



May, 2013
2nd Edition



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From the Team



Welcome to the latest edition of the GSNV E-Bulletin 'Bits and Pieces'. As with every edition, we once again encourage contributions and feedback from our network and welcome your thoughts on our communications. This month we are pleased to announce further details of the new GSNV Volunteer Program. This program is designed to help support the work of support groups in Victoria, whilst giving training genetic counsellors the opportunity to glean a deeper understanding of the role and relevance of support group activities. Please register your support group with us and we will be pleased to match you with a volunteer.

GSNV on Social Media

GSNV is now on [facebook](#) and [twitter](#)!

***'Like' and share our page or
follow us on [@gsnv_info](#).***



Being a part of the conversation is a useful tool for interacting with the community. The GSNV wants to *listen* and *hear* how you think we can help or what we can do for you, rather than just updating you on our activities. Join in our conversation!



Support Group News



The GSNV Volunteer Program for Support Groups

The new GSNV Volunteer Program has begun! Let us know how we can help you. If your support group would like to be involved, all we need is for you to suggest a small task that you could use some help with. Some tasks we've had so far are: teaching a support group staff member how to use Facebook, preparing an information sheet to explain a rare genetic condition to health professionals, and helping to fold newsletters for a mail-out. Let us know your ideas and we'll take care of the rest!

Email us at info@gsnv.org.au or see our [website](#) for more details



The Friends of Sammy Joe Foundation supports people living with Trichothiodystrophy, Xeroderma pigmentosa and Cockayne syndrome. The Foundation is active again this year campaigning for fundraising and awareness and has some exciting events on the horizon. Congratulations to Maria Liistro and her team of dedicated supporters for continuing the vital work of the Foundation. We also extend a very big heartfelt "get well soon" to Sammy-Joe who is currently unwell.

Dinner Dance

Date: Saturday 29th June

Venue: Firenze Receptions

134 Mc Bryde St, Fawkner

Price: Adults \$70 (includes 5 course meal with beer, wine and soft drink)

Children: \$30 (includes 3 course meal with soft drink)

See the Friends of [Sammy Joe Foundation website](#) or Facebook page for more details.

Prader-Willi Syndrome

As you may be aware, the month of May has been Prader-Willi syndrome (PWS) awareness month. Our last edition of Bits and Pieces promoted some of the activities of the Prader-Willi Syndrome Association of Australia. Also during PWS awareness month the Royal Children's Hospital presented a seminar to health professionals about the impact of PWS on families. Professionals were informed about the need for a multidisciplinary approach to care for families affected by PWS, and heard perspectives from a paediatrician, weight management specialist, social worker, psychiatrist and researcher. The presenters



also discussed the benefits of early intervention, in light of PWS being added to the Better Start funding program in 2013.

Sources: Grand Rounds seminar 'Prader-Willi Syndrome: What's the Big Deal?', presented at Royal Children's Hospital, 15th May 2013

<http://www.betterstart.net.au/can-i-get-better-start/>



In the Media



Breast cancer gene ("BRCA") testing

Angelina Jolie has made genetic testing for breast cancer a worldwide conversation this month. Angelina Jolie announced in her New York Times article that she had inherited a faulty BRCA1 gene, making her at increased risk of developing breast cancer. She discussed her complex decision to have prophylactic surgery and encouraged women with a family history of breast and/or ovarian cancer to seek medical advice.

Here are some recommended articles to follow this discussion in the media:

- Geoff Lindeman, Head of the Royal Melbourne Hospital Familial Cancer Centre explains the BRCA1 gene: <http://theconversation.com/angelina-jolie-has-had-a-double-mastectomy-so-what-is-brca1-14227>
- Clara Gaff, Manager of Genomic Medicine at the Walter and Eliza Hall Institute, and Clare Scott, Medical Oncologist, follow up with more information about what you need to know before panicking: <http://theconversation.com/panicking-about-breast-cancer-heres-what-you-need-to-know-14256>

Here are some useful resources to learn more about your breast cancer risk:

- <http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/your-risk-and-breast-cancer>
- http://www.cancervic.org.au/about-cancer/cancer_types/breast_cancer

Read the GSNV's upcoming Winter Newsletter for a discussion of this highly publicised issue!

Source: Angelina Jolie: My Medical Choice in *New York Times*, 14th May 2013

Consumer Health Forum – Hip Pocket Pain Hitting Australians Hard Media Release

A new Consumer Health Forum campaign has revealed that Australians are paying some of the highest out-of-pocket costs in the world for healthcare. An Australian Government report has shown that Australians pay \$1,075 in average out-of-pocket healthcare costs, above the OECD western nations



average. There is growing concern as the Australian Bureau of Statistics has released that show that Australians are avoiding seeing health professionals or filling prescriptions because of the financial costs. Look out for a further discussion of this issue in the GSNV's upcoming Winter Newsletter.

