



January, 2013



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From the Team



Happy New Year to the GSNV Community!

Hello and welcome to the first edition of Bits & Pieces for 2013. We hope all our members had a happy and safe Christmas and New Year. It is a slow start to 2013 with many of our support groups still enjoying the holiday period and not yet convening for formal meetings. We are keen to however get all the important dates and events locked into the 2013 calendar, so please let us know what's important to you in the coming months.

Save the Date
Rare Disease Day



RARE
DISEASE
DAY

28 FEBRUARY 2013

February 28th, 2013 marks the sixth international Rare Disease Day. On and around this day, hundreds of support groups and organisations will be holding awareness raising activities around the central theme: *"Rare Disorders without Borders"*. Stay tuned for more information on how GSNV will be celebrating this day and how you can contribute to an international commitment to the awareness and research of rare diseases.



GSNV Volunteer Program



The Genetic Support Network of Victoria is introducing a new Volunteer Program. This program is an opportunity for our support groups to source suitable volunteers to help them with various small tasks. The tasks may vary, but some examples are assisting with mail-outs, updating databases, creating a simple brochure, or assistance organising an upcoming event or fundraiser. The volunteers will be students in the Masters of Genetic Counselling program (the University of Melbourne), or students interesting in applying for the Masters and seeking some hands-on experience in the genetics community. The GSNV may also engage volunteers from its broader networks and community. In order to get this program off the ground, we need to know what you need!

In the coming weeks a GSNV representative will be contacting support groups to scope how we may assist with providing some volunteer time and how we can match volunteer skills with support group needs. Please help us to help your support group by providing your feedback and taking up this opportunity. Further information will be posted in coming editions of Bits and Pieces but in the meantime if you have a need for a volunteer, please let us know at info@gsnv.org.au.



Support Group News



Advisory for those with Asthma or other respiratory illnesses

The Asthma Foundation of Tasmania (AFT) is advising all people with Asthma or other respiratory illnesses in bushfire affected areas to ensure they take the necessary precautions to protect themselves against elevated levels of high intensity smoke.

Those without their blue/grey reliever medication are advised supplies are available at their local pharmacy and/or for those who are cut off by fires, supplies will be available at their nearest Refuge Centre, however should they have an uncontrollable asthma attack they are asked to simply dial 000.

For full article, <http://tasmaniantimes.com/index.php?pr-article/advisory-for-those-with-asthma-or-other-respiratory-illnesses/>

ALDS Group Assisting Those with Vision Impairments

The Australian Leukodystrophy Support (ALDS) Group is generously providing financial assistance to assist people with vision impairment as a result of their leukodystrophy/ leukoencephalopathy. Through the Brian Kirby Foundation for the donations of funds, ALDS has also set up a 'share library' of toys and equipment. This 'toy library' is free and available now to all ALDS members. Contact the ALDS office on (03) 9845 2831 or email mail@alds.org.au to discuss how ALDS can assist you.

Have your personal stories published

Spinal Muscular Atrophy Association (SMAA) of Australia will be publishing a book with 12 short stories about people's experiences with spinal muscular atrophy. Are you interested in adding your story to this book? SMAA has already begun to take submissions and subsequent books will be published pending on the number of submissions. Email your stories to smaaa@smaaustralia.org.au.

MDACTION

The MDA community recently launched a new association for Canberra and surrounding regions. MDACTION "is all about providing a solid base for the emerging growth in demand for even more support and services to our community" said long time supporter and fundraiser for MDA, and local Canberra resident David Hall.



Read more about MDACTION [here](#).

New Website for IDFA

Immune Deficiency Foundation Australia (IDFA) recently launched their new website. It is still undergoing construction with content uploaded regularly. Visit the new IDFA website on <http://www.idfa.org.au/>.

HeartKids Awareness Month

February is HeartKids Awareness Month. HeartKids is raising awareness and funds in your local community. Come down to the venues listed below for a BBQ and support HeartKids.

Saturday 2nd Feb: Chadstone Shopping Centre, Greensborough Plaza

Sunday 3rd Feb: Masters Burnside, Western Highway

Saturday 9th Feb: Eastland Shopping Centre (Ringwood), Box Hill Centro

Sunday 10th Feb: Bunnings Port Melbourne

Saturday 16th Feb: Bunnings Geelong, Echuca

If you are able to volunteer at any of the following, please email Sarah Currie at sarah.currie@heartkids.org.au for more details.



In the Media



Announced: Victorian State Disability Plan 2013-2016

On December 19th, 2012, the Minister for Community Services Mary Wooldridge announced the release of Victorian state disability plan 2013-2016. This plan outlines the government's vision and plan, and strategies for the next four years.

To read the Victorian State Disability Plan 2013-2016, visit <http://www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/plans-and-strategies/disability-services/victorian-state-disability-plan-2013-2016>

David Amor on Evenings with Dominic Knight 702 ABC Sydney

Victorian Clinical Genetics Services Director and Paediatrician David Amor joined the program 'Evenings with Dominic Knight' on Monday night (07/01/2012) to discuss genetics. Dr Amor says the cost of gene testing is plummeting, which will have dramatic implications for the management and diagnosis of patients, and discusses advances in areas including reproductive and cancer testing.

