



**August 17, 2011**



Life is like a game of cards. The hand that is dealt you represents determinism; the way you play it is free will". [Jawaharal Nehru](#)

## **GSNV Office Update**

With less than 100 days to go before the big move into the new Royal Children's Hospital facility, the GSNV is mindful of the cleanout and cleanup ahead. In the coming months we will once again audit and take stock and may have a few 'interesting items' no longer needed in the office. Stay tuned for notices on items we may pass on, at no cost, to willing takers.

Please inform the office if you wish to visit so that we can instruct you on how to find us. For those familiar with level 10 of the RCH building, we are located adjacent to Genetic Health Services.

## **Our Committee**

The GSNV welcomes Paula Forsyth to our committee. Paula has recently taken on the role of Social Worker in the Adult Metabolic Clinic at Monash Medical centre in Clayton and is also a counsellor in private practice. Paula also completed the Genetic Counselling Graduate Diploma several years ago and is eager to reconnect with genetic health. We warmly welcome Paula to our committee and appreciate her experience and insight in working together on important GSNV issues.

## **Peer Support**

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 advertise their details via the GSNV or contact us directly so that we can assist in making connections.

Information sessions are a great way to connect people with shared experiences and provide an important networking opportunity, particularly for those travelling from regional areas. The GSNV will be hosting a number of information sessions and events in the coming months so keep your eye on this space!

Information sessions and other GSNV events will be advertised in both 'Bits & Pieces' and our quarterly newsletter. If you are interested in providing peer support or would like to undertake peer support training please contact the GSNV office.



### [Cancer Council, Victoria: Genetic Peer Support Program](#)

The Cancer Council, Victoria has the following support services to assist you:

**Cancer Council Helpline (13 11 20):** Our friendly, experienced cancer nurses are here to listen. They can send you reliable cancer information, explain procedures and treatments in everyday language and link you to other support services.

**Cancer Connect Cancer Connect** is a confidential telephone support program that links people who carry a cancer gene with a volunteer in a similar situation. These volunteers may be able to help you feel less worried and more able to adjust to your situation.

**“Cancer in my family” Internet Support Group:** This online group allows those that are at high risk of developing cancer because of a cancer gene or family history, to share experiences and common issues with others via a professionally moderated, private online community.

For further information, visit [www.cancervic.org.au](http://www.cancervic.org.au) or phone 13 11 20.



### [Huntington's Victoria](#)

A collaborative presentation by Huntington's Vic and the Genetic Support Network of Victoria will be presented in the very popular Friday morning seminar series aimed at clinicians and genetic health professionals. This will be an informative session which will introduce the work of Huntington's Victoria and provide invaluable patient reflections on HD.

**Date:** Friday September 2<sup>nd</sup>, 2011  
**Time:** 9.00am  
**Venue:** Conference Rooms A and B Level 10 (Access via Blue lifts)  
Royal Children's Hospital, Parkville Vic.

## **Disability News**

### [DisAbility Expo](#)

Discover the Respite Possibilities at the Eastern Disability Expo

**Date:** 15<sup>th</sup> September, 2011  
**Time:** 10am to 3pm  
**Venue:** Brandon Park Community Centre, Glen Waverley



**Website:** <http://www.respiteeast.org.au/>

## **Youth**

### **[Victorian Equal Opportunity and Human Rights Commission update](#)**

You mean we have rights? : A new interactive online tool for young women.

Alarming low awareness rates among young women about discrimination are being tackled with a new interactive online tool – [myworkrights.com.au](http://myworkrights.com.au) – launched 9/08/2011 by the Victorian Equal Opportunity and Human Rights Commission.

Commissioner Dr Helen Szoke said *my work rights* was developed in response to Commission research which revealed that more than a third of Victorian young women have been discriminated against at work and a third have been sexually harassed.

For more details please go to:

[http://www.humanrightscmission.vic.gov.au/index.php?option=com\\_k2&view=item&id=1454:you-mean-we-have-rights?-new-interactive-online-tool-for-young-women-9-aug-2011&Itemid=3](http://www.humanrightscmission.vic.gov.au/index.php?option=com_k2&view=item&id=1454:you-mean-we-have-rights?-new-interactive-online-tool-for-young-women-9-aug-2011&Itemid=3)

**Source:** This e-mail is authorised by the Victorian Human Rights & Equal Opportunity Commission.

## **Support Groups**

### **[Heart Kids – Cuppa For HeartKids School Campaign, 2011](#)**

HeartKids are inviting primary and secondary schools to host a “Mad Hatter’s Tea Party” as part of the Cuppa for HeartKids activity. To find out more and register, visit [www.cuppaforheartkids.org.au](http://www.cuppaforheartkids.org.au)

### **[Porphyria Association: AGM](#)**

The Porphyria Association Annual General Meeting will be held on Thursday August 25<sup>th</sup>, 2011 at The Nerve Centre, 54 Railway Rd, Blackburn, Vic commencing at 2:30pm.