Source: <https://www.chf.org.au/pdfs/chf/HIP-POCKET-PAIN-MEDIA-RELEASE.pdf>

National Disability Insurance Scheme Update

DisabilityCare Australia welcomes Queensland! The Queensland Government reached an agreement in the recent weeks to have the national disability insurance scheme rolled out in Queensland by mid-2019. This now means that 90% of Australians will be covered by DisabilityCare Australia.

The weeks are counting down until DisabilityCare in Victoria, New South Wales, South Australia and Tasmania.

Keep up-to-date with the progress towards the launch at www.ndis.gov.au.

Source: [National Disability Insurance Scheme Update 43](http://us6.campaign-archive2.com/?u=055092cc7e42efbfc41d80045&id=1fe3f9a69f), <http://us6.campaign-archive2.com/?u=055092cc7e42efbfc41d80045&id=1fe3f9a69f>

To Vaccinate or Not Vaccinate - The Debate Continues...

A recent survey involving 1,300 Australians has doctors worried that too many parents are reluctant to vaccinate their children. The survey was released to coincide with the documentary 'Jabbed: Love, Fear and Vaccines' which aired on SBS on Sunday May 26th.

The documentary points out that in the past, people saw and were impacted by the effects of epidemics such as whooping cough, measles and polio. However nowadays, most people are likely to have not seen these diseases and may not realise how severe they can be. Today, the debate tends to focus on the 'side effects' of immunisation as opposed to the devastating effects of diseases.

The documentary also brings up the ethical argument that a child who is not vaccinated benefits from the 'herd immunity' of all the other children who have been vaccinated. In other words; some may rely on others being vaccinated in order to avoid contact with these diseases. This has previously been debated by ethicists and public health experts.

The GSNV supports the guidelines for immunisation set out by the Australian Government Department of Health and Ageing. Immunisations as a 'preventative measure' are deemed important, in order that we contain the spread of communicable and often life threatening diseases. We do however respect that each family will need to make an informed decision and may have preconceptions and or firm opinions on the immunisation question. Based on a range of factors, each family will weigh up the risks and benefits of immunisation differently. You can watch this eye-opening documentary online on [SBS On Demand](#) until 25th June 2013.

For more information on Australian guidelines for immunisation please also go to the [Immunise Australia Program](#)



Sources: Kate Hagan, Just One Little Jab in *The Age* 20th May 2013
Jabbed: Love, Fear and Vaccines documentary
Van den Hoven, M., Why One Should Do One's Bit: Thinking about Free Riding in the Context of Public Health Ethics, *Public Health Ethics* (2012) 5 (2): 154-160.



Conferences /Seminars/Workshops



down syndrome
VICTORIA

Down Syndrome Victoria

Choosing a School Information Session

Information session for parents of a child starting Primary or Secondary School

Date: Wednesday 12th of June

Time: 6:30pm-9:00pm

Venue: The Connie Benn Centre: 160 Brunswick St, Fitzroy.

An evening of information and discussion to assist with choosing the best educational setting for your child with Down syndrome starting primary or secondary school. To register your interest please email info@dsav.asn.au

Association for Children with a Disability 'Making it Possible' Parent Workshop

How can you create a fulfilling life with choices, purpose, friendship and happiness? If you want to take the lead in achieving these goals for your child (0-18) and family, then this workshop is for you!

Build on the strengths and skills you already have as a parent to better identify, plan and achieve your goals.

The presenters are parents or siblings of a person with a disability so they do understand issues from a family perspective.



Making it Possible!

A WORKSHOP FOR PARENTS OF CHILDREN 0-18 YEARS OLD



Eastern Region:

Mount Waverley:
Date: Wednesday 27th June 2013
Time: 9.30am – 2.45pm
Venue: Alvie Hall
Cnr High Street Road & Alvie Road
Mount Waverley 3149
http://www.trybooking.com/44702
or contact our office

Upway:
Date: Wednesday 13th November 2013
Time: 9.30am – 2.45pm
Venue: Upway Community Hall
1443 Sturwood Hwy
Lewing 3158
To Book: http://www.trybooking.com/45838
or contact our office

Cost: \$20 per patron – members*
\$40 per patron – non-members
Morning tea & light lunch included
*Membership is free for the first 12 months,
so ring the office to apply!

Workshops may be cancelled if numbers are low

Build on the
strengths and
skills you already
have as a parent to
create a fulfilling
life with choices,
purpose, friendship
and happiness!

