



## September, 2012 2<sup>nd</sup> Edition



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## From the Team



### A Note from the GSNV Team

#### Save the Date GSNV AGM

The GSNV AGM is just around the corner, **Thursday, 18<sup>th</sup> October**. We invite support group leaders, members and the GSNV community come along and hear about our work in the previous financial year and our plans for 2012/2013.

The GSNV AGM Notice has now been sent. You can also find this Notice, the agenda, nomination to Committee form and proxy forms on the [GSNV website](#). We also invite you to contribute to the AGM agenda. Any general business you wish to raise in relation to the GSNV AGM must be advised to GSNV Inc. no later than October 4<sup>th</sup>, 2012. Please forward suggestions to [info@gsnv.org.au](mailto:info@gsnv.org.au).

This edition's **featured competition** is asking you to **RSVP to the AGM before October 4<sup>th</sup>** to go in the draw to win a movie pass to see the 3D release of Finding Nemo.

Please RSVP to [info@gsnv.org.au](mailto:info@gsnv.org.au) or via post to:

Genetic Support Network of Victoria  
South Building, Level 9  
Murdoch Childrens Research Institute  
50 Flemington Rd  
Parkville, VIC 3052

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## **GSNV has Facebook!**

The GSNV is joining social media! There are many support groups that support individuals through online discussions on facebook and it is time that the GSNV joins the conversation! The GSNV facebook page is still under construction, but head to our page and post suggestions and how we can assist you and/ or your support group, or just say hi!

Look out for the [GSNV facebook page](#). Like it. Share it.



## **In the Media**



### **Personalised Medicine at the Ian Potter Centre for Genomics and Personalised Medicine**

As a joint collaboration between the Murdoch Childrens Research Institute and the Walter and Eliza Hall Institute of Medical Research, a new research centre was opened on September 13<sup>th</sup> 2012, specialising in delivery treatments specific to each patient.

For more information, please read the full article/ press release

<http://www.mcri.edu.au/news/2012/september/new-centre-to-develop-personalised-medicine.aspx>

Source: <http://www.mcri.edu.au/news/2012/september/new-centre-to-develop-personalised-medicine.aspx>

### **Bullying in the Workplace**

The GSNV President Moira Rayner was recently interviewed on the ABC program, 7.30, to discuss bullying in the workplace and outcomes of the new anti-stalking laws.

Go to the ABC website to [watch the video](#). Transcript is also available.

Source: <http://www.abc.net.au/7.30/content/2012/s3587167.htm>



### **Newborn screening for Cystic Fibrosis**

Cystic fibrosis (CF) is the most common inherited, life-shortening condition affecting Australian children. It is an autosomal recessive disorder caused by mutations in the cystic fibrosis trans-membrane conductance regulator (CFTR), a transport protein found in epithelial linings.



Since the pilot carrier-screening program in 2006, the Victorian Clinical Genetic Services (VCGS) have offered CF screening to couples planning a pregnancy or in early pregnancy.

For more information on CF carrier-screening, please read the full article, [http://www.lifescientist.com.au/article/435293/feature\\_breathing\\_easy/](http://www.lifescientist.com.au/article/435293/feature_breathing_easy/)

For more information on VCGS, please visit the [VCGS website](#).

### **Letter to the World – Ehlers-Danlos syndrome**

Maddison Parker is a nine year old girl with Ehlers-Danlos syndrome, who recently wrote an open letter to the world to raise awareness for her condition. She emailed her letter to thousands of people, and has recently been featured on Today Tonight. You can view the story on the link below:

<http://au.news.yahoo.com/today-tonight/health/article/-/14753623/maddison-fights-for-eds-awareness/>

Maddison wants Ehlers-Danlos syndrome to be recognised as an important condition, and research to be conducted into the condition. Maddison has also been nominated for a Pride of Australia award for her attempts to raise awareness for her condition. You can vote for her below:

<http://peopleschoice.prideofaustralia.com.au/child-courage.php>



## **Community**



### **Saints Come Marching in for the NDIS**

The Every Australian Counts campaign is pleased to announce that the St Kilda Football Club have offered their support to the campaign for the National Disability Insurance Scheme (NDIS).

