

GSNV UPDATE

April 2004

GSNV NEWS

Special Projects Grants

This year we have had an overwhelming response to the Special Projects Grants scheme, with many more applications than we can unfortunately fund. Our panel is currently considering applications, and applicants will be advised of the outcome by mid-April. Thank you all for your excellent applications, and for your patience during the deliberation period.

UPCOMING EVENTS

National Autism Awareness Week Autism Expo 2004

Autism Expo 2004 is for everyone working with someone with an Autistic Spectrum Disorder who wants to learn more. This includes parents, teachers, integration aids, home and respite carers and family support workers. The Expo this year will be held in the Darebin Arts and Entertainment Centre on Wednesday 12th May. Contact Donna Willis at the Autism Victoria office on 9885 0533.

GROUPS' EVENTS

Fragile X Syndrome Seminar

The Fragile X Alliance Inc. and the Fragile X Association of Victoria is delighted to present an evening seminar with Randi Hagerman MD, Professor of Paediatrics and Medical Director of the M.I.N.D Institute in California. Randi is a leading international expert on Fragile X syndrome and has more than 20 years experience in the field of neurodevelopmental disorders. The seminar will be held on Wednesday 14th April, 10th floor conference rooms RCH. Contact Jonathan Cohen on 9528 1910 or email jcohen@travelclinic.com.au to book.

Attention Deficit Hyperactive Disorder & Tourette syndrome-What's the connection?

Psychologist Dr Claire Graham will present up to date information on the evidence of the links between ADHD and TS, the "Big 3-ADHD, TS and OCD", waxing and waning of symptoms and managing ADHD and TS. Claire will speak at the Nerve Centre, 54 Railway Road, Blackburn on Saturday 1st May at 7.30pm. The cost is \$3 or free to TSA members. Contact 9845 283 or email: tourettes@mssociety.com.au for details.

Information Day

The Williams Syndrome Family Support Group Vic. Inc. (WSFSG) are organising an information day to be held on Saturday 29th May at the RCH. For more information contact Janine Wan on 9859 4450.

AGM

The WSFSG are running an African drumming workshop to coincide with their AGM on Sunday 18th April! The AGM will be held at 2pm, for more information contact Janine or Simon on 9859 4450.

Fragile X Support Group of Western Australia Inc.

This group are hoping to re-establish links with as many families as possible to reaffirm the value of meeting with other families facing similar issues, and sharing ideas and information. An informal gathering is scheduled for Saturday 1st May, for more information contact Sue on 08 9454 5953 email yorkie1@iprimus.com.au, or Judy on 08 9444 3698 email jwilllock@cygnus.uwa.edu.au

GIPPSLAND

Self Help Groups

The Collective of Self Help Groups (COSHG) presents two free workshops for self help groups in Gippsland. The workshops will provide the opportunity to share your skills and develop new ones. Topics include advocacy skills for you and your group, fundraising and grant submissions and conflict resolution. Workshops will be held on:

- Thursday 22nd April 11:00am-3:00pm at Bairnsdale Neighbourhood House, 27 Dalmahoy St, Bairnsdale. To book or for more info contact COSHG on 9349 2301 or email coshgmelb@yahoo.com.au
- Friday 23rd April 10:45am-2:30pm at LaTrobe Convention Centre, Princes Highway, Traralgon (COSHG will be running two workshops including the above topics as part of the GSNV Conference, and all self help groups are welcome). Contact the Conference Organiser to book at PO Box 1166, Traralgon 3844 or phone 5174 2076.

Lunch will be provided at both workshops. RSVP by 13th April.

Do you know your phone rights?

Know who to complain to about your Internet or phone service? Know how you can get more affordable phone access? Know how to get a phone you can use? Or a TTY? If not, then these Forums brought to you by COSHG are for you! The forums are free and will run in the Gippsland region:

- Thursday 22nd April 4:00pm-6:00pm at Bairnsdale Neighbourhood House, 27 Dalmahoy St, Bairnsdale
- Friday 23rd April 4:30pm-6:30pm at LaTrobe Convention Centre, Princes Highway, Traralgon (This is being run as part of the GSNV Conference. Everyone is welcome)

Representatives from the Telecommunications Industry Ombudsman and Telstra Country Wide will be present to provide information and answer your questions. Contact COSHG to book or for more information on 9349 2301 or coshgmelb@yahoo.com.au RSVP by 13th April.

