



GSNV UPDATE

December 2004

GSNV Committee & Staff wish you and your family a Merry Christmas and a safe and happy New Year!

GSNV NEWS

GSNV Office – Closed Times

The GSNV office will be closed from Thursday, 23 December and reopens on Tuesday, 4 January 2005.

GSNV Advocacy Worker

GSNV is pleased to announce that our funding application for an Advocacy Worker has been successful. The Worker will train people with genetic conditions and their families/carers to better advocate for themselves at work, in the community, in the health care setting and at governmental/policy making levels. The Worker will provide training in metropolitan and non-metropolitan areas, and will work two days a week for 12 months. The position will be advertised in early 2005. Thanks to DHS Innovation Grants for funding this project!

GROUP EVENTS

Do you want to advertise your group's activity in next month's GSNV newsletter? Please send a paragraph, including contact details, to info@gsnv.org.au by 14 January 2005.

Uncontrolled Epilepsy Parent Support Group Meeting – 10 December

The Epilepsy Foundation of Victoria (818 Burke Rd, Camberwell Vic 3124) are holding a workshop led by Dr Elizabeth Bruce, a developmental and consulting psychologist who specialises in working with parents of children with a disability. For more information, contact Jean Ewing by phone 9805 9111 or email jewing@epilepsy.asn.au

Gippsland Rare Conditions Support Group – 7 February 2005

You are warmly invited to the first meeting of the Rare Conditions Support Group of Gippsland. This group is for parents, family members and friends of children who have rare medical conditions or disabilities. All welcome, and an invitation is extended to people who would like to find mutual support, in a friendly environment.

Where? Traralgon Neighbourhood House, 61 Breed St, Traralgon

When? 7pm – 9pm, Monday, 7th February 2005

A light supper will be provided and if you need childcare to attend the meeting, please contact the Commonwealth Carer Respite Centre on 1800 059 059. To RSVP or for enquiries, please contact Yvonne Waite at Parent to Parent Gippsland on phone 1800 010 453 or 51 353 131, or email p2pg@vic.australis.com.au



VATER/VACTERL Syndrome Conference

Julie is keen to organise a conference for people living with VATER/VACTERL, possibly in Melbourne or Sydney. Before organising it, she needs to know how much interest there is for such a conference. To register your interest, please phone Julie on 0432 606 647 or email julie1982@bigpond.com

ADVOCACY

Health for Kids in the South East Project

The aim of this project is to improve health outcomes for children and young people in the Southern Health catchment area. Health for Kids will be looking at different strategies to create strong links between the hospitals and general practitioners, and develop guidelines and clinical pathways to ensure that sick children will get the best care. Ways of improving access to hospitals, and how to help families and carers look after their sick child at home, will also be considered.

Southern Health is looking for parents and carers who are interested in giving a consumer perspective to the project's activities. Training and ongoing support will be provided and any expense associated with participation will be covered. Phone Fiona Wilkinson 9594 7557 or email: Fiona.Wilkinson@med.monash.edu.au

People Power

People Power has released its **Draft Disability and Carers policy statements** for public comment. *"The inadequacy of the disability support system is Australia's national scandal. The injustice and invisibility faced by our 2.7 million family carers is also a national disgrace."* These statements define People Power's general policy approach to these issues, which centres on the concept of empowerment.

Visit: www.peoplepower.org.au/policy%20papers/DisabilityPolicyPaper.htm and www.peoplepower.org.au/policy%20papers/CarersPolicyPaper.htm

People Power will be registered as a federal political party in December, and will contest the next round of state elections in Victoria, New South Wales, Queensland and South Australia.

Consumer Affairs Victoria Develops a Disability Strategy

Consumer Affairs Victoria (CAV) is developing a Disability Strategy to help it provide accessible services for people with a disability. CAV would like to find out from you:

- How CAV can provide accessible services to people with a disability?
- What consumer issues are experienced by people with a disability?

CAV would also like to inform people with a disability about their consumer rights. If you would like CAV to come to talk with your support group, disability network or organisation, phone Maria Cesarello on 9627 6272 (Interpreter Service: 131 450, National Relay Service: 1800 555 677) or email consumer@justice.vic.gov.au

TRAVEL

Public Transport Ombudsman

Victoria now has an office that people can ring if they have any problems with train, tram or bus services. The Ombudsman, James Harnett, can be contacted on freecall 1800 014 111.



