

# GSNV UPDATE

## November 2004

For past GSNV updates, visit the "news & events" section of our website [www.gsnv.org.au](http://www.gsnv.org.au)

### GSNV NEWS

#### Your new Committee

We have some new faces and some familiar faces on the 2004/2005 GSNV Committee of Management. We are lucky to have such a dedicated and diligent crew of individual members, representatives of support groups and interested professionals keen to progress GSNV's vision of **overcoming genetic challenges**.

<i>President:</i>	Tony Briffa	Androgen Insensitivity Syndrome Support Group
<i>Vice-President:</i>	Tony McDonald	Down Syndrome Association
<i>Treasurer:</i>	Sharon Lewis	Public Health Genetics, MCRI
<i>Secretary:</i>	Ray Hee	Individual member
<i>General Committee Members:</i>		
	Jeff Craig	Chromosome Research, MCRI
	Marjorie Cresp	Porphyria Association
	Mark Files	Unique in Australia
	Andie Hider	Androgen Insensitivity Syndrome Support Group
	John McKenna	Individual member
	Carly Weber	Short Statured People of Australia
	Andrew Williams	ozED – Ectodermal Dysplasia Support Group

### 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](mailto:info@gsnv.org.au) by 1 December 2004.*

Event: **A Spring Sunday**

Date: **21 November**

Group: **Young Australians Fighting Friedreich's Ataxia (YAFFA)**

To raise money to support research into Friedreich's ataxia, a debilitating neurological condition, YAFFA are staging a live music event called *A Spring Sunday* at Xavier College, Kew on Sunday, November 21. Proceeds from the day will go towards helping researchers at the Murdoch Children's Research Institute find a cure for Friedreich's ataxia. For more information and to book tickets to the event, visit <http://www.yaffa.org.au/>

Event: **Research Day**

Date: **2 December**

Group: **Huntington Research Group**

All are welcome to attend this FREE research day at the Conference Room, Ground Floor, Main Building of St George's Hospital. Please email [maree.farrow@med.monash.edu.au](mailto:maree.farrow@med.monash.edu.au) if you are planning to attend for catering purposes.

Event: **Christmas Party**

Date: **4 December**

Group: **Gippsland Neurofibromatosis Support Group**

Christmas already? This year's lunchtime breakup/Christmas party is being held at The Reggardo's home in Bairnsdale. RSVP by 19<sup>th</sup> November to Eddie on phone 5134-1070.

## **WEBSITES OF INTEREST**

*If you know of any informative/thought-provoking websites, please email [info@gsnv.org.au](mailto:info@gsnv.org.au) with a few lines on what the site includes, and we'll share your discovery with other GSNV members.*

**<http://www.mav.asn.au/cpp>**

The **Civic Participation Project** aims to increase the participation of people with disabilities in local government by developing and strengthening disability advisory committees throughout Victoria.

**[www.healthinsite.gov.au](http://www.healthinsite.gov.au)**

**Health Insite**, an Australian Government initiative, is an information-rich, "gateway to reliable health information". It's really worth bookmarking, because everything at this site goes through a strict quality assessment process so you know that it contains up-to-date and trustworthy information. I had a quick look and found the sections below. See what sparks your interest.

- ❖ Disability Support Services (46 listings)
- ❖ How To Assess Health Information Online
- ❖ Living with a Disability (24 resources)
- ❖ Self Esteem in Childhood (16 resources)
- ❖ Self Esteem in Young People (32 resources)

**[www.nutritionaustralia.org](http://www.nutritionaustralia.org)**

**Nutrition Australia** aims to encourage all Australians to achieve optimal health through food variety and physical activity.

## **OPPORTUNITY**

### **SPAN Community Hub Project**

The SPAN Community House in Thornbury received funding from the Dept. of Victorian Communities to support the development of small non-profit community groups. They have the capacity to offer training and support to 4 more community-based organisations until December 2004. The training can include committee procedures, constitutions, financial systems, attracting funding, managing projects, volunteer management, recruiting members, management disagreement, computers and info management, needs analysis, policy development and strategic planning. For more details contact Justin Chubb by phone 9480-1364 or by email [justin@spanhouse.org](mailto:justin@spanhouse.org)

## **CONFERENCES / SEMINARS**

### **7<sup>th</sup> World Congress of Bioethics, Sydney – 9-12 November**

This Congress of the International Association of Bioethics is happening in Sydney from 9-12 November. There are events for members of the public to participate, as well as health professionals and students. For more information visit [www.bioethicsworldcongress.com](http://www.bioethicsworldcongress.com)

