



November, 2012 2nd Edition



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From the Team



A Note from the GSNV Team

It is hard to believe 2012 is drawing to a close and we are planning for 2013. With another AGM completed and some changes with our Executive and Committee line up, we will be once again assessing, planning and implementing the best possible strategies to achieve our goals in the New Year.

The GSNV has a new Committee of Management for 2012/2013. All Committee positions were declared vacant on the day of our Annual General Meeting on October 18th, 2012. And at the following Committee Meeting nominees were accepted unopposed. A full introduction to our new Committee and Executive will appear in our upcoming Summer newsletter.

The GSNV would like to take this opportunity to thank all previous Committee Members, Jan Hodgson (VP), Geraldine Allen (Treasurer), Alice Weeks (Joint Secretary), Amanda Springer (Joint Secretary), Amy Herlihy, Maria Trintafillou and Yvonne Waite for the time, commitment and dedication to the GSNV during their tenure.

GSNV Holiday Operating Hours

Please note that the GSNV office will be closed from December 22nd to January 6th, reopening on January 7th 2013.

If you require urgent assistance or genetic support, please contact Victorian Clinical Genetics Services on (03) 8341 6201 and ask to speak to the geneticists on call.



In the Media



\$1 million boost for National Let's Read Program

Expansion of the Let's Read National Early Literacy Campaign will help give all children across Australia greater access to books, songs and nursery rhymes.

For full article, <http://www.investinaustralia.com/news/1-million-boost-national-let%E2%80%99s-read-program-12c3>.

New Broadband for Seniors Website

The Australian Government has launched a new website, Broadband for Seniors, to provide seniors Australians, age 50 years and over, with access to free computers, internet and basic training to help build their confidence in using new technology.

Broadband for Seniors benefits community clubs and organisations that provide senior services and activities and want to encourage greater participation by senior Australians. It will expand their service offerings to include new technology equipment and a broadband service to form a focus within a club or organisation's area.

Head to the [Broadband for Seniors](#) website for more information.



Community



ArtAbility 2012 – Dreams

The Atrium, Federation Square
December 10th-17th, 2012

(Media Release)

In 2012, ADEC will again be proudly presenting ArtAbility® to the public.

The exhibition will run from 10th to 17th December, and will be located at The Atrium, Federation Square, as it has been in years past. This exhibition unites a range of talented artists of all ages from a variety of cultures.



This year's theme is Dreams, and we are eagerly anticipating interpretations of this theme, presented in



a variety of mediums including paintings (oil, acrylic, watercolour), sketches, photography, collage and 3D works.

ArtAbility[®] is now in its 8th year. It provides a high profile platform for artists to express themselves in a way that transcends language, race, age, physical and mental health challenges. Many up and coming artists have gone on to host their own exhibitions after taking part in ArtAbility[®], and artworks have been purchased by many high profile customers and are on display in public and corporate venues around Melbourne.

ArtAbility[®] is proudly sponsored by the Disability Services Commissioner, Hope For The Future, Federation Square, MediQuest, Motion Printing, iD-Concepts, Community Sector Banking and Dean's Art.

ADEC ArtAbility[®] 2012

International Day of People with Disability – 3rd December

This year is the 20th anniversary of International Day of People with Disability (IDPwD), a United Nations sanctioned day that aims to promote an understanding of people with disability and encourage support for their dignity, rights and well-being. The day seeks to increase awareness of the benefits of the integration of people with disability in every aspect of political, social, economic and cultural life.

Each year individuals and communities embrace IDPwD by hosting or attending celebrations. On average, 600 events are held across Australia to celebrate IDPwD. These celebrations can include sporting events, art exhibitions, morning teas, discos, festivals, fetes, stalls handing out merchandise, and many others! No event is too big or too small to celebrate IDPwD.

Go to [IDPwD](#) for events near you!

Free Public Speaker – Twanny Farrugia

Do you belong to a service club/ social/ sports/ church/ organisation or any other group where you require a free public speaker? Then Twanny Farrugia is your man! And it costs you nothing! Since retirement, Twanny has become a volunteer free public speaker for DonateLife Victoria. DonateLife Victoria raises awareness and educates the community on organ and tissue donation in Victoria, Australia. Being both a transplant recipient and a member of a donor family, Twanny's volunteering as a public speaker for DonateLife is an opportunity for him to contribute back to the community.