OF INTEREST

Achieving the Extraordinary

Our new Coordinator, Leah Lonsdale, has written a book to commemorate the 50th anniversary of Haemophilia Foundation Victoria. *'Achieving the Extraordinary'* is a brief but personal journey through HFV's history, in the context of life with haemophilia during different periods of time, and illustrated with numerous personal stories. The book is available for \$20 from the Haemophilia Foundation (phone 9555 7595).

Guide to Victorian Government Services

This new Guide will help Victoria's culturally and linguistically diverse communities access information about government services. The Guide has been **published in 11 languages** other than English (Arabic, Chinese, Croatian, Greek, Italian, Macedonian, Russian, Serbian, Spanish, Turkish and Vietnamese). It will assist people from all backgrounds in accessing vital support services such as health, education and housing, through to obtaining a boating licence, or registering a small business. FREE copies of the Guide are available by phoning Information Victoria on 1300 366 356.

Book and CD: The Living History Project

This excellent resource (written by Ruth Quibell and auspiced by SCOPE, Headway Victoria and Association for Children with a Disability) offers an insight into the lived experiences of people with disability and parents of people with disability between 1981 and 2002. Since the International Year of Disabled Persons (IYDP) in 1981, much has changed, but much has not for people with disability and their families. The Living History Project tracks those changes and identifies enduring and recurring themes, illustrated with many quotes. To obtain copies of the full report *and Easy English Summary*, please contact Leah at GSNV on 8341 6315. Contact Nicole Hau at SCOPE on 9843 2066 or email nhau@scopevic.org.au to order a CD (written and audio) version of The Project.

Wanted: Donation Collection Tins

Jeff's fund raising club is looking to raise money for a charity with collection tins at their 2005 "Red Dress Run". If you have suitable tins he can borrow, and/or are a charity looking for enthusiastic fundraisers, please contact Jeff on 8341 6307.

HAVING YOUR SAY

Review of Disability Legislation

The Victorian government has been reviewing state disability legislation and invites people and organisations to provide comment on how the recommendations will work in practice. For information and copies of the report, go to www.dhs.vic.gov.au/disability or phone 1200 366 731. The closing date for comments is Friday, 17th December 2004.

Are You Up to the Challenge?

The Birth Defects Register is trying to come up with another name that doesn't say "birth defects" but means the same thing. Can you come up with an appropriate alternative? A 'birth defect' is an abnormality in body structure, function or chemistry, present at birth, but not necessarily noticed at birth. If you have ideas, please contact Sharon on sharon.lewis@mcri.edu.au or Leah at GSNV on 8341 6315.



WEBSITE RESOURCES

Respite Finder Web Site

The Respite Finder and mini-directory are new tools developed to assist families of children with disabilities to find and access respite. It has been developed in the Hume and Moreland areas, but the Respite Finder will be useful for all families in the northern region of Melbourne, and for people of all ages with disabilities. To view the Respite Finder, go to www.respitenorth.infochange.net.au then click on Respite Finder. Congrats to Ellis Hughes who developed this excellent resource!

AnSWeR (Antenatal Screening Web Resource)

- Are you pregnant or thinking about starting a family?
- Are you puzzled about the screening and testing being offered to you?
- Do you need to know more about conditions such as Down syndrome for which antenatal testing is offered?
- Have you had a positive diagnosis, and are you now wondering whether to continue or terminate your pregnancy?

Then visiting this UK-based website <http://www.antenataltesting.info/default.html> may provide you with some answers.

Ability Online Support Network

Since 1991, Ability Online Support Network has been linking chronically ill children around the world! A computer network designed to enhance the lives of children and youth with disabilities or illness by providing an online community of friendship and support. Take a peek at <http://www.ablelink.org/public/default.htm>

FUN

Netball at Victoria University

Independent people with intellectual disabilities are wanted to play netball at Victoria University, Footscray in March 2005. This is a project promoting fun and laughter by Victoria University, VicHealth and Health Through Participation. For more information, contact Merrilyn Gamble on 9925 6516 or email merrilyn.gamble@rmit.edu.au

For past GSNV updates, visit the "news & events" section of our website www.gsnv.org.au

REMINDER - Next Committee Meeting

6:00 – 7:30pm

Wednesday, 2 February

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 Leah or Lindy in the GSNV office by phone (03) 8341-6315 or email info@gsnv.org.au

*Thought for the day: **TEAM** stands for **Together Everyone Achieves More***