



GSNV Update

March / April 2007

GSNV NEWS

Welcome to the March/April GSNV Update! We have lots of exciting things coming up in the next few months – our first Coffee Morning on April 16th, the Small Grants Project (applications close 20th April, so be quick!), and of course our second Genetic Support Awareness Week in July, kicking off with a midwinter Family Day on July 1 for all our members and their families. This month's personal story is from Donna at the Haemophilia Foundation. We hope you enjoy reading it...maybe even enough to volunteer a story of your own for our next edition or for the Family Book...? We could go on and on, but we won't. The Update speaks for us – we hope you enjoy it!

Morning Coffee- Monday, 16th April **New**

Join us for morning tea and meet others 'in the same boat'. (It's amazing how much people have in common, even when faced with different conditions!) Morning coffee will be held from 10.00-11.30am in Ascot Vale. See the flyer for details and a map.

GSNV Small Grants Project **Last Call for Applications **

Last reminder- applications close **Friday 20th April!** If you require another application form or more information, phone Leah on (03) 8341 6315 or email leah@gsnv.org.au .

Genetic Support Awareness Week – Sunday 1st to Saturday 7th July

Genetic Support Awareness Week raises awareness of genetic conditions and what it means to be affected by a genetic condition. Activities include a ***Family Day***, a ***Seminar*** and a ***Genetic Support Display*** at the Royal Children's Hospital. Details are on the next page, or phone Leah at GSNV on (03) 8341 6315.

Be part of Genetic Support Awareness Week!

You and your family are invited to join us at Family Day or come along to the seminar. Genetic Support Awareness Week is also a great opportunity to raise awareness about your genetic condition and increase the profile of your group. You may like to get behind Genetic Support Awareness Week by holding your own activity...a seminar, a family day, a special Genetic Support Awareness Week mailout, or perhaps share your story with the media. *Please tell us about your Genetic Support Awareness Week activities so we can include them in our calendar! We can also provide you with information about Genetic Support Awareness Week, support groups, GSNV and genetic-related topics. If you speak with the media, Leah is happy to be interviewed by your journalise or provide a GSNV Press Release about Genetic Support Awareness Week.*

GSNV CALENDAR

16 April	Coffee Morning
20 April	Small Grants Close

1-7 July Awareness Week

1 July	Family Day
TBA	Seminar
ALL WEEK	Display at RCH



genetic support network of victoria

support information ... education ... advocacy



GENETIC SUPPORT AWARENESS WEEK PROGRAM

GSNV Family Day – Sunday, July 1

This year's Family Day will be held as the very first event of our Genetic Support Awareness week! With a midwinter theme, this day will include yummy winter food, Giant Board Games, gingerbread people and animals to decorate (and EAT!), craft activities, and storytelling & entertainment from a mystery guest (so mysterious that even we aren't quite sure who it will be yet). Bring your family, photos for craft activities, and your inner child to this cosy winter gathering! (Venue and time TBA)

Seminar - Date & Topic to be advised

GSNV, in partnership with Genetic Health Services Victoria, will hold a seminar during Awareness Week. Speakers will raise awareness of key issues relevant to life with a genetic condition. The seminar will be open to health professionals, people affected by genetic conditions and interested members of the wider community. See the May-June Update for more information.

Display at RCH - Friday 29 June to Monday 9th July

Posters, photos and brochures will be on display in the first floor display area at the Royal Children's Hospital, near the cafeteria and gift shop. Posters will discuss key issues and aspects of genetic support available to individuals and families affected by a genetic condition.

You Can Help Us!

Help us tell people about the benefits of peer support – without leaving home! Leah is collecting photos and quotes for our display at the Royal Children's Hospital, as part of Genetic Support Awareness Week.

PICTURE DISPLAY

We're trying to show in picture terms what it means to be affected by a genetic condition – the happy, the funny, the everyday, the battles and the triumphs. We're after photos of you, your family, a support group event. Perhaps you're doing something special or maybe it's a happy snap taken in the kitchen. Whatever it is, please send it to us! Email your digital pic, or mail in your printed photo (if you'd like your photo returned, please make sure you provide your name and postal address).

IN YOUR WORDS

We'd also love to include short quotes from you about the value of speaking with others "in the same boat". Please send us a sentence or two about how meeting others in a similar situation has benefited you. Or perhaps you'd like to sing the praises of your own support group, and tell us about how your group has made a positive impact on your life. Quotes can remain anonymous – please let us know if you don't want your name to appear on the display.