Check out the video produced by St Kilda FC about the visit to Focus on Taste here: <http://www.saints.com.au/video%20%20audio/tabid/8662/contentid/475568/default.aspx>

Read the full article here:

[http://everyaustraliancounts.com.au/saints\\_come\\_marching\\_in\\_for\\_the\\_ndis/](http://everyaustraliancounts.com.au/saints_come_marching_in_for_the_ndis/)

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## **GSNV Volunteering Program**

The GSNV, in conjunction with the Master of Genetic Counselling program (University of Melbourne) is working on introducing a new Student Volunteer Program. This program is an opportunity for support groups to source suitable volunteers to help them with small tasks. This program will be rolled out between late 2012 and early 2013 and the GSNV looks forward to informing members on how we may provide some volunteer time. Please stay tuned for further information as this program is still in development stages.

## **Improved recognition and support for carers**

The Department of Human Services (DHS) provides financial support for carers through Carer Payment and Carer Allowance. The DHS has improved recognition and support for carers. From July 1<sup>st</sup>, 2012, the DHS has improved recognition and support for carers by increasing eligibility for those receiving Carers Allowance to also receive Bereavement Payment.

For those receiving payments such as Carer Payment, Partner Allowance or Parenting Payment, payments may continue for 14 weeks following the death of the dependent, to give you time to seek alternate income support if necessary. Please see the DHS website for criteria eligibility.

Source: [http://www.centrelink.gov.au/internet/internet.nsf/payments/carers\\_allow\\_child.htm](http://www.centrelink.gov.au/internet/internet.nsf/payments/carers_allow_child.htm).

## **Discount Parking at RCH**

A reminder to GSNV members that if your child is a Health Care Card holder, you are eligible for discounted parking at the Royal Children's Hospital. To receive your discount, simply go to the Security desk located on lower ground via the white lifts and exchange your car park ticket for the discounted concession ticket.



## **Support Group News**



## **Cancer Council Hotline**

On September 7<sup>th</sup>, the GSNV hosted a Genetic Health Services Victoria seminar focusing on the support available for Victorians with cancer. This session was presented by guest speaker Janet Philips from the

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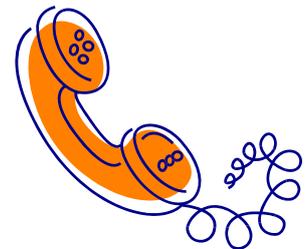
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Cancer Council's support service, Cancer Information and Support Services (CISS). One of the resources highlighted by Janet was the Cancer Council Hotline.

The Cancer Council Hotline is not only for patients and families, but also health care professionals and the general public. Lines are opened from Monday – Friday, 9-5pm and is attended by experienced cancer nurses with oncology, haematology, palliative care and a variety of other qualifications, providing up to date information on various cancer types and treatment, and support information ranging from support groups, programs to financial assistance and counselling.



Cancer Council Hotline – 13 11 20 or go to [http://www.cancervic.org.au/how-we-can-help/cancer\\_council\\_helpline](http://www.cancervic.org.au/how-we-can-help/cancer_council_helpline).

## **Caitlin's Retreat, a special place for special families**

Caitlin's Retreat in Eltham, Victoria is a beautiful property along the Yarra River. This special place is designed especially for families who have a child/ children with special needs and gives them an opportunity to getaway and enjoys a much needed break together as a family.

Caitlin's Retreat is free with facilities to accommodate up to 8 family members and able to cater to the needs of all. Bookings are now opened.

For more information, please visit the [Caitlin's Retreat website](http://www.caitlinsretreat.org) or contact Jacinta on [info@caitlinsretreat.org](mailto:info@caitlinsretreat.org).

Source: PWSA Victoria News. Issue No 15. June 2012.

## **I Can Dance Theatre**

I Can Dance Theatre is a not for profit education theatre offering programs such as performances and workshops from kindergarten through to secondary schools. All programs offered by I Can Dance Theatre promote courage, persistence and resilience, while developing social skills, self-esteem, physical well-being and cultural awareness.

