

GSNV UPDATE

October 2004

GSNV NEWS

The new face at GSNV - Leah Lonsdale

I have just joined the GSNV team, after spending seven years as Resource Coordinator for Haemophilia Foundation Victoria. During that time I was involved in several special projects including authoring a book to commemorate the Foundation's 50th anniversary (published December 2004). I am also a qualified teacher.

I'm a water enthusiast and spend a lot of time doing things that involve water...swimming, walks along the beach, cycling beside a river, snorkelling, scuba diving and kayaking. I'm a member of Rickett's Point Marine Care and love marine life (except the old coke cans under Rye pier). I particularly like dolphins and have a small collection of dolphin paraphernalia...it only takes up two rooms! Out of the water, I love Kath & Kim, cats and MSN.

Feel free to contact me on 8341 6315 or lonsdale@gsnv.org.au (not Thursday). I look forward to getting to know you!

2004/2005 GSNV Committee of Management

We congratulate the 8 recently-elected committee members: Andrew Williams, Carly Weber, Marie Karamesinis, Mark Files, Ray Hee, Sharon Lewis, Tony Briffa and Tony McDonald. We will be electing the office-bearers from this group of wonderful volunteers at the next general meeting on 18 October. However, there is still time for YOU to join the new Committee. Please contact Leah or Lindy in the GSNV office if you'd like to know more about what is involved in being a GSNV committee member or an "apprentice".

Our Tony McDonald, OAM

Did you see the great article and photo in The Age (September 30) about Tony McDonald and her son, Rohan? Tony is one of GSNV's long-standing committee members and she was recently awarded an Order of Australia medal for her tireless efforts in working for families of children with disabilities. Congratulations, Tony, we are most proud of you! (Visit <http://theage.com.au/articles/2004/09/29/1096401646588.html?oneclick=true> to view the article.)

Reprogenetics: Whose Rules Apply? – 27 October

The Infertility Treatment Authority (ITA) is holding a one-day symposium on Wednesday, 27 October to canvass issues associated with the regulation of assisted reproductive technologies, embryonic research and genetic testing. GSNV's Treasurer, Marie Karamesinis, is representing the GSNV on a panel at this important symposium. If you'd like to know more about the day, visit www.ita.org.au or phone the ITA on 8601-5250.

GROUP NEWS

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 3 November 2004.

Williams Syndrome Family Support Group – Parent Retreat – 16 October

The Parent's Retreat is at Highton Manor, Mansfield this year. It is a great opportunity to get away, relax, unwind and catch up with friends. The Retreat includes overnight accommodation, dinner and breakfast and costs \$185 for members and \$310 for non-members. Contact Kara Leonard on 9592-2233 to reserve your place.

Australian Leukodystrophy Support Group Medical Seminar – 25 October

The Australian Leukodystrophy Support Group is presenting a Medical Seminar on Monday, 25 October at the Ella Latham Theatre, The Royal Children's Hospital, Melbourne. This will be a Leukodystrophy update with a focus on diagnosis, patient care and family support. Keynote speaker is eminent neuro-radiologist, Professor Jaap Valk, from the Netherlands. ALDS members, friends, health professionals and members of the public are invited to attend. For more information check out the new website www.alds.org.au, email leuko@vicnet.net.au or phone 03 9584 7070.

Victorian Turner's Syndrome Association (VTSA) – 6 November

VTSA is having their 20 year celebration on Saturday, 6 November at the Carlton Crest Hotel, Melbourne – an all day educational conference (\$60) and cocktail supper (\$38). This day will be an exciting one of *dialogue* between experts. The VTSA reminds us that "each of us is the *expert* about our own life and how we experience it". Contact Alison Worboys on 9720-2620 to register, or for more details about the celebration.

OzED (Australian Ectodermal Dysplasia Support Group) AGM – 14 November

The inaugural Annual General Meeting of ozED (<http://www.ozed.org.au/>) is happening on Sunday, 14 November. Teleconferencing facilities are available so that interested people throughout Australia can participate. For more details contact Andrew Williams by phone (03) 9755 5626 or email info@ozed.org.au

NOTEWORTHY

Gene Patenting Report

The Australian Law Reform Commission (ALRC) has released a report, "*Genes and Ingenuity: Gene Patenting and Human Health*". The Report is the product of 18 months of extensive research and community consultation by the Commission. It examines intellectual property rights over genes and genetics and related technologies, particularly the impact they have on human health issues. The Report can be viewed online at <http://www.austlii.edu.au/au/other/alrc/publications/reports/99/>

National Disability Abuse & Neglect Hotline

This is a FREE service that takes reports of abuse and neglect of people with a disability.