Our presenters are parents
themselves, so they
understand the issues
families face



Association for Children with a Disability

For more information phone 9818 2000 or 1800 654 913 (rural callers)
Email mail@acd.org.au or visit our website www.acd.org.au

Other upcoming Making it Possible workshops around Melbourne:

Date: Wednesday 5th June 2013
Time: 9.30am – 2.45pm
Venue: Alvie Hall Cnr High Street Road & Alvie Road, Mount Waverley 3149

Date: Wednesday 19th June 2013
Time: 9.30am – 2.45pm
Venue: Café Bar, Swan Hill Town Hall
53-57 McCallum Street, Swan Hill 3585

Date: Thursday 20th June 2013
Time: 9.30am – 2.45pm
Venue: The Lotus Conference Room, Mclvor Motor Inn
45 Mclvor Road, Bendigo 3550

Places are limited so make sure you book early! You can see the booking details on the ACD [website](http://www.acd.org.au) or phone the ACD office on 9818 2000.

Source: Association for Children with a Disability, www.acd.org.au



The Teaching Pyramid

A Model for Promoting Children's Social Emotional Development
& Addressing Challenging Behaviour

Featuring

Associate Professor Mary Louise Hemmeter

The Teaching Pyramid is a comprehensive model designed to promote social emotional development and prevent challenging behaviour in young children. It reflects a public health model of promotion, prevention and intervention. The Teaching Pyramid provides early childhood professionals and educators with universal strategies for supporting social emotional development and preventing challenging behaviour in all children, secondary strategies for providing targeted social emotional supports for children who are at risk, and tertiary supports for children whose behaviours are persistent and ongoing.

Early Childhood Intervention Australia – Victorian Chapter acknowledge the support of [Early Learning Association Australia](#) & the [Creswick Foundation](#) in bringing Mary Louise Hemmeter to Australia.

Workshop details

Monday 3rd June 2013

The Teaching Pyramid Model

9.30am – 5.00pm \$220

Jasper Hotel, 489 Elizabeth Street Melbourne

Tuesday 4th June 2013

The Teaching Pyramid & the VEEJLDF

1.30pm – 5.00pm \$110

Jasper Hotel, 489 Elizabeth Street Melbourne

Tuesday 4th June 2013

Coaching to Implement the Pyramid Practices

9.30am – 1.30pm \$110

Jasper Hotel, 489 Elizabeth Street Melbourne

Tuesday 11th June

The Teaching Pyramid & the VEEJLDF

9.30am – 1.00pm \$90

QV Women's Centre, 210 Lonsdale Street Melbourne

Please note all sessions except for the 11th June include lunch.

If you are registering for all three events ECIA VC is offering the discounted price of \$380.

Register Now!

Log on to:

<http://www.eciavic.org.au/events/category/ecia-vc-workshops-conferences>

For enquiries please contact our office:

T: 03 9819 5266

E: exec@eciavic.org.au





Community



Chronic Illness Alliance Survey: Parking and Access to Melbourne's Public Hospitals

Over the years there have been many reports on the rising cost of parking in Melbourne's public hospitals. These costs are thought to be higher than in many other countries. Unfortunately such costs are likely to be most felt by people with chronic illnesses. Below is a link to a survey to explore how these expenses impact on the people we represent.

The results will be used to publicise the problems people with chronic illnesses face and to provide the basis for a better understanding of people's needs.

Complete the survey [here](#). This survey will remain open until 14th June.

Source: Chronic Illness Alliance

Doctors Not Doing Enough to Help Pregnant Women Quit Smoking

A Murdoch Childrens Research Institute study surveyed 2,500 pregnant women in Victoria. The research found that half of the women surveyed did not receive advice from their doctors about quitting or reducing smoking while pregnant. Guidelines were introduced one decade ago to help doctors to support women in reducing smoking while pregnant. While the guidelines have been helpful, researchers warn that more needs to be done.

New Laws in the USA Promote Balanced Information About Down Syndrome

A new law has been passed in Kentucky, USA, requiring health professionals who give a diagnosis of Down syndrome to give *balanced* information about the condition. The Down Syndrome Information Act follows similar legislation in Massachusetts and it is hoped that other states and countries may follow this model. The Act requires health professionals to provide evidence-based, up-to-date information that has been reviewed by medical experts as well as Down syndrome organisations. Health professionals are also required to provide information about relevant support programs or support groups by the Act.