**Encourage your school to have I Can Dance Theatre performance.**

Please note that I Can Dance Theatre is Victorian based.

For more information, please visit the I Can Dance Theatre website or email [enquiry@icandance.com.au](mailto:enquiry@icandance.com.au).



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## Conferences/Seminars/Workshops



### **GSNV Victorian Clinical Genetics Services (VCGS) Seminar – Klinefelter Syndrome**

The GSNV is hosting another Friday Morning Seminar. This seminar will be focused on Klinefelter Syndrome (KS) with presentations from a paediatric endocrinologist and persons living with KS.

Date: Friday 5<sup>th</sup> October, 2012  
Time: 9.00am – 9.45am  
Venue: Vernon Collins Theatre  
HELP Precinct, Level 1, West Building  
Royal Children's Hospital  
Flemington Rd, Parkville, VIC

For more information, please contact the GSNV office through phone or email.

### **GSNV Peer Support Training**

GSNV is excited to announce this year's Peer Support Training session is to be held on **Tuesday 4<sup>th</sup> 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
- loss and grief
- self-care
- community resources
- information about GSNV and what we can do to help the process

For more information, please contact the GSNV office on (03) 8341 6315. Places are limited and we advise you to make a booking. Further details will be announced closer to the date.

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## **VCFS 22q11 Forum Victoria**

Velo-cardio-facial Syndrome (VCFS) is a genetic syndrome which is a result of a deletion in chromosome 22. Individuals with VCFS have several presentations, such as cleft palates, congenital heart defects, and learning difficulty.

The VCFS 22q11 Foundation is holding the very first forum in Victoria on October 20<sup>th</sup>, 2012. This will be a great opportunity for people to come and discuss VCFS 22q11.



Date: Saturday, 20<sup>th</sup> October, 2012  
Time: 2pm—5pm  
Venue: Lecture Theatre 2, Monash Medical Centre (Ground Floor)

\$20 per person

Registration: Please register your interest by 8<sup>th</sup> October 2012.

For more information, or to register, please email Oliver [Oliver.Hopkins@southernhealth.org.au](mailto:Oliver.Hopkins@southernhealth.org.au)

## **Disability and Aboriginal Competence Workshop**

Darebin City Council invites you to attend a Disability and Aboriginal Competence Workshop to learn about providing culturally safe and responsive services to Aboriginal people with a disability and the community.

Date: Tuesday 2<sup>nd</sup> October OR Tuesday 23<sup>rd</sup> October,  
Time: 9.30am – 4.30pm  
Venue: Aborigines Advancement League  
2 Watt Street  
Thornbury, VIC

For more information, please see the [event flyer](#) or contact Christine Mulholland via email [Christine.Mulholland@darebin.vic.gov.au](mailto:Christine.Mulholland@darebin.vic.gov.au). RSPV is essential.

Source: Ross House e-bulletin. 14<sup>th</sup> September, 2012.

## **Amaze – Early Days Workshops**

Amaze (Autism Victoria) is holding FREE INTRODUCTORY WORKSHOP for parents and carers of children aged 0-6 years with a new diagnosis of Autism Spectrum Disorder. Parents with children ages 0-6 years who are currently going through the diagnostic process are also welcomed.

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Sessions are free, and lunch is provided. Bookings are essential.

For more information, venue location or to book your place, phone 1300 307 909 or [download the flyer](#) for a list of workshops in your area.

## **Leading: the next steps Association for Children with a Disability**



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.

Presenters at this workshop are parents or siblings of a person with a disability so they do understand issues from a family perspective.

Places are limited, book online or phone the Association for Children with a Disability office on (03) 9818 2000.

### **Southern Region**

When: Wednesday 24<sup>th</sup> October 2012  
Time: 9:30am – 2:45pm  
Where: Caulfield Park Pavilion  
280 Balaclava Road, Caulfield (melway ref: 59 C12)  
Cost: \$20pp – members, \$40pp – non-members

View the flier here:

[http://www.acd.org.au/community\\_ed/Downloads/2012%20Aug%20Leading%20the%20next%20steps%20Flier%20Southern.pdf](http://www.acd.org.au/community_ed/Downloads/2012%20Aug%20Leading%20the%20next%20steps%20Flier%20Southern.pdf)

Places are limited so be quick to book at: <http://trybooking.com/32010>.