You can email your photos and/or quotes to Leah at leah@gsnv.org.au or post them to GSNV, PO Box 1100 Parkville 3052. If you have any queries, please phone the GSNV office on (03) 8341 6315.



OTHER GSNV NEWS

GSNV Family Book

We've been getting some wonderful feedback about the personal stories in this newsletter which will eventually become part of the Family Book – but we really need your help to ensure that the book is more than blank pages! Tell us about yourselves, your hobbies, your experience of living with a genetic condition, of diagnoses or lack thereof, of helpful or unhelpful schools or medical personnel or...? What inspires you? What makes you happy, or angry, or sad? What made you join the GSNV? Still stuck for something to write about? Ring the office on 8341 6315 and have a chat to Catherine or Leah – we'd love to hear from you.

Seminar: Starting a Support Group

The Starting a Support Group seminar was held on Tuesday 7th March at the Wingate Avenue Community Centre in Ascot Vale. Six enthusiastic people joined us for a comprehensive rundown on starting a support group, some travelling from as far afield as Frankston and Geelong. Andrew Williams, founder of OzED, shared his experiences and tips, and Leah Lonsdale (GSNV Coordinator) provided some general information and hints. All participants received a copy of the great COSHG book called 'In the Same Boat'. Handouts are available from the GSNV office. Phone Leah on (03) 8341 6315 or email leah@gsnv.org.au to have a copy of the notes posted to you.

SG News – Newsletter for Support Groups

We have now sent out two editions of *SG News*, a newsletter specifically for support groups. This short-and-sweet newsletter includes a great selection of information and details of upcoming events of interest to support groups for people with genetic conditions. Sections include 'hot topics', upcoming grants, info for your members, Genetic Support Awareness Week information for groups, events and advocacy topics.

One of the features of *SG News* is the 'Your Say' section. GSNV has around 140 genetic support organisations on its mailing list – and each group has considerable knowledge and expertise. The 'Your Say' section is a great way for groups to ask questions and get ideas from other group leaders who have faced similar challenges while running their groups. Groups are invited to write in to 'Your Say' with questions and ideas, and to respond to questions asked by other group leaders.

...and of course, if you come across something of interest to other groups, please let us know so we can put it in the *SG News*!

Does your genetic support group receive *SG News*? Contact your group to check, or phone Leah on (03) 8341 6315.

GROUP EVENTS

Short Stature Symposium – Sunday 20th May

The Short Stature People of Australia and Victorian Clinical Genetics Services are hosting a Symposium on Sunday 20th May from 9.30am till 4.00pm. This symposium came about through parents and families wanting more information on the condition. For more information, contact Lisette Curnow at VCGS on (03) 8341 6250 or email lisette.curnow@ghsv.org.au.

Cri-du-Chat Support Group Meeting – Sunday, 22nd April

Horseshoe Bend Farm, 11am. Contact Wendy for details info@criduchat.asn.au

OzED Family Day – Sunday, 6th May

The OzED (Australian Ectodermal Dysplasia Support Group) Family Day for Victoria will be held on Sunday, 6th May at the White Hills Botanical Gardens (Bendigo) – Epsom Road, White Hills – from 11.00 am to 3.00pm. This is a chance for families to get together in an informal setting, and there is no cost for the day.

Cardiomyopathy Association of Australia Meeting – Sunday 20th May

The Cardiomyopathy Association will hold meetings in Victoria on Sunday 20th May,

Sunday 26th August (the AGM will be held prior to this meeting) and Sunday 25th November at the Coles Myer Auditorium, 1st floor, Epworth Hospital, Bridge Road Richmond. Meetings start around 10.30am and include a cuppa, informative guest speakers and a shared lunch. Contact Joan Kerr at jakerr@iprimus.com.au, or visit the web site at www.cmaa.org.au.

Camp MDA – 19th – 23th June

The Muscular Dystrophy Association (MDA) will be holding its winter camp from Monday 19th June to Friday 23rd June in Maldon. To learn more, visit: www.campmda.org/.

4th International Congress on Shwachman-Diamond Syndrome – Boston MA, 10-12 June

Venue: Conference Center at Harvard Medical School. Keynote speaker: Dr David Nathan. Further information: www.sdscongress07.com.

Cornelia De Lang Syndrome Conference – Niagara Falls, Canada, 25-29 July

Venue: Sheraton on the Falls, Niagara Falls, Canada; Date: 25th to 29th July 2007. Visit www.cdscanada.ca/page3.php to learn more.