Website: <http://www.disabilityhotline.org/>

Phone: 1800 880 052, TTY 1800 301 130 (between 8am-8pm every day incl. weekends)

Email: enquiries@disabilityhotline.org

Family Resource Centre, RCH

Have you visited the Family Resource Centre at the Royal Children's Hospital? The Centre provides a quiet, friendly, relaxing area for families within the hospital to prepare a snack, have a cuppa, access resources and information, or have some time out. It also includes a Personal Care Suite with shower facilities, change rooms and toilets with easy disability access. More information can be found at www.rch.org.au/frc or phone 9345-4662.

The Centre's hours will be extended to coincide with the Muslim Fast of **Ramadan** (15 October - 15 November). The Muslim community has organised volunteers to provide food for Muslim families in the hospital during the month, at times respectful to Ramadan.

CONFERENCE

Deafness Expo – 30 October

The Deafness Expo is ready to go, with nearly 60 exhibitors, a stellar cast of speakers and an engaging variety of activities for young and old. It is open to the public and admission to the expo and all seminar sessions and workshops is FREE. It is held at the Melbourne Town Hall on Saturday, 30 October from 10am-5pm. For more information visit the website: www.deafnessexpo.org, phone: (03) 5983-2400 or email: sr@asnevents.net.au

GRANTS

(To apply, you must be a charitable organisation with Deductible Gift Recipient (DGR) status)

Sunshine Foundation Grants

The purpose of these grants is to support projects, which help alleviate human suffering, attend to matters of social need, advance the frontiers of knowledge and enhance the quality of life. Maximum funding per grant: \$5,000, minimum funding per grant: \$500.

Closing date: 15 November 2004. *Website:* www.mgg.com.au/

Contact: The Secretary by phone: (03) 9419-5133 or email: sunshine@mgandg.com.au

Ronald McDonald House Charities Grants

These grants offer funding to projects which help seriously ill children. The funding is various and the grants are ongoing. For more information visit the website <http://www.rmhc.com.au> or write to RMHC, 21-29 Central Ave, Thornleigh NSW 2120.

FUN

Carers Week – 17-23 October

The theme for Carers Week 2004 is 'Health and Wellbeing' and the focus will be to:

- Raise awareness of the extra role that carers take on, and the health issues they may face
- Support carers to take action which positively enhances their own health and wellbeing

Carers Week provides an opportunity for carers to get together, share information and ideas, or just have a break from caring responsibilities. For more information about the many and varied FREE activities that are happening throughout Victoria, visit <http://www.carersvic.org.au/News%20and%20Events/Carers%20Week.htm>, or phone the Commonwealth Carer Resource Centre in your area on 1800 242 636.

Back To Back Theatre - Summer School 2004 – 20-21 November

Back to Back Theatre is offering 8 hot new workshops for people with and without disabilities in their summer school program. The action-packed weekend in November (at the Courthouse Youth Arts Centre, Geelong) includes workshops and performance making

with Back to Back and a team of guest artists. You learn new skills, make a short work in half a day, get fit and have fun. The workshop fees range from \$15-\$50 (concession) to \$30-\$105, including lunch. For bookings phone (03) 5221-2029 or email sue@backtobacktheatre.com

The Other Film Festival - 3 –5 December

Arts Access, the peak body for arts and disability in Victoria, takes pleasure in announcing the inaugural *The Other Film Festival* at The Age Theatre, Melbourne Museum from Friday, 3 to Sunday, 5 December 2004. The Festival (funded by the City of Melbourne, Ian Potter Foundation, Australian Film Commission, Percy and Ruby Haddy Foundation and Melbourne Museum) will screen exciting and challenging works by, with or about people with disabilities. It seeks to engage, enthuse, enlighten and entertain a diverse audience. Academy Award winner, Adam Elliot, is the Patron of Australia's first disability film festival. For further information contact Stella Young on (03) 9699-8299, TTY (03) 9699-7636, or syoung@artsaccess.com.au or visit <http://www.artsaccess.com.au/news/index.cfm?id=271>

HAVING YOUR SAY

Genetic Discrimination Project

The GDP is a national research study that aims to investigate the advantages and disadvantages of genetic information on people's lives and to examine cases of alleged discrimination in Australia. The researchers are "asking Genetic Support Groups around Australia to raise awareness about this research by distributing questionnaires to their members who may have experiences relating to genetic information, family history or genetic testing that they want to tell the researchers about". For more information and how to request questionnaires, refer to the enclosed flyer.

Genetics in General Practice - 18 October

Do you have an interest in genetics and want to participate in a Consumer Group Consultation? As part of her PhD research, Anna Flouris wants to explore what you expect from General Practitioners who have The Genetics File, a genetics resource.

When Monday, October 18th, 2004

5:30-6:45pm (prior to the GSNV committee meeting)

Where 10th floor, Murdoch Childrens Research Institute, RCH, Flemington Rd, Parkville

For more information please contact Anna at anna.flouris@mcri.edu.au or phone 8341 6209.

REMINDER - Monday, 18 October

5:30 – 6:45

Consumer Consultation: "Genetics in General Practice"

6:45 – 7:30pm

General Committee Meeting

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