

GSNV UPDATE

January/February 2005

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

GSNV NEWS

Survey

To help us stay in touch with what you and your support group needs, please complete the short survey (enclosed with this newsletter) and return it to Leah or Lindy by Friday 11th February. If you have feedback for GSNV, but do not wish to complete the survey, please phone us on 8341 6315 or email info@gsnv.org.au

GSNV Special Projects Grants 2005

See below under 'grants' for more.

Advocacy Worker

GSNV is advertising for an Advocacy Worker 2 days a week for 12 months. For a copy of the job description, contact Leah or Lindy on 8341 6315 or email info@gsnv.org.au Applications close Friday 4th February.

GROUP EVENTS

GO THE TAN - *Friedreich Ataxia Research Association (FARA)*

Tan Running track, Royal Botanic Gardens

Sprint, jog or walk your fastest around one lap of the Tan between January 29 and 31, and FARA will officially record your 'Tan time'. To find out when celebrities and Olympians will GO THE TAN, and the times when you can officially record your own personal Tan time, go to www.gothetan.com.au or phone Varlli on (03) 9824 8344.

Have a Heart: Stick on a Smile – *Heart Kids*

Heartkids are selling their unique multi-coloured smiling heart stickers during February. There are 17 stickers of various sizes per sheet, they retail for \$2 per sheet. Stickers are available from Guardian Pharmacies, Big W and Bendigo Bank. You can help sell stickers in your area by contacting Alison on 03 5783 3910.

CONFERENCE

Having A Say Conference, Benalla, 1-3 March 2005

Victorian Advocacy League for Individuals with Disability (VALID)

VALID's 'Have a Say' three-day conference includes 'Come & Try' sessions and a Parent & Carer's stream. Limited financial assistance is available. For full details, including a draft program, visit the VALID web site at www.valid.org.au or phone 9416 4003.

WORKSHOP

Need to brush up on basic genetics?

MCRI (Murdoch Childrens Research Institute) Genetics Education are offering a workshop, "What's In Your Genes?", on **Thursday 10 February** from **9am - 1pm** in the 10th floor conference room A of The Royal Childrens' Hospital. This workshop covers an introduction to molecular genetics, inheritance and disease and genetic testing. The workshop has been designed to meet the needs of the Graduate Diploma in Genetic Counselling students, but other interested individuals are invited to attend. A fee of **\$20** will apply to cover materials and morning tea. Please email Genetics Education at: edu.unit@mcri.edu.au by 2 February to register for the workshop.

FOCUS GROUP

Invitation to Participate in a Focus Group

Are you:

- Over 18 years of age *and*
- Have a genetic condition *and*
- Would like to discuss how you learnt about the genetics of your condition and give your views on genetic services for adults?

If you answered "yes" to all of the above, then we would like to invite you to participate in a focus group being conducted by Genetic Health Services Victoria.

Health care professionals and government policy makers are currently discussing the development of genetic services for adults. In order to ensure that services meet the needs of adults with genetic conditions, we would like to hear your experiences learning about the genetics of your condition & your views of what a genetic service might provide.

Your participation in this study will assist the development of genetic services for adults with genetic conditions. We cannot guarantee or promise that you will receive any direct benefits from this project.

Participation is completely voluntary. You would be reimbursed \$40 for the costs associated with attending the focus group. If you choose not to participate, this will not affect any future involvement with the genetic services.

This project is supported by the Genetic Support Network of Victoria.

If you are interested in participating, please phone the research co-ordinator, Lindy Hodgkin on 9342 7151 (Monday-Wednesday) or 8341 6315 (Thursday-Friday) for more information. *Dates: 1st or 2nd February 2005. Times and venue: To be advised.*

GRANTS

- Grant: **Special Projects Grants**
Provider: Genetic Support Network Victoria
Funding: \$50 - \$400 per grant (total of \$2,500 is available among all groups)
Closes: Thursday 17 March 2005
Purpose: This funding can be used for any special once-off project that meets GSNV's objectives. Examples from past years' recipients include:
- Printing new brochures;
 - Travel costs to national conference;
 - Conference registration;
 - Venue hire & catering for special event;
 - Purchase of books and resources

For full details and application forms, visit the GSNV web site (www.gsnv.org.au) or contact Leah or Lindy on 8341 6315.

- Grant: **Online Community Funding - My Connected Community**
Provider: State Government of Victoria
Funding: \$10,000 or \$30,000 depending on level sought
Closes: Thursday 10 February 2005 (at 4pm)
Purpose: The Victorian Government encourages applications from organisations able to provide support and training to those Victorians who have not been able to, and are currently unable to, gain Internet skills and access. This may include senior Victorians, recent migrants, unemployed Victorians and people with a disability.

For further information, application forms and guidelines (including criteria), contact the My Connected Community Secretariat on 1800 629 835 or visit <http://mc2.vicnet.net.au>

REMINDER - Next Committee Meeting

6:00 – 7:30pm

Wednesday, 2 February 2005

Conference Room B, 10th Floor RCH, Flemington Road, Parkville

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

For more information on anything you've read here, or to have your group's event advertised in the GSNV Update, please phone Leah or Lindy during office hours on (03) 8341-6315 or email info@gsnv.org.au

Not on the GSNV mailing list? Want to get this Update every month? Contact Leah or Lindy on 8341 6315 or email info@gsnv.org.au