For more information and to request Twanny to speak, please contact him on twannypac@gmail.com.



Support Group News



Toys for Christmas helps CleftPALS

CleftPALS is asking for your help!

[Toys and More](#) is a fundraising program that provides access to purchase great educational resources and toys whilst raising money for your nominated organisation.

Nominate 'CLEFTPALS VIC' when you order and help CleftPALS fundraise to support families who need help.

Have a browse through [Toys and More](#) for quality toys and fundraise for CleftPALS.



Huntington's Disease Youth Alliance Seminar 2012

Australian Huntington's Youth Alliance is a new body focussed on young people affected with Huntington's Disease and is putting together a friendly information day. Come along to hear personal stories and get information on: being tested for Huntington's disease, having babies, partners and relationships, unpacking the latest research and lots more!

Date: 24th November
Time: 9.00am – 5.00pm
Venue: 16 Wakefield St
Hawthorn, VIC
RSVP before November 18th.

This free information session is supported by Andrew Churchyard, Neurologist, Lisette Curnow, Genetic Counsellor, and Huntington's Victoria.

For more information, please [download the event flyer](#) or email Tony Mims on tonymims00@gmail.com.

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PWSA Victoria – 1000 Steps Fundraiser

The Prader-Willi Syndrome Association of Victoria's next major fundraising event is on Saturday 25th November. The PWSA Victoria will be venturing to Ferntree Gully to tackle 1,000 Steps and funds raised will support PWSA Victoria programs.

Date: 25th November
Time: From 8am
Venue: 1000 Steps Kokoda Track Memorial Walk
Burwood Highway & Mount Dandenong Tourist Rd
Upper Ferntree Gully, VIC

Pre-register by 21st November. You can also register on the day.

For more information, please take a look at the [fundraiser flyer](#) email info@pws.asn.au for further details.



**Funds raised will support
programs run by the
Prader-Willi Syndrome
Association of Victoria**



Conferences/Seminars/Workshops



GSNV Peer Support Training

GSNV is excited to announce this year's Peer Support Training session is to be held on **Tuesday 4th December, 2012**. This workshop is available for all individuals, including staff from support groups. It is designed to empower you to help those that are undergoing difficult situations. Some areas that the peer support training course will cover include:

- active listening
- communication skills
- empowerment
- self-care
- community resources
- information about GSNV and what we can do to help the process



This session will be facilitated by **Eilis Hughes**, Disability Services Coordinator from Disability Services Division at the Department of Human Services. You will receive a certificate upon completion as well as a Peer Support contract with the GSNV.

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Date: Tuesday, 4th December
Time: 10am – 2pm
Venue : HELP Precinct
Royal Children's Hospital
50 Flemington Rd, Parkville, VIC
Costs: \$65 per person

Please note that the GSNV has not called for membership fees this financial year and this fee is simply to cover expenses related to the session.

Places are limited and we advise you to make a booking. Registrations will close on Friday 26th November.

To book or have queries related to this training, please call the GSNV office on (03) 8341 6315 or email us at info@gsnv.org.au.

Melbourne Health – Community Health Board

Melbourne Health is holding the first Community Board meeting, where it will share the outcomes of a major initiative to develop a culture of person centred care. The Community Board meetings aim to provide the public with an understanding of how Melbourne Health operates and their plans for the future. This provides a chance for the public to get involved, to share perceptions and expectations of local health services.

This meeting is opened to all members of the public and are welcomed to attend but registrations are essential.

For more information on this forum, please download the [event flyer](#).
To register, please email communityboard@mh.org.au.

Date: 29th November
Time: 4.00pm – 5.30pm
Venue: Function Centre, Ground Floor
The Royal Melbourne Hospital
Cnr Grattan St and Flemington Rd
Parkville, VIC





Resources



“Learning to Lead” Resource for Children with Disabilities & Families

Association for Children with a Disability has produced a resource book and DVD to assist in planning support for your child with disability and family. This is a fantastic resource which is also available in different languages – Arabic, Chinese Mandarin, English and Vietnamese.

