



December, 2012



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From the Team



And that's a wrap for 2012! It is hard to believe that the year is almost over. The GSNV would like to thank you for your support during this past year. We hope you have enjoyed our communications, Friday Morning Seminars and other various training and information sessions. As always, we value your feedback and look forward to developing a range of relevant activities and events based on your suggestions in the New Year.

The GSNV would like to wish you all a happy and safe holiday season, and we look forward to working with you in 2013!

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 Memoriam

The Murdoch Childrens Research Institute is deeply saddened at the loss of its esteemed and respected patron, Dame Elisabeth Murdoch AC DBE.

A founding member of the Institute in 1986, Dame Elisabeth's unparalleled generosity has enabled Murdoch Childrens to improve the health and wellbeing of children all over the world.

A renowned and universally admired philanthropist, Dame Elisabeth dedicated her life to helping others. In the process, she influenced and inspired people from all walks of life – from politicians and business leaders to families and children – to discover the joy of giving.

The GSNV would like to extend our condolences to the Murdoch family on the passing of Dame Elisabeth Murdoch.



Holiday Season Resources



The holiday season can be difficult for some. Below, we have compiled a few resources which may be useful during this time.

Managing Holiday Stress

The holiday season is approaching, and we all know this time of year can be stressful. Whether it's a big deadline at work or an overwhelming experience with families, these helpful tips can help you stay calm and jolly during the holidays:

- As hard as it may be, try to keep a positive attitude. If you put on a happy face, before you know it, you just might feel happier!
- Be assertive instead of aggressive. Assert your feelings, opinions, or beliefs instead of becoming angry, defensive, or passive.
- Learn and practice relaxation techniques; try meditation, yoga, or tai-chi



- Exercise regularly. Your body can fight stress better when it is fit.
- Eat healthy, well-balanced meals.
- Take "me time." Make time for your personal hobbies and interests.
- Get enough rest and sleep. Your body needs time to recover from stressful events.

Source: Alyson Krokosky, Genetic Alliance Weekly Tip Series.

Australian Centre for Grief and Bereavement



Whilst many are celebrating this festive season, for some, Christmas brings with it the stark reminder that a loved one is missing from their lives. Grief isn't something we just 'get over', nor is it something we can put 'on hold' until after the holidays. The emotional rollercoaster following the death of a loved one can be a real struggle and many may need to ask for additional support along the way.

The Australian Centre for Grief and Bereavement Counselling and Support Service provides a state-wide specialist bereavement service for individuals, children and families who need assistance following the death of someone close to them. The service offers face-to-face bereavement counselling, as well as bereavement support programs such as support groups, meditation and creativity workshops, information evenings, massage therapy and an annual Ceremony of Remembrance.

The Australian Centre for Grief and Bereavement Counselling and Support Service is located at:
253 Wellington Road, Mulgrave, Victoria 3170.

For further information phone (03) 9265 2100, fax (03) 9265 2150 or email counselling@grief.org.au or visit www.grief.org.au

Lifeline

Lifeline is a 24 hour telephone counselling and crisis support service. Lifeline is available to everyone everyday of the year for just the cost of a local call.

Lifeline can also provide you with information about a range of local community services that you can access. To find out what services are offered in your local area, contact [your nearest Lifeline Centre](#).

For 24 hr crisis support call **13 11 14**.

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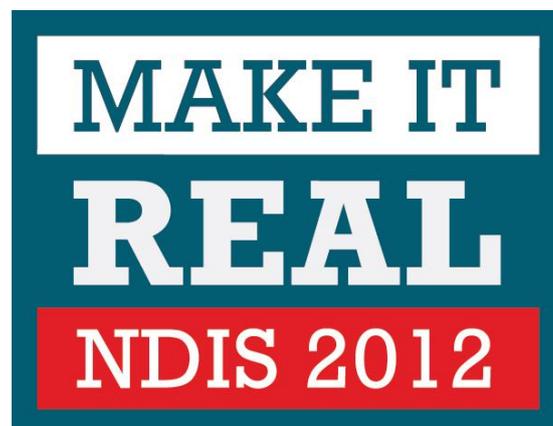


In the Media



NDIS Update

The Commonwealth and New South Wales government recently announced a full funded National Disability Insurance Scheme for NSW. This agreement will see approximately 50 per cent funding contribution by the Commonwealth and NSW. The NDIS will be fully rolled out in NSW by 2018, providing care and support for approximately 140,000 NSW residents with significant disability, and provide coverage in the event of disability to around one third of the Australian population.