Genetics, You & Your Family

A reminder that the first GSNV non-metro conference will be held in Traralgon on 23rd April, RSVP by 9th April to PO Box 1166 Traralgon 3844 or 51 74 2076.

GETTING AROUND



Demand Response Bus Service

If you use a wheelchair or you have a physical disability which prevents you travelling on buses or trams and you wish to travel anywhere within the St Kilda/ Port Melbourne area, a hoist-equipped minibus will transport you and your friends (space permitting) anywhere within this area for the normal Metcard fare. The bus is capable of carrying up to three customers using wheelchairs and four other customers. The bus will not transport beyond Flinders Street or Spencer Street stations, and the service must be booked. Call 1800 012 061 or 008 013 920(TTY) for bookings.

RESOURCES

The Genetics Files

A new resource for GPs means that they will now be able to advise and manage patients with a range of genetic conditions. *The Genetics File - A Resource for GPs* was launched late last year and is available to all GPs in Victoria. The resource has been produced by the Genetics Education Unit of the Murdoch Childrens Research Institute, and Genetic Health Services Victoria, with input from clinicians, GPs and consumers. The resource focuses on the practical aspects of some more common genetic conditions, genetic testing, where and when to refer, and includes information for patients and support groups. Workshops are have been conducted throughout Victoria to help GPs use the resource and incorporate genetics into their everyday practice. The Genetics Education Unit is also interested in finding out whether more GPs are referring families to genetic support groups as a result of having the resource. For more information about how you can help or for requests for the resource contact the Genetics Education Unit on 8341 6298.

Ask your GP if they have the resource.

<http://www.autismhelp.info/main.htm>

This user-friendly website is comprehensive and very easy to use. The Education section is designed for teachers and integration aides, with other sections to support child care workers, health professionals, respite carers and swimming instructors. The site features an interactive autism training program, a discussion forum and many practical suggestions that will benefit both parents and professionals.

<http://www.abc.net.au/health/cguides/elixir.htm>

The Internet is booming as a source of health information. Where we once phoned our mother, or reached for the 'home doctor' book on the shelf, we now hop online and use a search engine. But how can we know which information to trust online? Here's a handy guide for evaluating what you'll find.

CONFERENCES

Mucopolysaccharidoses (MPS) Society Conference

Melbourne 16-18th April

Will celebrate the spirit displayed by children with MPS and by those caring for them, both family and professionals. Families and individuals with MPS will share their experiences of MPS. The latest exciting research developments will be explored and conveyed by professionals, including therapists who will share their knowledge and management skills of MPS. Visit www.mpsociety.org.au for more information.

Empowering Individuals and Families in the Human Service

Melbourne 27-28th May

Is a national strategy conference with a practical orientation towards project development, partnership formation, and public policy agenda-setting. The purpose is to explore what must be done in communities, government departments, service providers, social institutions, and philanthropic foundations to further an empowerment agenda. This presents a fantastic opportunity for individuals, families and community groups to come together and create models and strategies that work. Contact Vern Hughes on 9326 4481 or email hotham@sub.net.au

NZORD Conference, Wellington, 28-29th May

The New Zealand Organisation for Rare Disorders (NZORD) is holding a conference with a great cast of speakers on matters covering basic science, translation into therapy, genetics, ethics, human blood and tissue banking, the "expert patient and family" and more. Keynote speakers include Sharon Terry, President of the US Genetic Alliance. If any of you would like to hop across the ditch for a few days in Wellington, you can be assured of a very interesting time, despite the fact that it will be winter. Check out more details at www.nzord.org.nz

Community Development, Human Rights and the Grassroots

Melbourne, 14-18th April

This conference will explore the questions: What does community development look like today? How is it operating at the grassroots and in global contexts? What are the links between community development and human rights? The conference runs from April 14th to 18th at the Hotel Y, 489 Elizabeth Street, Melbourne. Contact Caty Kyne on 03 94817894 or Ben Leeman on 03 9819 3239 for more information or visit www.deakin.edu.au/cchr

REMINDER

Next Committee Meeting

Monday 19th April 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