

GSNV UPDATE

July 2004

GSNV NEWS

GSNV 5th Birthday Celebration

We look forward to sharing our 5th birthday with all our members and supporters on Sunday the 1st of August. Let us know ASAP if you can come. If you haven't received an invitation and want to know more, please call us here at the office on 8341 6315. We are accepting nominations for **The Art of.....Awards** up until the 21st of July, in the categories of information/education, support and advocacy so let us know who you think has made a difference to your life. See you all there!

Dear GSNV Members and Supporters,

After 3 ½ years at the GSNV desk I am soon going to be moving on to new challenges. I will still be here on Fridays until the 17th September so this isn't farewell just yet. Our management committee has put plenty of thought into how to move forward from here with staffing, and we are advertising a four-day per week position to share responsibility for the co-ordination of the GSNV with Jo Kelley (2 days per week). These are exciting times of opportunity for the GSNV and if the ad below interests you, I encourage you to consider applying for our position.

See you all at the 5th Birthday Celebrations on the 1st of August,
Eilís Hughes.

Exciting Opportunity

The Genetic Support Co-ordinator provides information, education, support, and advocacy for people affected by genetic conditions throughout Victoria.

We seek someone who has:

- ◆ A genuine interest in and an awareness of the types of issues that exist for people affected by a genetic condition.
- ◆ Excellent written and verbal communication skills
- ◆ Ability to work without close supervision
- ◆ Readiness to learn office management skills
- ◆ Enthusiasm and flexibility

Employment will be an ongoing appointment with a six-month probation period. Visit <http://www.employment.foxchange.net.au/employment/vic.shtml> or contact Nicki Carr on 8341 6378 for a position description. Applications close Monday 26 July 2004.

Special Projects Grant



Tourette Syndrome (TS) is a neurological disorder characterised by tics-involuntary, rapid, sudden movements that occur repeatedly in the same way. These tics may occur many times a day nearly every day or intermittently. Some children with TS also experience Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder and learning difficulties in varied severity. Part of my job as volunteer with the Tourette Syndrome Association (TSA) is to visit schools in Victoria to advocate for children with TS and their parents. I also help teachers with practical behaviour management and learning strategies. The GSNV Special Project Grants Program funding is appreciated and will go towards maintaining this valuable service.

Agnes Zillner

Education Advocate

NEW GROUP

Beckwith-Wiedemann and Related Disorders (B.A.R.D) Victoria

B.A.R.D provides a contact and information point initiated by Brenda Fearon, a parent with a background in paediatric nursing. The site offers parents new to Beckwith-Wiedemann syndrome (BWS) information on the condition and links to local Victorian resources. Some parents also welcome the opportunity to meet with other families and this can also be arranged. Some of the medical issues surrounding Simpson-Golabi-Behmel Syndrome and Isolated Hemihyperplasia are similar to those of BWS, and parents of children with these conditions may also benefit from using this contact point. Congratulations to Brenda for all her hard work and for providing such a valuable reference point for families. Visit <http://www.geocities.com/bwsandsqbs/BARDVicindex.html> for more information.

GROUPS' EVENTS

SSPA Grand Gala Dinner, 31st July 2004

Enjoy a two course meal, dance and grab the opportunity to purchase some incredible bargains during the infamous auction. Contact Meredith Young on 0438 882 478, 9555 7676 or email young.merry.m@edumail.vic.gov.au for tickets and details.

NF Information Day, 22nd August 2004

The Neurofibromatosis Association of Victoria are hosting an information day with speaker Professor Kathryn North, Head of the Institute for Neuromuscular Research at The Children's Hospital in Westmead. Professor North will discuss learning difficulties that can be associated with NF, and what can be done to support children at home and at school. Lunch will be provided, and opportunity for informal discussion. Contact John Patsikatheodorou on 0414 766 600 or email patsioz@optusnet.com.au for details.

UPCOMING EVENTS

Perspectives on Gene Patenting, July 20th 2004

The Victorian branch of the Human Genetics Society of Australasia (HGSA) are holding their AGM starting at 6.15pm in the 10th floor conference rooms, RCH. Bob Williamson will facilitate the meeting, with perspectives sought from investors, lawyers, clinicians and consumers. Drinks and fingerfood served afterwards.

Ethics

What is a question of ethics and who decides? How do researchers on ethics committees make decisions in the absence of evidence? How do they communicate their decisions? Would Australia be well served by a unified, national ethics committee to streamline the approval of multi-centre studies? Presenters and panellists will address these issues through a series of case studies and debate on Friday July 23rd 2-5pm, Sunderland Lecture Theatre, Ground Floor, Medical Building, The University of Melbourne. Admission is free.

Genes West, Perth, 10-13th August 2004

HGSA Annual Scientific Meeting in Freemantle, WA. Incorporating the Annual Scientific Meetings of the HGSA Special Interest Groups. The meeting will follow the Genetics and Population Health meeting (August 8-10) and concurrently with the 4th Australasian Gene Mapping Meeting (August 10-11). Visit <http://GenesWest-HGSA2004.org>

RESOURCES

hidden TreaSure – *thoughts about living with Turner's Syndrome*

'hidden TreaSure' was released last year and is a fantastic resource that provides a unique insight into the social and emotional issues for girls, women and their families living with Turner's syndrome. Therapeutic – for the scores of people who told their stories, and for its readers -its wisdom and resilience are applicable to all people. There is a new website for this resource at www.hiddentreasure.tk

Green PC

Green PC is a not-for-profit initiative of Infoxchange Australia, who have subsidised PC's and lap top computers ready to go from as little as \$99.00. Many come with 3 months free internet access, all have Windows 98E legally installed, with a back up operating system disk, warranty and after sales support and help desk. For more information call 9418 7429 or visit www.greenpc.com.au

In My Experience

Men speak about their experiences as fathers of children with a disability

Produced by MacKillop Family Services as the result of a research project, this booklet explores the range of thoughts, feelings, and experiences of fathers of children with disabilities. The topics covered are wide-ranging and include thoughts from fathers of other cultures and ethnicities. The booklet is available in English, Vietnamese, Arabic, Turkish and Chinese. For copies contact MacKillop Family Services on 9689 4799.

WEBSITES

www.healthtranslations.vic.gov.au/

The Health Translations Directory links to multicultural health information. There are fact sheets on many topics presented in a variety of languages.

www2.accesshousing.com.au/

This portal provides an independent point of reference to link people with a disability, an injury, the elderly, their carers and support team with real estate agents, business, travel agents, product distributors, employers and associations to assist people in retaining their independence and individuality.

www.cancervic.org.au/familycancer

The Victorian Family Cancer Genetics Service, funded by the Department of Human Services, has launched a website that will provide valuable information to many Victorians who have questions about cancer and genetics. The site is hosted by The Cancer Council Victoria at

www.beyondblue.org.au

The beyondblue website has been completely revised with more information added along with links to the beyondblue youth program, a post-natal depression website and the Victorian Centre of Excellence.

REMINDER

Next Committee Meeting

Monday July 19th at 6pm

Conference Room B

10th Floor RCH, Flemington Rd Parkville

All members and interested parties are very welcome to attend our meetings

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