

# **GSNV Update**

## **March 2005**

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

### **GSNV NEWS**

Special Projects Grants – Submissions Close 17th MARCH!

See the Grants section of this newsletter.

### **Farewell Lindy**

Lindy Hogkin has been our Genetic Support Worker for almost twelve months. She has decided to leave, to focus on her career as a Genetic Counsellor. While we are sad to see her go, we wish Lindy well and thank her for her contribution to GSNV.

### **GSNV EVENTS**

**YOUR SAY - Participation in Your Health– 15th March**

The Department of Human Services (DHS) and GSNV are holding a focus group to discuss your experiences and how the ‘Participation in Your Health Service System: Victorian consumers/patients, carers and the community working together with their hospital and the DHS’ policy affects you and your family. The focus group will be held on Tuesday 15th March at 10 am at RCH (10th floor). For information about the policy, phone Catherine at DHS on (03) 9616 9055 or visit [www.health.vic.gov.au/consumer](http://www.health.vic.gov.au/consumer). RSVP to Leah at GSNV on 8341 6315. Morning tea provided.

### **YOUR SAY – GPs – 31st March**

Australian Genetics Alliance and GSNV want to hear what you have to say about GPs. What makes the GPs role different? What do GPs do well? What could GPs do better? This is part of a national project and will lead to a national report. Come along to a half-day forum at RCH (10th floor) on Thursday 31st March. Light breakfast from 8.30, start at 9am. Please RSVP to Leah on 8341 6315. We have funding to cover your parking expenses for this session.

### **Brochure Workshop - 28th April 2005**

Are you interested in creating a fantastic brochure for your group? Come along to a workshop on Thursday, 28 April at The Royal Children’s Hospital to get tips on how it’s done. The wonderful and talented MaryAnne Aitken (Murdoch Children’s Research Institute, Genetics Education) will facilitate this workshop. FREE for GSNV members, \$5 for non-members. Reserve your place by phoning Leah on 8341-6315.

### **Klinefelter Syndrome Evening**

We are considering holding an information evening for boys and men with Klinefelter syndrome (KS). We’d like to hear whether you are interested in a seminar on KS and your suggestions about what the information should involve. To express your interest in attending, and for any suggestions, please contact Leah on 8341-6315.

### **GROUP EVENTS**

**MDA 2005 Medical and Scientific Seminar – 15th & 16th March**

The Muscular Dystrophy Association is holding its annual Information MD! 2005 Seminar on the 15th & 16th March at the National Neuroscience Facility. The seminar provides information on Muscular Dystrophy and related Neuromuscular Disorders. The Seminar is being held during International Brain Awareness Week. For more information, please contact the MDA on 9320 9555 or visit [www.mda.org.au](http://www.mda.org.au)

### **CleftPALS Family Fun Day – 20th March**

CleftPALS are celebrating 30 years in Australia with a family fun day on the 20th March from 11:00am – 3:00pm at Diamond Valley Railway Eltham, Eltham Lower Park. Free entry. Rides \$2.50/passenger. For more information, email [cleftpalsvic@hotmail.com](mailto:cleftpalsvic@hotmail.com)

### **Parents Cancer Connect Program Launch – 6th April**

The Cancer Council Victoria is launching its Parents Connect Program. The guest speaker will discuss communicating with children when there is a cancer diagnosis. The launch will be held at the Cancer Control Research Institute, 100 Drummond Street Carlton at 12.30pm. RSVP by 1st April by calling the Cancer Helpline on 131120.

### **Sibstars**

Sibstars is a 6-week program for families to support siblings of children with a disability or chronic illness (aged 8-16 years) and their parents. The aim is to help siblings and parents work together to deal with stressful times in the family, and to help parents support siblings. Participation involves one parent and one sibling in the family reading written information and receiving weekly telephone support. No travelling is required. For more information phone Rebecca on 9482 1939 or email [beccg@yahoo.com](mailto:beccg@yahoo.com)

### **CONFERENCES**

#### **Rubinstein Taybi Syndrome (RTS)**

Are you interested in attending a conference on Rubinstein Taybi Syndrome? To register your interest, phone Helen Johnson on 51742076 or email [helenjohnson@dodo.com.au](mailto:helenjohnson@dodo.com.au)

#### **RCH Expo 2005 – 10th & 11th March**

The RCH Expo 2005 “Interconnections – health, education, communities and families working together for better outcomes” will be held on the 10th & 11th March in the Ella Latham Lecture Theatre of The Royal Children’s Hospital, Flemington Road, Parkville.