## **A Workshop for Self Help Groups in Shepparton– 12 November**

COSHG - The Collective of Self Help Groups - is running a **FREE** workshop for people setting up or involved in self-help groups. The workshop, supported by funding from the Reichstein Foundation, offers a chance to share your skills and develop new ones. The main topics of discussion will be:

- ❖ Advocacy skills for you and your group
- ❖ Running meetings
- ❖ Fundraising and grant submissions
- ❖ Conflict resolution

Afterwards, there is a forum called "*Do you know your phone rights?*". Contact COSHG to book or for more information on (03) 9349-2301 or [rural@coshg.org.au](mailto:rural@coshg.org.au)

## **Physical Disability Council of Australia Conference, Perth – 19 & 20 November**

The conference entitled, "*Nothing about us without us. Empowering ourselves and others!*" is a national forum hosted by the Physical Disability Council of Australia Ltd (PDCA). For program details and to register, visit <http://www.pdca.org.au/>

## **GRANTS**

*Before applying, we strongly recommend that you contact the provider to ensure your eligibility.*

### **Grant: Fund for Individuals**

Provider: Foundation for Young Australians

Funding: Max. per grant: \$3,000. (Average grant expected to be from \$500 - \$1,500.)

Closes: Ongoing

Purpose: To financially support young people aged 12-25 years to enhance their skills and experiences in order to continue to make a positive contribution to the community.

The Foundation aims to promote "meaningful change for young people". For further information including selection and exclusion criteria, application forms, examples of funded grants, visit [http://www.youngaustralians.org/funding\\_opp/youth\\_part\\_ind.html](http://www.youngaustralians.org/funding_opp/youth_part_ind.html) or phone 1-800-252-316 or email [fya@youngaustralians.org](mailto:fya@youngaustralians.org)

### **Grant: Hewlett-Packard Grants**

Provider: Hewlett-Packard Australia Ltd

Funding: Mainly in kind donations

Closes: Ongoing

Purpose: To provide grants of **computer products and systems** to support not-for-profit or charitable organisations in the area of education and e-inclusion.

Application forms, HP's general policy outlines and assessment criteria can be found at <http://hp.com.au/hpinfo/philanthropy.asp>

### **Grant: Disability Employer Incentive Strategies – Workplace Modifications Scheme**

Provider: Dept. of Family and Community Services (FACS)

Funding: Various

Closes: Ongoing

Purpose: To provide employment opportunities to eligible job seekers with disabilities through the provision of financial assistance for specific workplace modifications or purchase of special equipment.

For additional information search for "workplace modifications" at <http://www.facs.gov.au> or phone 1-800-814-838 or email [workmods@facs.gov.au](mailto:workmods@facs.gov.au)

Grant: **Tattersall's Centenary Award**

Provider: Tattersall's

Funding: \$8,000

Closes: 22 November 2004

Purpose: To provide assistance to the "less fortunate, the needy and the infirmed", as stated in the 1904 will of George Adams, the Founder of Tattersall's.

Charities, organisations or individuals whose sustained efforts make a difference to the quality of life for people in the local community are eligible to be nominated for the \$8,000 award. Look for the official nomination forms in participating Leader Newspapers (phone 9875-8000).

*Strictly speaking, this isn't a grant program. However, if you know an AMP Financial Planner, why not approach them about this program so that you can double the amount you fund raise?*

Grant: **Community Fundraising Program**

Provider: The AMP Foundation

Funding: Max. per grant: \$10,000

Closes: Ongoing

Purpose: To encourage and support AMP Financial Planners to fundraise for their local community.

The AMP Foundation matches dollar for dollar, any money the Planners raise, up to \$10,000. In the past year, AMP Financial Planners have raised more than \$1.6 million through charity balls, relays, lunches and firework displays for not-for-profit organisations throughout Australia. For more information search for "community fundraising" at the <http://www.amp.com.au/au/home> website.

## **FUN**

### **Pram Jam 2004 – 27 November**

Pram Jam 2004 is a family fun run and pram push aimed at raising money for the **Children's Cancer Centre** and to promote a healthy lifestyle for the whole family. Kick off the holiday season with a 3K or 6K walk or run around Royal Park in Parkville with your friends and family. Included in your registration fee (family -\$45, adult -\$25, child -\$15), you will receive jingle bells to wear on shoes, and a T-shirt with the Pram Jam 2004 logo. Following the run there will be live music, food stalls, a raffle with great prizes to give away and "show" bags for all. For more information and to download the registration form please click on [http://www.rch.org.au/ccc/index.cfm?doc\\_id=7419](http://www.rch.org.au/ccc/index.cfm?doc_id=7419)

### **REMINDER - Next Committee Meeting**

6:00 – 7:30pm

**Wednesday, 1 December**

Venue: To be Announced

*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](mailto:info@gsnv.org.au)**