The rights of people with Down Syndrome are supported in the USA at a number of legislative levels. Early intervention and the provision of intervention services before the age of three for children with disabilities is mandated by Federal law under the Individuals with Disabilities Education Act (IDEA), which is the nation's special education law. IDEA also requires that special education and related services be made available free of charge to every eligible child with a disability, including preschoolers and all people age 3 -21. These services are specially designed to address the child's individual needs associated with the disability—in this case, Down syndrome



The Developmental Disabilities Assistance and Bill of Rights Act of 2000 provides a process in the US for identifying and reporting on progress achieved through advocacy, capacity building, and systemic change activities. The Act is designed to promote and expand progress in activities resulting in individuals with developmental disabilities and their families participating in the design of and having access to needed community services, individualized supports, and other assistance that promotes self-determination, independence, productivity, and integration in all facets of community life. In 2008 The Prenatally and Postnatally Diagnosed Conditions Awareness Act 2008 was a very positive step in the USA toward providing better information and support to pregnant women and new mothers whose foetus or newborn is diagnosed with a disability. The Act specifically states that families who receive a diagnosis of Down syndrome or any other condition will be offered up-to-date and accurate information about the condition and will be connected with support services to offer assistance.

“The GSNV supports the provision of evidence-based, up-to-date, accurate information about Down Syndrome to parents, when a prenatal or postnatal diagnosis of Down syndrome is delivered. This should include contact information for relevant support groups, either Down Syndrome Victoria or the GSNV. Provision of balanced information about Down syndrome is also an essential component of parents making informed decisions about prenatal testing. There is no equivalent legislation in Australia, but best practice professional guidelines also support this stance. The GSNV also supports the NDIS, The Better Start Program and all initiatives and legislative developments that provide full access and equity to education, disability and other essential services in the community as right.”

Sources:

Kentucky Legislative Research Commission, <http://www.lrc.ky.gov/record/13RS/SB34.htm>

Global Down Syndrome Foundation, <http://www.globaldownsyndrome.org/about-down-syndrome/history-of-down-syndrome/down-syndrome-human-and-civil-rights-timeline/>

Victorian Medical Research Week

The Australian Society for Medical Research’s annual national ASMR Medical Research Week® is coming up (June 1 -8). The Victorian Branch of ASMR have lots of events and activities promoting health and medical research including a Gala Dinner featuring the ASMR Medalist 2013, Professor Anna Wirz Justice, a 3RRR radio broadcast, visits to regional schools, a Scientific Symposium for young investigators and the presentation of the Commonwealth Health Minister’s Award for Excellence in Health and Medical Research as well as the Victorian Premier’s Award for Health and Medical Research.

See the ASMR website, <http://www.asmr.org.au/MRWVic.html>, for more details.

Source: <http://www.asmr.org.au/MRWVic.html>



Resources



New App helps you locate a doctor wherever you are

A holiday with a child who falls ill can make even the most relaxed parent groan. But a new website and smartphone app now shows you the way to the nearest GP or after-hours pharmacy with just a few taps on a screen.

Health Minister Tanya Plibersek launched in late-2012 a \$4.9 million internet directory which shows the addresses, opening times and phone numbers of GP clinics, pharmacies, emergency departments and hospitals in towns and cities across Australia. Ms Plibersek said the [National Health Services Directory](#) was a free service developed to provide patients accurate information about local health services wherever they are, whenever they want.

Patients can search the directory using a computer or by downloading the app onto an iPhone or Android device. Once a location is entered into the directory, services are listed and their locations can be viewed on a Google map, making them easy to find.

“This directory will be expanded over the next 12 months to include more detailed information and cover more types of health services, such as allied health providers.” Information such as languages spoken, whether they bulk bill, whether new patients are accepted and prerequisites/referral criteria will also be included. The directory is an initiative of the Council of Australian Governments and is managed by the National Health Call Centre Network, which also manages a range of services including *healthdirect* Australia, the *after hours GP helpline*, the *Pregnancy, Birth & Baby Helpline*, and the Australian Government’s new mental health web portal *mindhealthconnect*.

For the full article see: <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr12-tp-tp107.htm#>

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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
- Steroid 5-alpha reductase 2
- 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.

For a listing of support groups in Victoria see the links page on the GSNV website: www.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

| | | |
|---|--|-----|
| ASMR Victorian Medical Research Week | June 1 st – 8 th | VIC |
| IDFA National Conference | June 1 st – 2 nd | QLD |
| ECIA – Complete Teaching Pyramid Workshops | June 3 rd – 4 th | VIC |
| CCV – Role of BCNA in Breast Cancer | June 4 th | VIC |
| ECIA – Coaching to Implement Practices | June 4 th | VIC |
| ACD – ‘Making it Possible’ Parent Workshop | June 5 th | VIC |
| ECIA – The Teaching Pyramid & The VEYLDF | June 5 th | VIC |
| DSV – Choosing a School Information Session | June 12 th | VIC |
| ACD – ‘Making it Possible’ Parent Workshop | June 19 th | VIC |
| DisabilityCare conference | June 23 rd – 24 th | VIC |
| The Friends of Sammy-Joe Foundation Dinner | June 29 th | 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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