Top Genetic Findings of 2012

Research organisation 23andMe has compiled the top genetic findings of 2012. Take a moment and look back at the ten most interesting and significant findings of 2012.

Source: <http://blog.23andme.com/23andme-research/top-genetic-findings-of-2012/>

Computer games to benefit children with cerebral palsy

Computer games aren't usually thought of by health practitioners for their health benefits, but thanks to developments recently completed by the Flinders University and the UniSA, they may become a prominent part of rehabilitation programs.

To read the full article, <http://www.abc.net.au/local/stories/2013/01/08/3665717.htm>



Conferences / Seminars / Workshops



Inaugural Angelman Syndrome Symposium

Foundation for Angelman Syndrome Therapeutics is hosting a research symposium at the Royal Children's Hospital on Friday 1st February. The symposium will include scientific and clinical presentations and workshops for medical and research professional with the focus on creating pathways for Australian research and funding opportunities.

Date: Friday 1st February
Venue: Ella Latham Theatre
Royal Children's Hospital
Flemington Rd, Parkville, VIC

For more information on the symposium, please view the [event flyer](#).



Forum for Young People Living with Rare Diseases: The challenges of the many transitions to adulthood!

The Australian Paediatric Surveillance Unit is holding a forum for young people aged between 15 to 20 years old who have a rare disease or condition. It's not just about transitioning from child to adult health services but also other transitions you might be going through: final exams, higher education, employment, and relationships.

This forum aims to:

- Connect with other young people with similar experiences
- Share views and focus attention on issues that matter to you
- Give you an opportunity to contribute to advocacy for better health and community services for young people living with rare diseases
- Share and listen to inspirational young people living with a rare condition

A limited number of support packages will be available to off-set the costs of attending for young people from rural areas of NSW and from interstate.

Date: 23rd February, 2013
Time: 8.30 – 2.30pm
Venue: The University of Sydney
New Law Building
Camperdown, NSW

For more information or to register your interest, please contact the APSU.

Phone: 02 9845 3005

Email: apsu@chw.edu.au

4th Annual National Dementia Congress

The Federal Government already recognises dementia as a national health priority. Now, more than ever, there is a need to share findings and discuss the progress of dementia care initiatives to allow for greater understanding and collaboration of ideas. The event will delve into a broad range of topics from diagnosis through to palliation across the continuum of care. Topics include early detection and diagnosis of dementia, the difficulties of acute care, partnering with disability services, developing a person-centred care approach, younger onset dementia, the use of psychotropic medications, environmental design, pain relief and palliative care. The conference also features a number of real-world examples of innovative practice, exploring the theme of doing things differently in dementia care.

Date: 21-22nd February, 2013
Venue: Novotel Melbourne on Collins
Melbourne, VIC

For more information, http://www.iir.com.au/conferences/government/national-dementia-congress?utm_source=Carers+Victoria&utm_campaign=213e90a099-VOICE10_01_20131_10_2013&utm_medium=email

Carer Support Group Facilitation Workshop

Carers Victoria is offering a one-day, introductory program for new carer support group facilitators, a refresher for current facilitators, or for those wanting to start up a carer support group.

This workshop is FREE for family carers and \$80 for workers. Lunch, morning and afternoon tea will be provided for participants. Bookings are essential: Tel – 03 9396 9560 or email judith.oliver@carersvictoria.org.au.

Please note: If workers are able to bring along two carers (per worker), the workshop is free for both workers and carers.

Date: Tuesday 12th March, 2013

Time: 10am – 2.30pm

Venue: Footscray

For more information, please contact [Carers Victoria](#).



Community



Carn the Kids

“Carn the Kids” is all about providing some fun for kids with events and fundraising. Melbourne Victory Football Club and North Melbourne Football Club are kicking off their kids ‘Fun Day Out’ around the country. Carn the Kids provide kids who may have never had the chance, the possibility to experience a fun day out at a football match: the sights, the smells, the sounds - accompanied by the quintessential Aussie meat pie.

For upcoming Carn the Kids events, visit the [Carn the Kids website](#).

Run For Strength – Sunday February 24th, 2013

The 4th Run For Strength event will be held on 24th February to raise funds for research into Muscular Dystrophy at the National Muscular Dystrophy Research Centre. The event is held at Albert Lake Park and event options are a 5km walk, a 5km run or a 10km run.

For more information, contact the Muscular Dystrophy Australia office on (03) 9320 9555.

65Km for Cystic Fibrosis – Saturday March 2nd, 2013

65km for Cystic Fibrosis is an endurance walk around a 10.8km track in the beautiful Royal Park and Princes Park in central Melbourne. Either take on the challenge and go for the full 65kms yourself, or put together a team of your friends or colleagues and share the distance!