The education topic and discussion to follow the AGM will be “Accessing Information on Porphyria”.

**Enquiries:** (03) 9845 2737, [porphyria@msaustralia.org.au](mailto:porphyria@msaustralia.org.au)

### **[Spina Bifida Awareness Week](#)**

This year Spina Bifida awareness week is Thursday 1<sup>st</sup> to Wednesday 7<sup>th</sup> September.

If you have any ideas to help with fundraising or educating people about Spina Bifida, please phone the SBFV office on (03) 9663 0075. Brochures, fact sheets, donation slips etc are available to be sent out.

Some suggestions:

- Arrange a morning tea or BBQ at work
- Give a talk at a local school



- Write to local paper
- Hold a sports or social event

### **Australian Leukodystrophy Support Group (ALDS) AGM**

The ALDS AGM will be held on **Sunday 14<sup>th</sup> August, 2011** at The Kildara Centre, rear 39 Stanhope St, Malvern, Vic, commencing at **2:00pm** until 4:30pm. The guest speaker will be Kirsten Deane, Executive Director of the National Disability and Carer Alliance.

Please RSVP directly to ALDS:

54 Railway Rd, Blackburn, 3130,  
Tel (03)9845 2831 or 1800 141 400, [mail@alds.org.au](mailto:mail@alds.org.au)

### **Other ALDS dates:**

#### **3<sup>rd</sup> ALDS Sydney Fundraising Golf Day:**

An opportunity to play a little golf and raise a little money for ALDS will be on Tuesday 11<sup>th</sup> October, 2011. See [www.alds.org.au](http://www.alds.org.au) for more information.

### **Meniere's Support Group of Victoria Annual General Meeting**

Annual General Meeting will be held on Saturday 20<sup>th</sup> August 2011 at Fenton Hall, Deaf Children Australia, corner St Kilda Rd and High Street Prahran (enter via boom gate on High St), commencing at 11.30am. The AGM will follow a presentation by Ross McKeown, from Tinnitus Association Victoria, which will examine the many claims made by pseudoscientific treatments for tinnitus.

Please RSVP directly to:

**Menier's Support Group of Victoria**

Suite 4 18-28 Skye Rd Frankston Victoria 3199, Tel: (03) 9783 9233 TTY: (03) 9781 4190 Fax: (03) 9783 9208, [info@menieres.org.au](mailto:info@menieres.org.au), [www.menieres.org.au](http://www.menieres.org.au)

### **CMTAA AGM**

**Date:** Sunday 18<sup>th</sup> September 2011  
**Time:** 3pm  
**Venu:** Lecture Room 2, Clinical Science Building  
Concord Hospital, Concord NSW  
**Contact:** [cmtaa@email.cs.nsw.gov.au](mailto:cmtaa@email.cs.nsw.gov.au)

## **Conferences/Seminars/Workshops**

### **Free Session**

Raising children can be challenging and isolating at times. Sometimes it is good to have someone with whom you can talk things through. The Parent Support Program is able to offer free counselling sessions with an advanced diploma student at Hartnett House on Wednesdays.



Free counselling will be available from Patricia Yeung, Advanced Diploma Student of The Australian Institute of Family Counselling.

Please call Thea on 9385 3235 to book a session with Patricia.

**Source:**

Thea Calzoni  
Northern Parent Support Program  
c/- Melbourne Citymission  
123 Albion Street, Brunswick 3055  
Phone: 9385 3235

**[The R.E. Ross Trust Seminar - Memory, Attention, Trauma and Learning: Translating Research into Educational Practice](#)**

**Date:** Monday 29<sup>th</sup> August, 2011

**Time:** 9.30am - 12.30pm (Registration from 9.00am)

**Venue:** Ella Latham Theatre, The Royal Children's Hospital, Parkville.

The Centre for Community Child Health at the Royal Children's Hospital Melbourne in conjunction with The R.E. Ross Trust wish to invite you to a seminar Memory, Attention, Trauma and Learning: Translating Research into Educational Practice on Monday 29<sup>th</sup> August, 2011 at The Royal Children's Hospital, Parkville. This is the third seminar in the Early Years: From Research to Policy to Practice seminar series for 2011, supported by a grant from The R.E. Ross Trust.

