. Sessions will cover Medical Decision-Making, Social Decision-Making, Empowerment and Decision-Making Techniques. Cost will be \$5 for non-members, and free for members. More information is included with this update.

2001/2002 Committee

We're very pleased to introduce the new GSNV Committee of Management for 2001/2002:

President:	Matt Doyle	
Co-Vice-Presidents:	Dani Blanden	
	Julian Pearce	CAH Support Group Australia
Treasurer:	Tony Briffa	AIS Support Group Australia
Secretary:	Tanya Files	Unique in Australia
Genetics Advisory Group Rep:	Dani Blanden	
Genetics Advisory Group Observers:	Andie Hider	AIS Support Group Australia
	Helen Georgiou	Thalassaemia Society of Victoria
General Committee Members:	Debbie Dalton	
	Panos Ioannou	Thalassaemia Society of Victoria
	Tony McDonald	Down Syndrome Association Victoria
	Sylvia Metcalfe	Murdoch Childrens Research Institute
	Peter Phillips	Australian Leukodystrophy Support Group
	Margaret Sahhar	Genetic Health Services Victoria
	Sandra Timbrell	
	Sue White	Genetic Health Services Victoria
	Natalie Wiggins	Metabolic Dietary Disorders Association

If there are issues that you'd like the GSNV Committee to consider, please contact one of our committee members, or telephone Eilís or Caroline in the office (03) 8341-6315.

Promoting the Positive – Early Childhood Intervention Conference

Early Childhood Intervention Australia invites you to its 17th Annual Conference, to be held at The Heath Function Centre, Caulfield Racecourse, on 14-15 September. The theme for the conference is "promoting the positive". This is an important conference for parents, professionals, academics, policy makers and all those involved with young children with developmental problems and their families. Please contact the conference administrator Jenny Dale on ecia@cryptic.rch.unimelb.edu.au or (03) 9345-7903.

Charities Definition Enquiry

The federal Treasurer, Peter Costello, released the report from the inquiry into the definition of a charity last week. We hope that the recommendations will be accepted and that the inconsistencies that currently exist, and which affect some of our member groups, will be removed. More information about this inquiry can be found at www.cdi.gov.au.

CFC Family Network

The cardio facio cutaneous (CFC) syndrome Family Network has recently expanded from the USA to include Australian families. The network is looking for any families affected by this very rare genetic condition who would like to be in contact with other families. Contact Judy, the Australian co-ordinator, by phone on (08) 8988-6065 or by email on kpdeer@dove.net.au. The website can be found at www.cfcsyndrome.org.

9th National MPS Conference – “Sharing Our Story”

MPS Australia's 2002 Conference to be held in Canberra in April provides an ideal opportunity to meet with professionals and families to disseminate the latest in research and medical management of MPS and other lysosomal storage disorders. It will be held from Friday 12 April to Sunday 14 April. For more information please visit www.mpsociety.org.au, or email mps_aust@compassnet.com.au, or telephone (02) 9476-8411.

www.myDr.com.au

As well as being a resource for medical information, the myDr website also lets people find out what you'd like them to know about your support group or organisation. Currently it offers a database of support groups, but they now also offer you a free website. If you already have a website they will provide a link to it. The GSNV is already listed there, as are several of our member groups. Make sure your group is there too, as this is a great way of increasing public awareness of your group.

Angelman Syndrome Conference

The Angelman Syndrome Association will be holding its 5th National Conference on Angelman Syndrome on Saturday 29 September. It will be held at The Southern Cross Club in Canberra. Professional and parent speakers will present sessions on behaviour management, education, communication and living with Angelman children and adults. All enquiries to Kerry O'Kane on (02) 6291-7693 or bradkane@bigpond.com.

Are you STILL getting this by snail mail?

Please help us to protect valuable resources by allowing us to email this monthly bulletin to you. If you would like to receive this by email, please drop us a line at gsnv@murdoch.rch.unimelb.edu.au and we will add you to our email list.

Next GSNV Committee Meeting

The next meeting will be held at 6pm on Wednesday 19 September, in the conference rooms on the 10th floor of the Royal Children's Hospital. All members and other interested parties are welcome to attend.

For more information on anything you've read here, please contact Eilís or Caroline in the GSNV office on (03) 8341-6315.