GROUPS AND SERVICES

Supporting Aussie Kids with Kabuki Syndrome (SAKKS)

SAKKS is an Australia-wide group with representatives and contact people in each State. Further information: www.sakks.org.

XXWhy: The Australian Support Group for Klinefelter Syndrome * NEW GROUP*

James has recently started an online group for people with Klinefelter Syndrome. Visit the website at <http://www.xxwhy.com> or email James@xxwhy.com.

Support After Fetal Diagnosis of Abnormality (SAFDA)

SAFDA is a facilitated shared experience group for parents who have ended a pregnancy because of fetal abnormality. Contact Alison Thornton on 9344 2121 for more information.

Support Group for Parents Preceding with an Affected Pregnancy *NEW GROUP*

Support, information, coffee and TimTams for parents and families proceeding with an affected pregnancy. Contact Kitty on 9571 6246 for more information.

MEET OUR MEMBERS

Haemophilia Foundation Victoria (HFV)

Assisting people with bleeding disorders, their family and friends in Victoria

About HFV

Haemophilia Foundation Victoria Inc (HFV) is a self-help, not for profit organisation that provides support, information and services for people affected by bleeding disorders, their families and carers in Victoria. HFV lobbies and advocates for the best possible services for its members, and provides education to the community about bleeding disorders.

HFV provides telephone contact with other members, workshops and information sessions, Family Camps, picnics and social functions, conferences and peer support groups. HFV can also assist with SOS Talismans and Medic Alerts, Ambulance Subscriptions, Conference Attendance and Educational costs. Counselling is also provided through professional counsellors are based at The Alfred.

HFV has a range of pamphlets, books and videos on bleeding disorders, pain relief, diet and exercise, blood borne viruses and alternative therapies. Some information is

also available through the HFV website. HFV can organise speakers on request.

A quarterly newsletter keeps members informed of Foundation activities and events and provides information on bleeding disorders and other relevant topics.

History of HFV

HFV has come a long way in the 53 years since its launch in 1954. Here are just a few of our achievements:

- the option of home treatment
- safer product
- prophylactic treatment
- free equipment
- free product

Contact HFV

The Centre is open from 8:30am to 4:30pm, Monday to Thursday.

Address: 13 Keith Street, Hampton East,
Victoria 3188

Phone: 03 9555 7595

Email: info@hfv.org.au

Website: <http://www.hfv.org.au>

About Haemophilia

Haemophilia is a bleeding disorder in which one of the clotting factors in blood (Factor VIII in Haemophilia A, or Factor IX in Haemophilia B) is deficient. The lack of clotting factor means that people with haemophilia tend to bleed internally into joints and muscles, leading to chronic pain and arthritis. These bleeding episodes may occur spontaneously (without any apparent cause) or as a result of injury. Bleeding can be stopped by infusion of the missing clotting factor by intravenous (i.v.) injection. Haemophilia can be mild, moderate, or severe, depending on the level of clotting factor deficiency.

Haemophilia primarily affects males, who inherit the gene for haemophilia from their mothers, although approximately one third of all cases appear in families with no history of haemophilia. Women who carry the gene for haemophilia are usually healthy, although some may have reduced Factor VIII levels, leading to a mild bleeding disorder.

Treatment

There is no cure for haemophilia, however the development of clotting factor concentrates has meant that it can be managed effectively through i.v. injections of blood plasma or recombinant (synthetic) concentrates to replace the missing or defective clotting factor. Australian children with haemophilia today face few limitations and their life expectancy is the same as that of any other Australian child.

OUR STORY: ADAM – A simply Amazing Little Boy

By Donna

I remember the first time I was asked "Do you have a bleeding disorder in your family?" It was in the early hours on the morning of 6th May 2004 and I was sitting in the Emergency Ward of the West Gippsland Hospital at Warragul. I had just sent Grant my husband home with our two year old daughter Emma, to try and get some sleep while the doctors were working out what was wrong with our seven-day-old son Adam. As far as I knew, neither of our families my family nor my husband's had a history of a bleeding disorder in them.

The paediatrician on call explained that Adam's body was shutting down as he was bleeding internally everywhere. Adam's odds of surviving were 50/50. I could not believe what I was hearing; we went from thinking Adam had picked up gastro (as he earlier projectile vomited two feeds) to now knowing he was in a life threatening situation. I remember thinking if only they could find out why he was bleeding he would stand a chance of surviving.