For more information, to register or to donate, visit the [65Kms for Cystic Fibrosis website](#).



Run for the Kids – Sunday March 24th, 2013

Join over 35, 000 Melbournians in 2013's *Herald Sun/CityLink Run for the Kids*, to raise money for the Royal Children's Hospital Good Friday Appeal.

Entries are now open for the 8th annual event. Register for Victoria's largest fundraising fun run in either the long super course or the family friendly short course and contribute to raising money for a cause that touches all Victorians.

Visit [Run for the Kids](#) to register.



Resources



FoodSwitch

The George Institute and Bupa Australian Health has just released a great new app, FoodSwitch, to help you make better and healthier food choices when grocery shopping for you and your family. This app has two major features, FoodSwitch and SaltSwitch, both which features a traffic light styled labelling for fat, saturated fat, sugars, salt and energy content.

For more information and to download, visit

<https://itunes.apple.com/au/app/foodswitch/id478225318?mt=8>



Better Health Channel App

The Better Health Channel (www.betterhealth.vic.gov.au) has provided Australians with trusted, up to date and easy to understand health and medical information - quality assured by the Victorian Government. The site has consistently been ranked Australia's No.1 health and medical information website. The app builds on the superior information you've come to expect from the Better Health Channel by providing only the best healthy living and medical information – all quality assured for your peace of mind.



Livewire.org.au

Livewire.org.au, a program of the Starlight Children's Foundation, is an online community to help young people aged 10 to 20 years, and their families, cope with the impact of a serious illness, chronic health condition or disability. It is a safe online space where members can connect and share experiences with others not only in Australia, but also the United States and Canada, who understand what they are going through.

Visit www.livewire.org.au for more information and to register online.

Solu-Cortef Care Kit for CAH

Solu-Cortef pouches are now available Australia wide to individuals to store and carry their injectable medications for adrenal crisis. Normally obtained through endocrine nurses, you can now contact the Pfizer Customer Service Unit directly on 1800 675 229 to receive your pouch.

Seeking Contact

The GSNV works hard to connect individuals and families interested in sharing their experiences and insights with others. People interested in contacting others “in the same boat” can contact the GSNV to provide details and we will assist in making connections.

- Atypical Haemolytic Uraemic Syndrome
- Osteogenesis Imperfecta
- Ring Chromosome 8
- Langer-Gideion syndrome
- Undiagnosed genetic conditions
- Hereditary Sensory Autonomic Neuropathy
- Incontinentia Pigmenti
- Palmar Plantar Keratoderma
- Carriers of Balanced Translocation
- Stickler syndrome
- Cloacal Anomalies
- Pitt Hopkins Syndrome
- Noonans Syndrome

If you would like to make contact with others in the same boat and share your experiences with the above conditions, please either contact the GSNV office by phoning (03) 8341 6315 or by emailing info@gsnv.org.au.

We are committed to your privacy

No details will be published without your consent, and those that are published will not include personal contact details. We will obtain consent from both parties before connecting individuals and families.

Disclaimer

The GSNV works to support contact between individuals and families to share experiences. However, in individual cases, there may be differences in approach and opinion. Those placed in contact are alone responsible for the views and opinion shared.



GSNV Calendar

Inaugural Angelman Syndrome Symposium	1 Feb	VIC
34th Annual Lorne Genome Conference	17 Feb	VIC
4th Annual National Dementia Congress	21-22 Feb	VIC
Forum for Young People Living with Rare Disease	23 Feb	VIC
Run for Strength	24 Feb	VIC
Williams Syndrome Family Support Group Pool Party	24 Feb	VIC
Rare Disease Day 2013	28 Feb	National
65 Kms for Cystic Fibrosis	2 March	VIC
Carer support Group Facilitation Workshop	12 March	VIC
Run for the Kids	24 March	VIC

For more events, please see our website: www.gsnv.org.au

About the GSNV

The Genetic Support Network Victoria (GSNV) is a vibrant and active organisation committed to promoting the interests and well-being of people affected by genetic conditions. We assist individuals and families with the 'human', non clinical side of genetic diagnosis, living with a genetic condition, and gaining access to supports and services. The GSNV assists in the set up of new support groups and for those already established, helps to broaden awareness and assist in their activities. The GSNV is committed to improving the sense of isolation the community may feel in dealing with genetic conditions.

The GSNV is closely associated with a wide range of support groups, clinical genetic services and peak professional bodies.

Keeping up to Date

Please continue to notify GSNV of your change of contact details either by calling the GSNV office, or via email to info@gsnv.org.au. We have launched an exciting new website and database but are still finalising the upgrade. Please bear with us as we make the updates.

Contacting the GSNV

South Building, Level 9, Murdoch Children's Research Institute
Royal Children's Hospital
Flemington Road
Parkville, Vic 3052 (Australia)
Ph: (03) 8341 6315
Fax: (03) 8341 6390
Web: www.gsnv.org.au

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