

GSNV UPDATE

August/September 2004

GSNV NEWS

GSNV AGM – 20 September

Don't forget the GSNV's AGM on Monday, 20 September (10th floor conference rooms of The Royal Children's Hospital) from 6:00-7:30pm and supper afterwards. Ms Beth Wilson, Victoria's Health Services Commissioner, is our guest speaker. This will be Eilís' last GSNV meeting, so it's your chance for a final catch-up and goodbye over supper.

Staff news

There have been some changes in the office, recently. **Jo Kelley** left the GSNV in early August and began a new job as a genetic counsellor at the Royal Women's Hospital. We miss you Jo, but wish you every success in your new career. **Eilís Hughes** finishes with the GSNV on 17 September after 3½ years. It is hard to imagine the organisation without her – Eilís' energy and enthusiasm have been so crucial to GSNV's continuing growth and success. However, we shouldn't be greedy – we need to share Eilís' with the rest of the world. Profound thanks, Eilís, for a job extraordinarily done.

Welcome to **Leah Lonsdale** who starts on Monday, 20 September as the new GSNV Co-ordinator. Look out for more news about Leah in the next newsletter.

Feedback Requested

Is the monthly GSNV update meeting your needs? Is the information relevant to you, your family or group? What else would you like to hear about? We'd welcome some feedback from you.

GROUP EVENTS

Ectodermal Dysplasia Family Day – 3 October

The Australian Ectodermal Dysplasia Support Group, ozED, is holding a family day on Sunday, 3 October 2004 in Ballarat, Victoria. All are welcome! It will be from 11.00am to 4.00pm at the Eureka Family Resource Centre, 507 Humffray Street, South Ballarat. Drinks and afternoon tea will be available. For more information visit <http://www.ozed.org.au> or contact info@ozed.org.au

Kabuki Syndrome Family Day – November

There is going to be a Kabuki Syndrome Family Day in South Australia. Any patients or families who would like more information please contact Kerrin Windsor-Male on (08) 8338 2520 or 0438 609 788. The date will be either the 6th or 7th November, depending on family preferences.

Australian Leukodystrophy Support Group Bi-Annual 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 neuroradiologist, 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 birthday celebration on Saturday, 6 November – an all day educational seminar, craft workshop, and cocktail supper. More details soon.

TRAVEL

Companion Card

The State Government has extended the Companion Card benefits to include free travel on Victorian public transport services for the companion/carer of an eligible cardholder. This entitlement came into effect on 18 April 2004 when the new public transport partnerships with Yarra Trams and Connex commenced. The Companion Card holder is required to purchase the correct/valid ticket for their travel on any Victorian public transport service. The companion travels free and is not required to carry a ticket on metropolitan public transport services. Visit the website at www.companioncard.org.au or phone the Companion Card information line on 1800 650 611.

FUN

Cafe Sunflower

A singing, percussion and music making group for people who have disabilities. The Sunflowers Singing Group is currently open to new members! Do you enjoy singing, playing musical instruments, making up new songs or just having fun singing and meeting friends? Come along and join the Sunflowers Singing Group! The Sunflowers have been running for 10 years! We perform and hold concerts in the community. We sing songs in different languages. We sing songs from our repertoire of over 150 songs! We have a special interest in contemporary styles and songs that participants choose. We use percussion instruments and our voices for creative sound and music making. Contact: Ngame on 9532 9211 for more information and for joining.

Khaki Rebels

Khaki Rebels is an organisation for youths aged 5 to 18 years of age with or without a disability who live in the Western Areas of Melbourne. There are currently several positions vacant for youth members to join the club. The group has 3 chatrooms on the internet including Starchat, khaki-rebels room for Youth members, kidzone room for children of all ages and Families-r-us room. All chatrooms are strictly monitored by operators. Contact Wayne Jones on 040 269 7018 or email co_ordinator@khaki-rebels.org.au or visit www.khaki-rebels.org.au

Libraries for All

Communication aids are now available in all public libraries to make libraries more accessible for people with disabilities. The aids are for use by people who cannot talk or have speech that is difficult to understand. For more information visit the Scope website at www.scopevic.org.au/therapy_crc_news_libraries.html or Victoria's Virtual Library at www.librariesvictoria.net/infonet/

GRANTS

Victorian Volunteer Small Grants

These grants offer up to \$5,000 to any incorporated group in Victoria that involves volunteers. Their purpose is to encourage local community organisations to attract new volunteers from diverse backgrounds and create new volunteering opportunities. Funding is ongoing until 1 October 2005. Priority will be given to groups with small operating budgets and a higher dependency on volunteer support. For further information visit <http://www.grants.dvc.vic.gov.au> or phone the Department for Victorian Communities grants information helpline on 1-300-366-356 between 8:30am-11pm.

Interact Foundation Grants

General Community grant to assist community organisations in the provision of their services and represents the company's commitment to social responsibility. Funding is ongoing with various amounts available. Phone 03 8650 7000 or check out the website at www.interactaust.com.au/recruit/int_australia3.htm

Homefirst - Dept. of Human Services (VIC)

Disability grant for Community Service Sector organisations. To provide a range of home and community based support services to enable individuals with a cognitive disability who require a significant level of support to live as independently as possible in the community. Funding is ongoing, with various amounts available. Visit www.dhs.vic.gov.au or phone 1800 783 783 for details.