### **Hume Region**

When: Wednesday 31<sup>st</sup> October 2012  
Time: 9:30am – 2:45pm  
Where: North Shepparton Community & Learning Centre  
10-14 Parkside Drive, Shepparton  
Cost: \$20pp – members, \$40pp – non-members

View the flier here:

[http://www.acd.org.au/community\\_ed/Downloads/2012%20Aug%20Leading%20the%20next%20steps%20Flier%20Hume.pdf](http://www.acd.org.au/community_ed/Downloads/2012%20Aug%20Leading%20the%20next%20steps%20Flier%20Hume.pdf)

Places are limited so be quick to book at: <http://www.trybooking.com/BWTO>.

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## Events



### DisabiliTEA 2012

The Every Australian Counts campaign for the National Disability Insurance Scheme (NDIS) will hold its second annual 'DisabiliTEA', a nationwide tea party, on Friday 26 October right across Australia.



We want this year's event to be bigger and better than last year and send a clear message to Australia's political leaders that the NDIS has strong community support.

[Host DisabiliTEA again in October](#). The more people who participate in this event, the more likely our politicians will hear our call for the NDIS.

Source:

[http://everyaustraliancounts.com.au/%E2%80%98disabilitea\\_2012%E2%80%99\\_nation\\_wide\\_tea\\_party\\_on\\_october\\_26\\_to\\_demand\\_the\\_ndis/](http://everyaustraliancounts.com.au/%E2%80%98disabilitea_2012%E2%80%99_nation_wide_tea_party_on_october_26_to_demand_the_ndis/)



## Grants



### GSNV Small Grants Scheme 2012 – applications are now closed!

Just a quick update from us regarding the Small Grants applications. Applications are now closed. We are in the middle of reviewing all applications and all successful applicants will be notified shortly. Our upcoming Spring newsletter will be featuring a few of the funded projects.

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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.

- **Osteofibrous Dysplasia**
- **Smith Magenis syndrome**
- **Coffin-Siris syndrome**
- **Pallister-Killian syndrome**
- **Osteogenesis Imperfecta**
- **Ring Chromosome 8**
- **Langer-Giedion syndrome**
- **Hereditary Sensory Autonomic Neuropathy**
- **Incontinentia Pigmenti**
- **Palmar Plantar Keratoderma**
- **Carriers of balanced translocations**
- **Undiagnosed Genetic Condition**

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](mailto: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

<b>Disability and Aboriginal Competence Workshop</b>	<b>October 2<sup>nd</sup> (or October 23<sup>rd</sup>)</b>	<b>VIC</b>
<b>GSNV Friday Morning Seminar – Kleinfelter Syndrome</b>	<b>October 5<sup>th</sup></b>	<b>VIC</b>
<b>Haemophilia Awareness Week and Red Cup Day</b>	<b>October 7-13<sup>th</sup></b>	<b>National</b>
<b>Huntington’s Disease Charity Gala Ball</b>	<b>October 12<sup>th</sup></b>	<b>VIC</b>
<b>GSNV Annual General Meeting 2012</b>	<b>October 18<sup>th</sup></b>	<b>VIC</b>
<b>VCFS 22q11 Forum</b>	<b>October 20<sup>th</sup></b>	<b>VIC</b>
<b>Association for Children with a Disability Leading: the next steps (Southern Region)</b>	<b>October 24<sup>th</sup></b>	<b>VIC</b>
<b>FSDH – “I Believe in Miracles” Gala</b>	<b>October 27<sup>th</sup></b>	<b>VIC</b>
<b>Association for Children with a Disability Leading: the next steps (Hume Region)</b>	<b>October 31<sup>st</sup></b>	<b>VIC</b>
<b>GSNV Peer Support Training</b>	<b>December 4<sup>th</sup></b>	<b>VIC</b>

**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](mailto: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](http://www.gsnv.org.au)

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