

GSNV August Update

GSNV AGM

Don't forget 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?)"**

GSNV Committee

We have received fewer nominations for the GSNV committee than there are places, so we will still be accepting nominations at the AGM on Saturday. Please consider making a contribution to the GSNV by joining the committee. Proxy nominations can be arranged. Contact Caroline or Eilís in the office on (03) 8341-6315 if you'd like to discuss it further.

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. To register please call the GSNV office on (03) 8341-6315.

Decision Making Processes for Families Affected by a Genetic Condition

This two-part seminar has been postponed from July to September. The new dates for it are 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. Call us now to find out more, or to register as a participant.

Gene Patenting

The topic of gene patenting and the legal issues surrounding it were mentioned at a recent GSNV meeting. Margaret Sahhar, Genetic Health's Senior Social Worker and GSNV Committee Member, is a member of the Ethics and Social Issues committee of the Human Genetics Society of Australasia (HGSA), which is the professional body for scientists and clinicians working in the field of genetics. Margaret has pointed out that the HGSA has recently published a position paper on gene patenting, which can be accessed at <http://www.hgsa.com.au/policy/patgen.html>. Incidentally, the HGSA held its annual conference last week, which Caroline attended on behalf of the GSNV. A full report on this conference will be published soon.

Heartkids AGM

Heartkids was formed in 1990 by a group of parents who have children with heart problems. The group offers non-medical support and understanding to other families who have had a child diagnosed with a congenital or acquired heart defect. The group comprises families, professionals, and others interested in the care of children with heart conditions. The Heartkids AGM will be held on Saturday 11 August at 6.30pm at the Royal Children's Hospital. A guest speaker will speak on the topic of "Emotional and Psychological Outcomes Following Cardiac Surgery in Childhood." For more information or to RSVP email heartkids@hotmail.net.au or telephone Alison on 5782-0287.

Leukodystrophy Conference

The Australian Leukodystrophy Support Group (ALDS) is pleased to present the first ever national event on leukodystrophy. This two-day conference is a "must-go" opportunity for those affected by and those who want to know more about the range of inherited, neurologically progressive metabolic disorders known as leukodystrophy. The conference is aimed at interested health professionals and of course the families and individuals who live with this disorder. It will be held at the Royal Children's Hospital on Friday 17th & Saturday 18th of August. For more information or to register, please telephone (03) 9584-7070.

Fourth Australian & New Zealand Cystic Fibrosis Conference

Sheraton Brisbane Hotel & Towers, 23-25 August 2001. The conference aims to provide a forum to exchange information on the latest developments in research and treatment of CF. International presenters include speakers from the UK, the USA, Denmark and Canada. For further details, contact the Conference Secretariat on Phone (02) 9878-5250 or email general@cysticfibrosisaustralia.org.au

Dialysis and Transplant Association (DATA) AGM

Did you know that the average waiting time for a kidney transplant in Australia is about 5 years, with a lot of people waiting more than 8 years.

The Annual General Meeting for the Dialysis and Transplant Association of Victoria is being held on Sunday 26 August at 2pm in the 10th Floor Conference Rooms at the Royal Children's Hospital. For more information or to RSVP please telephone (03) 9894-0377.

Short Statured People of Australia AGM

It must be the time of year for AGMs! The SSPA's AGM will be held on Sunday 2 September at 2pm in the 10th Floor Conference Rooms at the Royal Children's Hospital. Guest speaker will be Dr Tom Shakespeare, from the UK. For more information please telephone (03) 9580-8107.

The Chromosome 18 Registry and Research Society Conference

The Chromosome 18 Registry & Research Society is a lay advocacy organisation composed primarily of the parents of individuals with one of the chromosome 18 abnormalities. They are also proud to count among their members affected individuals, extended family members and professionals. A conference for families and professionals will be held on Saturday 22nd and Sunday 23rd September at the Cronulla Sharks Leagues Club, Cronulla, New South Wales. If you are interested or would like to know more, please telephone Marlene on (02) 9580-5707.

Australian Volunteer Search

www.volunteersearch.gov.au - Whether you are an individual looking for volunteer work or a volunteer organisation seeking suitable volunteers, this new website should be able to help you. It is Australia's biggest online volunteer site and is free of charge.

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 15 August**, in the conference rooms on the 10th 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.