"In the Community" - Sponsorship Partnership Program Alcoa

General Community grant to fund positive community change and enhancement. Alcoa's major categories are Environment, Community, Health and Wellbeing, Education, Culture and Sport and Safety. Alcoa prefers to sponsor projects in the local areas that they operate including Anglesea, Geelong and Portland. Various amounts are available and funding is ongoing. Contact Mr Paul Hurkmans, Employee Communications and Sponsorship Officer, on 03 5245 1219 or email paul.hurkmans@alcoa.com.au or visit www.alcoa.com/global/en/community/foundation.asp

Henry Berry Fund

The Henry Berry Fund assists charitable and care-giving organisations who have a particular focus on groups that are concerned with elderly care, family and youth and support those who aid the homeless and help provide a basic standard of living. Funding is usually around \$500, and grants are ongoing by mail (assessed twice a year in September and March). Contact the Secretary Mr David Wilson on 03 9288 8000 for details.

Flack Trust - Deaf Children Australia

Deaf Children Australia provides financial and in-kind support for a wide range of projects that benefit deaf and hearing impaired children and their families, and addresses the broader issues surrounding deafness. Funding is ongoing by mail. For details phone 1800 645 916 or TTY (03) 9510 7145 or visit www.deafchildrenaustralia.org.au/html/default.asp

Neville Smith Foundation

General Community grant to disburse smaller grants to groups who often find other strict criteria hard to meet. The closing date for applications is **16 September** by mail. For details visit www.frnsfoundation.com/ or email info@frnsfoundation.com or phone 03 9682 0655.

Women's Community Leadership Grants

These grants, offered by the Department for Victorian Communities (DVC), provide financial support to individuals and groups to undertake activities that will assist them in their leadership roles, or allows them to advance leadership projects in their communities. Individual grants are up to \$2,000, and grants to organisations are up to \$5,000. Applications close 30 September 2004. The guidelines and application form are available at http://www.grants.dvc.vic.gov.au/docs/ProgramOverview_WomensCommunityLeadershipGrants.pdf or phone the DVC grants information helpline on 1-300-366-356 between 8:30am-11pm.

HAVING YOUR SAY

Genetics in General Practice - 18 October

Come along and join others with a keen interest in genetics and participate in a Consumer Group Consultation (CGC). As part of her PhD research, Anna Flouris wants to explore what you expect from GPs 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
Royal Children's Hospital, Flemington Rd, Parkville, 3052

For more information please refer to the enclosed flier (which you are welcome to distribute) or contact Anna at anna.flouris@mcri.edu.au or on phone (03) 8341 6209.

People Power - Family Carer Survey

People Power (<http://peoplepower.org.au>) is a new political movement in Australia aiming to empower people who have become invisible in our political system. This includes families, rural communities, volunteers, individuals and communities who practice self-help, and people with disabilities and chronic illnesses. People Power is asking family carers to participate in a survey to "help us understand your situation better - and give you a chance to make an input to our campaign strategies". If you are interested, the survey can be found at <http://peoplepower.org.au/FamilyCarerSurvey.htm>

JOB VACANCY

Siblings Worker (7hrs pw)

The Association for Children with a Disability has a job vacancy for a siblings worker "servicing input and updates to www.yourshout.org.au working with a team of young sibling volunteers". Applications close 5pm 17 September. For more details visit http://www.acd.org.au/about_us/job_vacancy.htm or phone (03) 9500 1232 or 1800 654 013 (rural callers only).

OF INTEREST?

Who Own's My Disease?

In the scramble to patent human genes, companies have put profits ahead of patients' needs. Now some families with congenital disease are staking a claim on the genetics revolution – and their own DNA. For the full article visit <http://www.motherjones.com/news/feature/2001/11/gene.html>

Access To Easy English Articles and Fact Sheets

Disability Online (www.disability.vic.gov.au) in conjunction with the Better Health Channel (www.betterhealth.vic.gov.au) are translating many of their health and disability topic articles and fact sheets into "easy English" format. Examples of recent news and media releases: "An insight into the world of autistic children", and "Who cares? What becomes of the state's forgotten people when their ageing parents die?" For more details and to view articles go to <http://www.disabilitynews.infoxchange.net.au/>

Untangling the Web - Where can I go to get information about disabilities?

You may like to check out <http://www.icdi.wvu.edu/others.htm> This website contains a USA listing of disability information and links to sites that provide information on multiple disabilities or disability issues.

LEADERSHIP OPPORTUNITY

Leadership Plus - Calls For Nominations

Leadership Plus is a community organisation that promotes people with disabilities as leaders in Australian/Victorian society. They are seeking nominations from individuals or organisations, of people with disabilities to undertake their inaugural Leadership Program 2004/05. They are targeting people with disabilities who have leadership potential. The Program is TAFE accredited, run by RMIT, and requires a time commitment of 7 X 3 day workshops, the first of which is a retreat in November 2004. Nominations close 20th September. For information, selection criteria and application/nomination forms email taskey@leadershipplus.com or contact Leadership Plus by phone (03) 9481 7154.

