

# GSNV July Update

## **Design Your Own Website**

Get in quick to register for our Design Your Own Website workshop – to be held this Sunday (8 July, 1pm-5pm) with follow-up sessions on the following two Wednesdays (11 and 18 July, 6.30pm-8.30pm). This is a totally hands-on experience, where you'll end up with your very own website for yourself, your family or your group. This seminar is free for members, and just \$5 for non-members. If you're interested in joining us, call the office on (03) 8341-6315.

Check out the Krelle Family website made at our previous workshop:

<http://murdoch.rch.unimelb.edu.au/gsnv/krelle/index.html>.

## **Decision Making Processes for Families Affected by a Genetic Condition**

This two-part seminar will be held on Tuesday 17 and Tuesday 24 July, from 6.30pm to 8.30pm, here on the 10<sup>th</sup> floor of the Royal Children's Hospital. 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. Call us now to find out more, or to register as a participant.

## **GSNV AGM**

The Genetic Support Network of Victoria Annual General Meeting will be held on Saturday 4 August, from 10am to 12 noon, followed by a light lunch. Guest speaker Dr MaryAnne Aitken, from the Education Unit of the Murdoch Childrens Research Institute, will answer the question on everyone's lips:

**“What *IS* the Human Genome Project?  
(And what's it got to do with me?)”**

Your invitation for this meeting will arrive soon, but please pencil it into your diary now.

## **MDDA Conference**

The Metabolic Dietary Disorders Association is hosting a national conference on Saturday 28 July. Speakers include Dr Michael Wooldridge, Federal Health Minister, and Dr Susan Waisbren, a psychologist and renowned speaker from the Children's Hospital Boston, USA. Please contact the MDDA on (03) 9850-7484 or (03) 9728-5510 for more information.

## **Journey from Diagnosis**

The journey from diagnosis is one for which it can be difficult to prepare, and which may take unexpected turns. We will be holding a three-part seminar in August, on Thursdays 9, 16 and 23 to discuss some of the milestones on this journey. More information on this will be mailed to you during July. For enquiries please call the GSNV office on (03) 8341-6315.

## **Genetic Alliance**

The GSNV have recently become members of the Genetic Alliance, which is an international coalition representing more than 300 consumer and health professional organisations with millions of members - all working together to promote healthy lives for everyone impacted by genetics. We look forward to building strong alliances with groups similar to the GSNV internationally. You can visit the website at <http://www.geneticalliance.org>, and we will pass on items of interest from the regular newsletter, Alliance Alert.

## **Membership Fees**

Thank you to everyone who has recently joined or renewed their memberships! A reminder to all members that membership fees are due annually, and your membership may have expired. To assist administration, all fees will become due at the end of June each year, starting from this year. (Previously they became due on the anniversary of your joining, regardless of the month.) Any memberships which are paid from now will remain current until the end of June 2002.

Membership fees are:

- \$22 Groups (all members of your group are entitled to GSNV membership benefits)
- \$22 Family/Individual
- \$22 Professional/Service Provider
- \$11 Concession

## **GSNV Special Projects Grants**

The recipients of the Special Projects Grants have been decided, and all applicants will be informed of the result of their application shortly. Thank you to everyone who submitted an application – there is certainly plenty of exciting activity going on among our member support groups, not all of which we are able to fund at this time. We do hope to be able to offer financial support in the form of grants on a recurring basis – watch this space for future opportunities!

## **Could Your Group Use \$15,000?**

The National Bank invites you to participate in the National CommunityLink Volunteer Awards for 2001. There are awards of up to \$15,000 for community programs run largely by volunteers, and nominations close 27 July. Pick up a brochure from a National Bank branch, or contact us on (03) 8341-6315 and we'll send you a copy.

## **Health Privacy Guidelines**

The Federal Privacy Commissioner, Malcolm Crompton, invites you to comment on the draft Health Privacy Guidelines, before 20 July. The draft Health Privacy Guidelines complement the National Privacy Principle Guidelines, but focus on specific issues relating to the handling of personal health information within the private health sector. These draft guidelines reflect the direction of the National Privacy Principles in seeking to ensure greater consumer involvement and choice in decisions about the handling and protection of their health information. These guidelines can be found at <http://www.privacy.gov.au/rfc>, or contact us in the GSNV office to have a copy sent to you.

## **Save Time! Save Money! Save Trees!**

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](mailto: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 18 July**, in the conference rooms on the 10<sup>th</sup> floor of the Royal Children's Hospital. All members 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.**