Also recently introduced into Parliament was the NDIS legislation. This draft legislation sets out a framework for the national scheme – the first stage of which will benefit more than 20,000 people with disability, their families and carers in the Hunter in NSW, the Barwon area of Victoria, South Australia, Tasmania, and the ACT.

To view the NDIS draft legislation: <http://www.ndis.gov.au/towards/ndis-draft-legislation/>

For more information on NDIS, visit <http://www.ndis.gov.au>.



Community



Direct employment providing independence and choice

Direct Employment is now available for people with a disability who are directly paid their Individual Support Package funding, and offers them greater choice, control and flexibility over their supports.

As a direct employer, direct payments users have the choice of who to employ as support workers and how they provide support. This means that the direct payments user will be responsible for all of the legal, financial and human resource management obligations that come with being an employer.

The initiative is designed for people who are confident they can manage their support arrangements, along with the responsibilities and obligations required of an employer.

Individuals considering Direct Employment can visit the [Direct Employment](#) webpage on this site.



Run for the Kids – Sunday March 24, 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.

Royal Children's Hospital – Howie's Place

The Royal Children's Hospital in Melbourne has recently launched '[Howie's Place](#)', an interactive website to assist both parents in preparing their child for cardiac treatment, tests and hospital admissions.

Source: <http://www.heartkidsvic.org.au/>

12 Rules of Friendship, from a mother of a child with special needs

An email came across the GSNV desk recently which we wanted to share with the GSNV community. Written by Eliana Tardio and re-blogged by John McKenna.

1. Please educate your children about my child's condition. Don't ask them to be nicer to him because of his disability. Ask them to treat him like any other child. That's what I teach my child about yours.
2. For my birthday don't bring me flowers or presents, just give me a break and let me have some time for myself. Help me take care of my child for a couple of hours. I trust you like nobody else.
3. Don't feel sorry for me. I'm growing and learning from this. There's nothing really different between you and me. We both do our best every day.
4. Take me out! Don't let me say no. Let's wear high heels and our best make up. I need to enjoy myself.
5. Don't worry if you see me crying. Let me be alone, and understand that sometimes I need to fall to get up stronger than ever.
6. Don't be shy about sharing your children's' achievements. I'll celebrate this special time along with you. My child has his own achievements and I'm thankful that you are always there to celebrate simple things with me.



7. I know you want to help but please don't tell me how to do things better. As mothers we have plenty of things in common, but we have also some different challenges and prizes in this task. Just understand that there are things about my child that you would probably never understand, and that's okay. You don't need to understand us, just accept us. I'll do the same for you.
8. Please remind me to have faith. I know sometimes I'm over protective and I get easily scared of simple things.
9. Call me anytime when you need to talk, or stop by if you need a hug. I know my life seems complicated sometimes, but I'll always do my best to be there for you, as you are always there for me. I feel proud and happy to be able to help you.
10. Let's laugh and have fun. Call me whenever you need to talk bad about your mother in law, enjoy the latest magazine cover of Ryan Gosling, or discuss Angelina Jolie's legs. I'm here for the important stuff but I'm also here to share some laughs and "girl talk".
11. Please excuse me if I talk too much about therapies, inclusion, and stuff that's foreign to you. Sometimes I have nothing else to share. I'm not obsessed, I'm just trying to understand.
12. Finally and the most important: Love my child in his ups and downs. I swear I'll love yours the same.



Grants



Disability Self-Help Grants

The Victorian Government's commitment to supporting people with a disability and their families is reflected in the provision of non-recurrent operating grants of up to \$5000 for disability self help groups.

Disability Self-Help Grants are available to assist disability self help groups in financing general expenses and minor works and equipment.

More information on the next round of Disability Self-Help Grants is expected to be published in a few weeks. Visit the [Department of Human Services](#) website, or contact Shirana Nash on (03) 9096 0574 for more information.

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Telstra Kids Fund

The **Telstra's Kids Fund**, provided by the Telstra Foundation, aims to support a broad range of initiatives and projects, including education, sports and recreation, arts and culture, environment, social issues and disability programs. If you are Telstra employee or know someone who is this is a great opportunity to assist a not for profit/support group. For more information please got to:

<http://www.telstrafoundation.com/dir148/tfweb.nsf/telstraskidsfund/telstraskidsfund?OpenDocument&menu=3>



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.

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GSNV Calendar

GSNV Office Closes	22 Dec – 6 Jan	VIC
Portsea Polo	12 Jan	VIC
CMAA Luncheon	19 Jan	VIC
Camp MDA	20-25 Jan	VIC
34 th Annual Lorne Genome Conference	17 Feb	VIC
Run for Strength	24 Feb	VIC
Rare Disease Day 2013	28 Feb	National

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

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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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