Contact the Association for a Children with a Disability on (03) 9818 2000 or email mail@acd.org.au to get yourself a copy.

Source: <http://www.johnmckenna.com.au/blog/2012/11/06/learning-to-lead-resource-for-children-with-disabilities-families/>

Ross House Facilities Survey 2012

Ross House is the only self managed and community owned non profit building in Australia and has been an important part of the social justice and environment community in Melbourne for over two decades.

Have a say on how Ross House facilities can be improved! To make Ross House as useful and accessible as possible, please fill in the 2 minute survey.

[Count me in! I'd like to fill in the survey now](#)

Connecting Up – Donor Tec program

Donor Tec is a great program from not for profit organisation Connecting Up, which provides a variety of information, IT products and resources for the not for profit and community sector. Through Donor Tec, your nonprofit organisation can access the latest products, both hardware and software, at a discounted rate.

For weekly updates on the latest software, hardware available through Donor Tec, subscribe [here](#).

For more information on Donor Tec and/ or to register your nonprofit organisation, please visit [Connecting Up](#).





Apps For You!

Advancing technology is all around us. Children these days are learning how to swipe on surfaces faster than learning how to walk! Here we have compiled a selection of apps that you may find useful.

Please note that the GSNV has not thoroughly tested all apps listed below. Refer to the iTunes web link listed for compatibility requirements.

Gene Screen

This app is a great and fun way to learn the basics of genetics. Learn how recessive genetic traits and diseases are inherited and how certain diseases are more prevalent in different populations. Gene Screen also provides information on some recessive genetic diseases and genetic screening programs.

<https://itunes.apple.com/au/app/gene-screen/id447754230?mt=8>



National Public Toilet Map

Funded by the Department of Health and Ageing, the National Public Toilet Map shows the location of more than 14, 000 public and private toilet facilities across Australia. It also includes information about each toilet, such as location, opening hours, availability of baby changing rooms, accessibility for people with disabilities and the details of other nearby toilets.

<https://itunes.apple.com/au/app/national-public-toilet-map/id323279108?mt=8>



Help Me

The Help Me app was created by Daniel Morcombe Foundation and is a great way to not only help keep kids safe but assist people of all ages by covering all kinds of personal emergency situations. This app features a 'Help Me' button which sounds a warning and allows you to send a SMS to two nominated 'safety' numbers with details of you GPS co-ordinates.

<https://itunes.apple.com/au/app/help-me/id510561786?mt=8>



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Speak it! Text to Speech

Speak it! app is a speech App which is able to read typed text out aloud. You can also copy and paste emails, documents and PDF files into Speak it! to have it spoken back to you. This app is a great resource to assist people with a speech disability with clear, natural sound voice.

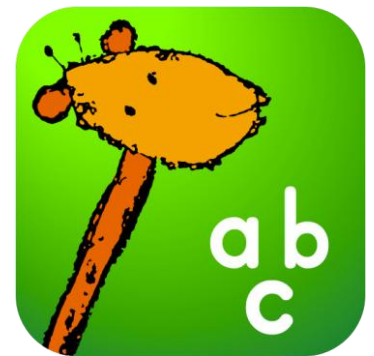
<https://itunes.apple.com/us/app/speak-it!-text-to-speech/id308629295?mt=8>



iWrite Words

Drag your finger down the screen and follow the illustrations; iWrite is an interactive, game based app which helps young children to write. This app has been listed on the New York Times for one of "The Best iPhone Apps for Kids" and the Washington Post's one of "the best iPad apps for special needs kids".

<https://itunes.apple.com/us/app/iwritewords-handwriting-game/id307025309?mt=8>



Autism Apps

This app is an app finder for people diagnosed with an autism spectrum disorder, Down syndrome or other genetic condition. Autism Apps links to any available information that can be found for each app with user reviews and video demonstrations. Using the Autism Apps, you can search through using over 30 categories such as numbers, alphabet, colours and topics to look for the app you want!

<https://itunes.apple.com/au/app/autism-apps/id441600681?mt=8>



Easy Diabetes

Easy Diabetes is a great little app for iPhone and iPad users to help easily record all information required in order to manage your diabetes. All data entered are optional and includes the ability to set glucose target levels for easy tracking. Your data can also be emailed as a spreadsheet or table!