#### **Australian Cerebral Palsy Association National Conference – 14th & 15th March**

“Pathways to Citizenship - Therapy, Communication & Technology”

The Conference is on 14th & 15th March at Hilton International Hotel, Adelaide. For more information, visit [www.sapmea.asn.au/conventions/acpa2005/index.html](http://www.sapmea.asn.au/conventions/acpa2005/index.html)

#### **Autism Victoria 2005 State Conference – 19th & 20th July**

Autism Victoria will be holding a state conference on 19th & 20th July at the Melbourne Exhibition Centre. For more information, phone Autism Victoria on (03) 9885 0533 or visit the web site at [www.autismvictoria.org.au](http://www.autismvictoria.org.au)

#### **International Congress of Human Genetics**

The International Congress of Human Genetics will be held in Brisbane in August 2006. For more information, go to [www.ichg2006.com](http://www.ichg2006.com) or phone (07) 3844 1138.

## **CONNECTING FAMILIES**

Ehlers-Danlos syndrome (EDS) Type 1

An 11-year-old girl in Victoria, who likes piano and choir and has EDS Type 1, would like contact with a girl about her age with the same condition.

A family in Victoria would like contact with other families anywhere in Australia living with EDS type 1 to share experiences, either on-line or in person.

Please contact Leah in the GSNV office by phone (8341-6315) or email ([info@gsnv.org.au](mailto:info@gsnv.org.au)) if you would like to contact either of these families.

## **ADVOCACY**

New Advocacy Service - DEAC Legal Advisory Service

Disability Employment Action Centre (DEAC) Legal Services provides legal and industrial advocacy to people with a disability who have been discriminated against in the areas of employment, education and training. Their new Legal Advisory Service operates Wednesday nights from 6pm-9pm as a drop-in service at level 5, 55 Swanston St, Melbourne. Clients from regional/rural Victoria can access this service via the free toll number 1800 332 265 (free call). For more information, phone Noni Lord on 9655 1117.

## **GRANTS**

GSNV Special Projects Grants

GSNV is offering \$50-\$400 per grant for one-off projects that meet GSNV objectives. A total of \$2,500 is available among all groups. For an information sheet and application form, visit the GSNV web site ([www.gsnv.org.au](http://www.gsnv.org.au)) or contact Leah on 8341 6315.

Applications close Thursday 17 March 2005

### **The Jack Brockhoff Foundation**

A Community Services & Development grant is available to assist a wide range of charitable organisations, particularly the smaller and lesser known groups which do not have access to widespread publicity and professional fundraising. No specific limits to funding amounts given. For more information, contact Mr Kem Mayberry on 9842 0667

Applications close 30 March 2005. Apply by mail

### **Perpetual Trustees Grants**

The Foundations managed by Perpetual support a wide range of charitable projects in the areas of: social & community welfare, education, medical & scientific research, environment and arts & culture. Amounts granted vary, with the average between \$5,000 and \$10,000. For more information, phone Charitable Planning Services (02) 9229 3951 or visit [www.perpetual.com.au/subject.asp?subject=philanthropic&page=1](http://www.perpetual.com.au/subject.asp?subject=philanthropic&page=1)

Closing date: 31 March 2005 Apply via website

### **Utility Relief Grant Scheme - Dept of Human Services (Vic)**

Community Services & Development grants provide once-off assistance for domestic customers who are unable to pay their utility bills due to a temporary financial crisis. Assistance is available for the following bills: Electricity, Gas and Water. People wishing to apply to the scheme for assistance must contact their gas, electricity or water company to obtain an application form. Ph: DHS 9616 7839

Closing date: Ongoing

## **GROUPS & SERVICES**

### **Parent Support Network – Eastern Region**

The Parent Support Network – Eastern Region (PSN) provides support and information to parents and carers of people with disabilities, who reside in the Eastern Region of Melbourne. Services include: access to support groups in the region, volunteer contact parent coordination, advocacy, information, and workshops. To find out more, contact Nektaria on 9853 3229.

### **Association for Children with a Disability**

The Association for Children with a Disability provides information, support and advocacy to families who have a child with any type of disability in Victoria. Most of the Association's staff and committee are parents so they know what it means to have a child with a disability. Parents/family members, professionals and service providers are welcome to contact the Association for information and advice on any issue, phone 03 9500 1232 or 1800 654 013 (rural callers only) or visit [www.acd.org.au](http://www.acd.org.au).

### **Holoprosencephaly Australia Support Group**

This is a new group is for parents, relatives and friends of children with Holoprosencephaly and related brain malformations. To find out more, contact Lee-Anne on 0409 444 863, email [rlbroeren@optusnet.com.au](mailto:rlbroeren@optusnet.com.au) or visit <http://groups.yahoo.com/group/ausholoprosencephaly>

## **WEBSITES**

### **On-line Support Group for People with Chronic Illnesses**

In 2000, the Chronic Illness Alliance established a delphi forum on-line discussion group as a means for people with chronic illnesses to contact others around the world about issues of concern. Web: <http://forums.delphiforums.com/chronicillness/start>

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

6:00 – 7:30pm, Wednesday, 6 April 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 on (03) 8341-6315 or email [info@gsnv.org.au](mailto:info@gsnv.org.au)

*Want to get this Update every month? Not on the GSNV mailing list? Contact Leah on 8341 6315 or email [info@gsnv.org.au](mailto:info@gsnv.org.au)*