

GSNV April Update

GSNV Conference

Included with this update is the program for our conference. As you can see, it is an interesting and exciting program – and it's not too late to register to attend! Call us on (03) 8341-6315 or email us on gsvn@murdoch.rch.unimelb.edu.au now to register. Don't miss this opportunity to meet others in the same boat and to have your say on the issues that affect you, your family and your organisation.

GSNV News

We're very pleased to announce that we have a new editor for our quarterly newsletter. Stephanie Herbert-Wall has taken on this task and we are delighted! You can contact Stephanie on gsvnnews@hotmail.com, and she says *"I would love for people to write to this email address with suggestions on what they want out of the newsletter (more personal stories, more scientific news, fewer features, etc.). It would be great to get some reader feedback in the beginning to work with."* So if you have any great ideas, or have a story that would interest our readers, drop Stephanie a line! (If you don't have email, you can contact Stephanie via the GSNV office on (03) 8341-6315).

"Charity Mail" from Australia Post

We apologise for any confusion caused by the Charity Mail announcement in our March Update. This service has not yet been launched, but we have been informed that full information on the service will be released soon after Easter, and application forms and brochures will be available by mid-April. The GSNV will have more information then.

How to Please the Tax Office

The GSNV has worked with the Freehills law firm to create three fact sheets for groups to help you to obtain deductible gift recipient status and income tax exemption from the ATO. This is quite a process and has proved difficult for some of our groups, and we hope that these fact sheets will help groups to avoid the difficulties other groups have faced. Please contact us at the GSNV office to obtain copies.

Get Ready to Dance the Night Away!

The Thalassaemia Society of Victoria is holding their 2002 Dinner Dance on Friday 10 May 2002 at 7pm, at The Reggio Calabria Club, L'unica Reception. 476 Brunswick Road, West Brunswick. 3 course meal with beer, wine and soft-drinks provided. Dress: Smart-casual
Tickets: Adults \$45- Children \$25. Signed & framed Essendon, Carlton & Collingwood 2002 football jerseys to be auctioned. Contact the Thalassaemia Centre on (03) 9888 2211 or thal.office@bigpond.com.

Open Garden for MPS

The Kelynya Park Alpaca Stud will be hosting an Open Garden Day on Sunday 21 April, in aid of the Mucopolysaccharide & Related Diseases Society Australia. You can enjoy over 350 roses, with cottage and native garden, as well as devonshire tea, sausage sizzle, raffles and plant sales. 305 Pakenham Road, Pakenham (Melway 315 D11) from 10am till late. Please phone Wendy Boon on (03) 5943-2407 for more information.

Haemophilia Awareness Week

14-20 April is Haemophilia Awareness Week. Please visit <http://home.vicnet.net.au/~haemvic/> to find out all the latest news on haemophilia.

Ain't Misbehavin'

The Australasian CHARGE Association will be holding their 5th Australasian conference on 5-7 July at the Hotel Y Cato Conference Centre in Melbourne. Experts in medical, educational and behavioural experts in CHARGE syndrome will be sharing the latest information. For more information about CHARGE, visit www.austcharge.com.au. For more information about the conference, please call Rob Last on (03) 5983-2675.

Parent Information Sessions – Child Development

The Department of Child Development and Rehabilitation at the Royal Children's Hospital are putting on a series of parent information sessions in May.

- 1st May: Developmental Delay: What does it mean? What can be done to help?
- 8th May: Cognitive Assessments: How, when and why are they done?
- 15th May: Moving on from Preschool to School.
- 22nd May: Developmental Delay: A session for professionals working with children with developmental delay.
- 29th May: Cerebral Palsy: Update of causes and management.

Time: 7.30 – 9.30pm. Cost \$5.50 per head per session, or \$8.80 per couple. Please phone (03) 9345-5898 for more information or to register. Numbers are limited.

NIDKIDS - Colonic Dysmotility Symposium

A symposium for families of children with severe chronic constipation is being held at the Royal Children's Hospital on Saturday 20 April, hosted by NIDKIDS. There is a full day designed mainly for health professionals and those who are interested in the scientific side of neuronal intestinal dysplasia. Or you may choose to just attend the afternoon session which is orientated towards parents and lay people. This is also an opportunity to invite people who play an important part in your child's life, such as relatives, medical practitioners, classroom teachers and maternal and child health nurses. For more information please contact Helen on helen@nidkids.org.au or (03) 9528-1118.

Creative Memories

Your priceless photographs are worth a thousand words. Yet for all their importance we shove them in drawers and shoe-boxes or worse, store them in albums that chemically destroy the very image they were meant to protect. Creative Memories help you to create beautiful albums that protect your photos and enhance your memories through decorations and captions. One of our members, Michele, invites you to come to an introductory workshop where we will learn how to start one of these gorgeous albums – we're going to make one for the GSNV! Please call us at the office if you'd like to join in at this workshop – it's a great idea for your family or for your group.

Sick of Pink Paper?

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 17 April**, in the conference rooms on the 10th floor of the Royal Children's Hospital. All members and other interested people 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.