After what seemed like an eternity, the Warragul emergency team and the N.E.T.S team were able to stabilize Adam enough for him to be moved by ambulance to the Royal Children's Hospital. Within an hour and a half of walking through the Neo Natal Unit intensive care doors at the RCH, Adam was diagnosed with severe Haemophilia A and rushed into the operating theatre to stop the intracranial hemorrhage that had occurred (unbeknown to anyone) at birth. Adam had two thirds of his body blood in his head and one third in his body. He was in a critical condition. At that point I wanted to be sure I fully

understood what Haemophilia was and how I could help Adam with his recovery. I studied every piece of Haemophilia information that I could get my hands on (and I still do).

Remarkably, from the moment Adam came out of theatre, he never looked back. He really is a little fighter and his progress amazes everyone. We were determined to provide Adam with every opportunity for his development so with lots of love, positive attitude, physiotherapy and external stimulation (often expertly provided by his sister Emma); Adam has caught up in nearly all developmental areas. Adam is still overcoming some balance issues associated with the bleeding to the left side of his brain which may take twelve months to overcome.

Yes, there have been plenty of bruises and bumps and stress attacks by Grant and I along the way and there will be more to come. Especially, as we are learning the boundaries of Adam's condition as far as what may make him have a bleed etc. Quite amazingly, Adam hasn't had another trip to the hospital since his initial diagnosis. Yet he is a typical boy and at times plays quite rough. We are still working through the process of finding out how Adam came to have Haemophilia.

Adam starts three-year-old preschool in the second term of this year and he is testament to the saying that 'miracles do happen' and there is no limit as to his future.

From this experience Grant and I now understand what it means to be an advocate for your child.

RESOURCES

Technical Aid to the Disabled – TADVic

TADVIC is an organisation whose volunteer members design, construct or modify equipment for people with disabilities where no commercially available solution will meet their needs. It is funded by a DHS grant and donations, and staffed by occupational therapists, who co-ordinate metropolitan projects, and admin support staff. There is no charge for the TADVIC service, but clients are asked to reimburse the volunteer for any cost of materials and travelling expenses incurred.

TADVIC operates throughout Victoria, with over 200 volunteers throughout the state, and approximately 500 projects completed each year. The central office is based in Kew, Melbourne, but branches are also located in Ballarat, Barwon, Bendigo, Central Gippsland, East Gippsland, Peninsula, Shepparton, South Gippsland, South West and Sunraysia.

Visit www.tadvic.asn.au to learn more, or call the central office on (03) 9853 8655 or 1300 663 243 if you would like one of the above branches to assist you.

Green PC opens 'Super Store'

Green PCs are recycled personal computers that are refurbished and repackaged into usable Internet-ready computers and then made available to low-income communities, individuals and community organisations. The only qualification for an individual or family to have access to a Green PC computer is that they be holders of current Health Care Cards or are able to verify their low income status in some other way. Green PC have opened a "Super Store" in the Brotherhood of St Lawrence shop at 462 Geelong Rd Footscray, with a range of PCs on display, as well as 2nd hand printers and other peripheral devices. Visit Green PC online at <http://www.greenpc.com.au> or call 1300 306 645 for more information.

GRANTS AND FUNDING

DHS Capital Grant Scheme

This grant assists by repairing or replacing major essential gas, electrical or water appliances which are faulty and/or have failed within the last 12 months. It is available to households which hold a current Concession Card and own the property for fixed appliances. You do not need to own the property if you are applying to have a fridge or washing machine repaired. For more information phone 1800 658 521 or 9616 7600, or visit <http://hnp.dhs.vic.gov.au/wps/portal> .

DHS Utility Relief Grant Scheme

The Utility Relief Grant scheme provides assistance to low-income individuals and families who are unable to pay electricity, gas or water bills due to a short-term financial crisis. The grant provides for full or partial payment of an outstanding utility bill where the applicant is at risk of disconnection for non-payment. Application forms are available from electricity and gas retailers, and water authorities. For more information criteria for this scheme visit the website at http://www.dhs.vic.gov.au/concessions/guide/g_finance.htm , or call the Concessions Unit on 1800 658 521.

If you don't have access to the internet, the GSNV staff are happy to print information on any of these grants or awards and post it to you. Please phone GSNV on (03) 8341 6315.

ADVOCACY

GSNV takes on Secretariat role in the AGA

There are more than 1000 genetic support groups in Australasia. The Australasian Genetic Alliance (AGA) facilitates networking between these groups, health professionals and patients and families to improve community and professional knowledge of genetic conditions, their impact and available services.

The Alliance has taken a lead advocacy role in representing members' interests in national genetics issues. The AGA provides written and verbal submissions to Government and others in the field of genetics and participates with like bodies nationally to further represent Genetic Support Groups and their members.

