

# GSNV November Update 2002

## **Celebration**

Congratulations to long time GSNV supporter and founding committee member, Tony McDonald on her inaugural Life Membership to the Down Syndrome Association of Victoria. A celebratory dinner was held in her honour to mark the 24 years of service Tony has given to the DSAV.

## **GSNV Rejoices International Day of People With A Disability**

The GSNV will be celebrating IDPWD with a kids activity day in the foyer of the Royal Children's Hospital on December 3. Children will be able to make fridge magnets, badges and laminated pictures. All welcome, activities start from 9.30 and will run through the day, come along and help make the day a success. For more info call the GSNV office on (03) 8341 6315 or for more info on IDPWD hit the web at

[www.nican.com.au](http://www.nican.com.au)

## **DHS Self Help Funding Program 2002 - 03**

The Department of Human Services is offering small non-recurrent operating grants for self help groups which support people with a disability or chronic illness. To be eligible the group must be a non profit making group which is controlled by its members, has an ongoing membership and is not eligible to apply for other government grants.

Applications will close early December and groups will be advised of the outcomes in February 2003. More information available from the DHS web site from November 9

<http://www.dhs.vic.gov.au/selfhelp>

## **Self Help Funding Workshop - COSHG**

The Collective of Self Help Groups will be holding a short workshop for people who are considering applying for DHS Self Help Grants. Very useful for the first time applicant or if you would just like to brush up on your application skills. Bernice Murphy from the DHS will be speaking and available to answer your questions.

### **COSHG Self Help Funding Workshop**

Venue: COSHG Office 22 Pitt St Carlton

Cost: \$2

RSVP: to COSHG on (03) 9349 2301 or email [coshgmelb@yahoo.com.au](mailto:coshgmelb@yahoo.com.au)

## **Autism Support Groups**

We have recently received a Directory of Victorian Autism Support groups, compiled by Cristina Isaac from the Asperger's Syndrome Support Network. There are a number of local support groups around Victoria for parents of children with autism spectrum disorders and one for adults with an autistic disorder. Call GSNV if you need information.

## **Turner's Syndrome AGM**

The Victorian Turner's Syndrome Association will be holding its Annual General Meeting on November 28. The meeting will be held in the Conference Room on the 10<sup>th</sup> floor,

Royal Children's Hospital starting at 7.30pm. Guest Speaker Dr Janet Duke on the role of Hormone Replacement Therapy and TS in light of recent controversy.

### **New Neuro-fibroma-tosis Support Group In Melbourne**

As a result of numerous enquires for getting together with others who have NF in Melbourne, the Neuro-fibroma-tosis Association of Australia (NFAA) is attempting to get a support group established. The only way to feasibly organise this from Sydney is to set a date and time and see who turns up! So if you have NF or are the parent of someone with NF please come along – it should be a great day.

#### **NF Support Group Meeting**

**Time:** 10.00am to 2.00pm Sunday December 1

**Venue:** Parliament Gardens, State Parliament House

BYO Picnic BBQ facilities are available and bring a yellow balloon so we can all find each other!

**Enquiries:** Helen on (03) 9338 4661

(The day will be postponed in the event of wet weather)

### **Do You Know Of Cutis Laxa?**

Cutis Laxa is a rare genetic disorder of the connective tissue where the skin is loose and baggy. GSNV recently received correspondence from "Cutis Laxa Internationale" the French based international support group for the condition. Chair and Co-Founder, Marie-Claude Boiteux is seeking Australians with the condition. If you have been diagnosed with this condition or know of someone who has Cutis Laxa you can contact Marie-Claude Boiteux by email [mcjlboiteux@aol.com](mailto:mcjlboiteux@aol.com)

### **2002 UMMS Lecture – Thursday November 14 – 7.15pm**

The Human Genome Project, 'Medical Miracles, Ethical Dilemmas', presented by the Director of the Murdoch Children's Research Institute, Professor Bob Williamson and Prof David Danks Professor of Medical Genetics, University of Melbourne. The lecture will be held in the Sunderland Lecture Theatre, Ground Floor, Medical Building, The University of Melbourne, corner Grattan St and Royal Parade, Parkville. RSVP on (03) 8344 5888 or by email [gael@unimelb.edu.au](mailto:gael@unimelb.edu.au)

### **Symposium – Breaking The Code**

The Centre of Law and Genetics presents 'Breaking The Code' a symposium on the ethical and legal implications of the increasing accessibility of genetic technologies. The symposium will be held at the Murdoch Children's Research Institute and the Walter and Eliza Hall Institute on November 28 and 29.

Contributors will seek to address the question 'In breaking the gene code what other codes have been broken?' Specifically addressing issues of:

- reading genetic information,
- use of the code: property and access issues, and
- reforming the code: setting the new ethical boundaries.

For further information or to register visit the web site at

<http://www.lawgenecentre.org/symposium2002-10-29>

**For more information on anything you've read here, please contact Eilís or Emma in the GSNV office on (03) 8341-6315 email [info@gsnv.org.au](mailto:info@gsnv.org.au)**