

GSNV January Update

It's your GSNV!

Last month you received a survey asking about the GSNV's activities, and how we can best meet your needs, keeping in mind our vision of *Overcoming Genetic Challenges*. Now that the festive season is over, could you please take the time to read it, respond, and mail it back to us so that we can plan the GSNV activities for 2002. If you've misplaced your copy amongst all your Christmas cards, contact us and we'll send you a new one.

GSNV Conference

The GSNV Conference has been set for Friday 3rd and Saturday 4th of May. Please mark these dates in your diary. An invitation to participate will arrive in your mailbox soon. Here's what you can look forward to at the conference:

Day One - Ever wondered who is else is in the GSNV? Friday's program will give all our member groups the opportunity to learn about each other, through short presentations outlining your work.

Day Two - There are many issues facing us in our common vision of *overcoming genetic challenges*, and we will use Saturday to identify and discuss those issues.

Display - Throughout the two days there will be an expo for all our members to display information and other material.

Dinner - After a busy two-day program we'll all be ready to unwind and talk about things other than genetics! We will be having a conference dinner on the Saturday night, with surprise entertainment.

Your Privacy: Genetic Health Policy

Genetic Health Services Victoria is the organisation that provides genetic health services such as genetic testing and genetic counselling. Genetic Health is committed to providing quality health care. They are also committed to protecting client privacy and confidentiality. Genetic Health has developed policies for the protection of client privacy in compliance with privacy legislation. These policies encompass:

- That they need your consent to collect information about you;
- Why they need to collect your information;
- How your information will be used by them, and to whom they may need to disclose it;
- That you may request access to the information they hold about you. They are equally committed to protecting the confidentiality of other family members who may come to see them for genetic counselling;
- That you may discuss any concerns about the way Genetic Health manages your information.

Further information on these policies is available. Ask for a copy of their client privacy policy pamphlet. Contact the Genetic Health Services Quality Officer Robin Forbes on (03) 8341-6278.

Accessible Housing

The Special Needs Accessible Housing project was set up by Geoff Buck to assist people with disabilities in finding houses for sale that have already been modified or built specifically for accessibility. If you would like more information, please contact Geoff Buck on 0418 306 588 or Sarah McFarlane on 0408 807 782, or visit their website at www.accesshousing.com.

Wanted – People with Arthrogryposis

Arthrogryposis is a medical condition that you can be born with. It can be as minor as just affecting wrists or you can get the full box & dice, where it affects all your limbs (like I have.) Don't get depressed, doctors tell those of us who have arthrogryposis, that we will live until we are about 164 (joke). On the 2nd of March 2002 a friend (who also has arthro) and I, are organising a * FIRST EVER * in Australia "Adults with Arthrogryposis lunch in Melbourne". This informal lunch is all about an opportunity to network with other adults with arthrogryposis. We hope that by using 'word of mouth', email and support agencies that we can make contact with other adults with arthrogryposis living in Australia. If you're interested, please contact me for more details. John McKenna - 0419 8 777 12 or john.mckenna@team.telstra.com

COSHG Directory

The Collective of Self Help Groups are currently updating their Directory of Self-Help and Social Action Groups. Please make sure your group is listed, by sending your details to COSHG at PO Box 251, Brunswick East 3057, or emailing coshgmelb@yahoo.com.au. It costs nothing to be listed in the COSHG Directory, and copies of the directory can be purchased for around \$34. This is COSHG's only source of income, so please consider supporting them.

COSHG Workshop

COSHG are planning a short workshop for people who applying for the DHS Health Self Help or Disability Self Help Grants in February. There will be a speaker from DHS. The workshop will probably be held on a weekday at COSHG in Carlton and go for one or two hours. COSHG will not have much time to organise this workshop, so contact them now on (03) 9349-2301 or coshg@infoxchange.net.au if you would like to register your interest.

HACC: Home And Community Care / Holistic And Creative Choices

The national Home and Community Care Conference will challenge delegates in their thinking by providing a dynamic forum to discuss policies, strategies, programs and needs, facilitate networking opportunities and information exchange and encourage debate about topical issues. The Conference aims to:

1. Raise awareness of the whole life of a person
2. Explore new ways of tailoring services to individuals.
3. Encourage the empowerment of consumers to influence decisions that affect their lives.

Who should attend?

Older people; People with disabilities; Carers / Family members; Service Providers; Health professionals and GP's; Administrators and policy makers; Funders; Academics and researchers. For more information contact the Department of Veteran's Affairs on (08) 8379 8222, or visit their website at <http://www.plevin.on.net/HACC2002/>.

Next GSNV Meeting

The next meeting will be held at 6pm on **Wednesday 16 January**, in the conference rooms in 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.