The Australasian Genetic Alliance (AGA) is an alliance between genetic support and advocacy networks from around Australia and New Zealand. GSNV is one of the founding members of the Alliance and continues to be very active within the Alliance to represent people in Victoria affected by genetic conditions and their families.

Because the AGA has no funds of its own, duties are shared between all participating groups. The Secretariat rotates between member groups every two years.

From July 2007, the GSNV will take up the mantle of Secretariat to the AGA. This means GSNV will be the official contact point for the AGA. The AGA Co-Chairs from July will be GSNV's Vice President and immediate-past President, Mr Tony Briffa, and our multi-talented Coordinator, Leah Lonsdale.

If you have something you would like raised at a National/Australasian level, you can contact Tony on (03) (03) 9315 8809 or email aissg@iprimus.com.au, or phone Leah at GSNV on (03) 8341 6315 or email leah@gsnv.org.au.

Want to know more about the AGA? Visit www.australasiangeneticalliance.org.au

Calling for Community Consultants!

Are you living with a genetic condition? Interested in health provision and policy? If you've answered yes to these questions, the GSNV would love your help in a new project to improve consumer representation in healthcare. In 2005-2006, our Advocacy Worker, Claire, trained 17 'Community Consultants' to represent themselves and their peers on health policy and provision committees. Now, the GSNV is seeking volunteers to act as 'emergency consultants' for occasions when our Community Consultants are unable to help out due to illness or short notice – but when community representation is still needed. If you are living with a genetic condition – either your own, or as the carer of someone with a genetic condition – are interested in advocacy, and would be available to attend occasional meetings (generally during the day, but sometimes on evenings and weekends), we'd love to hear from you. Training in advocacy is preferred, but not essential – our priority is to have a list of people to call on in emergency situations. Call Leah on 8341 6315 or email her at leah@gsnv.org.au to learn more.

DISABILITY AND AND TELECOMMUNICATIONS

Linking people with communication or speech difficulties into telecommunications - CAUS

CAUS is a provider of services to people with disabilities. Its new national project links people with communication or speech

difficulties into telecommunications. The project will involve meeting with people who experience communication or speech

difficulties throughout Australia and identifying their telecommunication needs e.g. mobiles, national relay service, internet, telephones and any barriers preventing them from accessing these services. CAUS will promote and raise awareness about telecommunication to people who experience speech and communication difficulties and ensure that

appropriate training and support exists to build confidence in using the technology provided. Focus groups will be held in each major city Australia-wide in early 2007 and questionnaires will be available to fill out. For more information, or to participate, visit www.caus.com.au or phone 03 9557 5551, rural: 1800 995 383 or email mwilliams@caus.com.au.

New guideline for making payphones more accessible to people with disabilities

A new industry guideline to ensure that payphones are accessible for people with disabilities has been developed by Communications Alliance and the Human Rights and Equal Opportunity Commission (HREOC).

The Accessibility of Payphones Industry Guideline (G630:2006) sets benchmarks that can be used in the design, siting and installation of payphones.

The guideline states that payphones should be installed so they can be more easily accessed by people with wheelchairs or other mobility aids; they should have features including volume control so that people with hearing impairments can use the phone; and they should have other features such as keys that are recessed or concave, with clear lettering and/or numbering that allows easy use for people with vision impairments or other physical disabilities.

Communications Alliance, in collaboration with HREOC, brought together representatives from government, the payphone industry and the disability sector to develop a draft guideline, which was subsequently released for public comment. After consideration of the responses, the guideline was finalized and approved by the Communications Alliance board last Friday, 1 December.

Communications Alliance CEO Anne Hurley encouraged payphone manufacturers, installers and operators to use the guideline in their disability action plans as a new benchmark for payphone accessibility in Australia.

"Publication of this guideline represents a commitment to the development of industry-wide best practices for increasing the level of accessibility of payphones and thus to a narrowing of the digital divide," Ms Hurley said.

Human Rights Commissioner and Commissioner responsible for Disability Discrimination, Graeme Innes, said there was a growing number of Australians with particular needs for whom communications equipment, including payphones, must be accessible.

"Although adoption of this guideline by the payphone industry is voluntary, we are encouraged by the cooperative spirit that has gone into its development and see this as an important achievement," Mr Innes said.

The guideline can be viewed and downloaded from the Communications Alliance website www.commsalliance.com.au

Got any news for this page? Know of an advocacy group or organisation that should be featured? Contact the office on 8341 6315 or email info@gsnv.org.au to tell us about it...