<https://itunes.apple.com/au/app/easy-diabetes/id388621370?mt=8>



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Talking Anxiety

Sane Australia just released an app for helping people managing their anxiety. Learn how to manage anxiety face-to-face from the experts – people who've 'been there' and discovered techniques that really work and complement medical therapy. The app includes videos of people explaining the tips that worked for them, 4 sections cover a comprehensive range of topics, quizzes to test your own progress, and an optional Daily Tip sent to your iPad or iPhone.



<https://itunes.apple.com/ag/app/talking-anxiety/id542101737?mt=8>



The Victorian Women's Trust

2012-2013 General Grants Program

The Victorian Women's Trust (VWT) is currently accepting applications for projects enhancing women and girls in Victoria that lead to long term, socially progressive change and in particular address social and economic disadvantage and discrimination.

Applications for the 2012-2013 General Grants program are now opened and closes on Monday 4 February, 2013.

In addition, the VWT has a suite of Sub-Funds which are aimed at specific issues for women.

The Joan Hudson Sub-Fund

This sub-fund supports projects that provide community assistance for mothers and their children, respite care for mothers of children with high need disability and practical support for young women from disadvantaged backgrounds to access educational opportunities.

Expressions of interest for Sub-Funds are opened in early 2013.

For more information on eligibility and to view the application form, please visit the [Victorian Women's Trust website](#).



Victorian Aids and Equipment Program

The Victorian Government is providing a state-wide service which provides people with a permanent or long term disability with subsidised aids, equipment, home, and vehicle modifications. The program is funded by the Department of Human Services and administered by Ballarat Health Services Statewide equipment program (SWEP) and Yooralla Electronic Communication Devices Scheme.

Statewide Equipment Program

[SWEP](#) provides people who have a permanent or long-term disability with subsidised aids, equipment, oxygen and continence and vehicle and home modifications.

Yooralla

Yooralla manages the [Electronic Communication Devices Scheme](#) that provides electronic communication aids and associated environmental control units.

For more information on eligibility, application process and limitations, visit the [DHS website](#) or email disability.services@dhs.vic.gov.au.

Bupa Foundation Grants

Ever year, the Bupa Health Foundation looks to fund new initiatives that provide a clear benefit to the Australian community. This year, the Foundation is inviting expressions of interest for funding in these areas:

- Wellbeing
- Chronic disease
- Healthy ageing
- Empowering people about their health, and
- Promoting affordable healthcare

Charitable and not-for-profit organisations, community groups and incorporated associations (community or industry) are eligible to apply. For a more detailed look at the assessment criteria, head to the [Bupa Grants Program](#) page. Applications close 17 December 2012.

National Respite for Carers Program Expansion Funding Round

The National Respite for Carers Program (NRCP) helps support and maintain caring relationships between carers and their dependent family members by providing respite care, facilitating access to information and providing other support for carers. The NRCP currently funds community-based respite services, Commonwealth Respite and Carelink Centre and carers Australia.

The Department of Health and Ageing (DOHA) is seeking applications from health related services/ organisation/ consortia to expand or establish new respite services across Australia under the NRCP. Applicants must be incorporated bodies, financially sound and have the experience, management approach and resource capacity to provide flexible and responsive respite at the required standard.

For more information on NRCP, please visit [DOHA website](#). Applications close 14 December 2012.



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.

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

If you would like to make contact with any people with experiencing the above conditions, please either contact the GSNV office by phoning (03) 8341 6315 or by emailing lynley.donoghue@vcgs.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.

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GSNV Calendar

Huntington's Disease Youth Alliance	Nov 24 th	VIC
Prada Willi Syndrome Australia 1000 Steps	Nov 25 th	VIC
Melbourne Health – Community Health Board 2012	Nov 29 th	VIC
International Day of People with Disability	Dec 3 rd	International
GSNV Peer Support Training	Dec 4 th	VIC
ArtAbility – Dreams 2012	Dec 10 th -17 th	VIC
GSNV Offices Closes	Dec 22 nd -Jan 7 th	VIC

For more events, please see our website.

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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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