Working memory is recognised as a vital cognitive system that supports learning, particularly during the childhood years. This presentation will provide an overview of the relationship between working memory and other kinds of memory and executive functions, and evidence linking working memory with a range of aspects of academic attainment will be reviewed. The cognitive and behavioural characteristics of children with poor working memory skills will be described, and methods for minimising the learning difficulties associated with working memory problems including both training and classroom interventions will be discussed.

The impact of trauma on memory and brain function in young children will then be discussed and the neuropsychology and evidence in respect of interventions and how parents and children experience recovery will be outlined.

This seminar will be of interest to early childhood professionals, community child health professionals, psychologists, school counsellors, guidance officers, teachers, support and special education teachers and medical professionals.

For more information on this seminar please go to:

[http://www.rch.org.au/emplibrary/ccch/The\\_R\\_E\\_Ross\\_Trust\\_Seminar\\_Invitation\\_29\\_8\\_11.pdf](http://www.rch.org.au/emplibrary/ccch/The_R_E_Ross_Trust_Seminar_Invitation_29_8_11.pdf)

**Source:** Centre for Community Child Health, RCH



## iTaNGO

### Free workshops for non-government organisations on IT planning, cloud computing, social media & more...

In follow-up to the iTaNGO information sessions held over the past months we now invite you to attend an iTaNGO workshop.

These workshops are designed for community sector organisation (CSO) leaders to help:

- Break down the barriers to improving your use of information and communications technologies (ICT) and drive their setup forward;
- Develop an ICT plan that aligns with your organisational objectives;
- Provide information on IT training for staff;
- Understand current trends and applications and how these can assist your organisation;
- Work with similar CSOs and learn and develop from each other;
- Advise on IT infrastructure and procurement;
- Grow your understanding of cloud computing and social media and how these tools can be of use to non-government organisations.

The session will use a 'World Café' process, and provide participants with the opportunity to discuss, explore and share ICT issues. This session will also cover the philosophy and possibilities of Communities of Practice (CoPs) and encourage participants to form a CoP to take learning in this knowledge domain further. It will also cover the use of Web 2.0 tools as collaborative supports.

### **Register now**

Whether you are a member of a nation-wide or pint-sized organisation, or consider yourself technologically-savvy or IT- adverse, iTaNGO can assist you to maximise your digital proficiency.

**Melbourne:** [Tuesday 30th August](#), 10:00am- 2:00pm

**Melbourne:** [Thursday 1st September](#), 1:00pm- 5:00pm

For more info please visit: [www.itango.eventbrite.com](http://www.itango.eventbrite.com).

Source: Infoexchange

## **Government**

### NEWSFLASH from the Office for the Community Sector...

Creative Innovation Conference 2011 – Ten Complimentary Places for Regional Not-For-Profits

The Department of Premier and Cabinet, Victorian Government, is offering 10 free places for regionally based not-for-profit organisations to attend Creative Innovation 2011 – a conference where participants will have the opportunity to learn, think, connect and share ideas with over 35 of the world's most influential thinkers.



The conference will be held from 16-18 November in Melbourne. Each conference package is valued at \$3,100, and includes a complimentary pass to the conference, gala dinner and master classes. The theme of this year's conference is "The challenges and opportunities of a super-connected world".

Expressions of interest now being sought for ten free places

Ten free places are up for grabs for regionally based NFP organisations. To express your interest to attend this conference, please respond to [communitysector@dpcd.vic.gov.au](mailto:communitysector@dpcd.vic.gov.au) by Friday 26 August 2011. Applications will be assessed by a panel based on their responses to the following:

- A brief description of the work your organisation does
- How the conference will benefit your organisation
- Your capacity to attend without this opportunity
- Your organisation must be regionally based.

For more information see: <http://www.creativeinnovationglobal.com.au/ci2011/>

**The latest Policy Brief 'Policy Brief - Five Years On' is now available.** "It has been five years since the first edition of 'Policy Brief' was launched with the strapline translating early childhood research evidence to inform policy and practice. The goal was to select important issues in child and family health, review and analyse the relevant research, and 'translate' this into a series of practical recommendations that could inform policy and practice. After 21 Policy Briefs, it seems an appropriate time to review what we have achieved to date and how much there is still to do..."

Read the full issue go to: [http://www.rch.org.au/ccch/resources.cfm?doc\\_id=10885](http://www.rch.org.au/ccch/resources.cfm?doc_id=10885)  
Past editions and references are available from the Policy Brief [archives page](#).

## **NDIS Update**

The Commission's inquiry into Disability Care and Support has now been completed, and the final report sent to the Government for consideration.

The public release of the report is a matter for the Government to decide. When that occurs, the report will be available on the inquiry website, and printed copies will be sent to all participants who made submissions or who met with the Commission.

Please go directly to: <http://www.pc.gov.au/projects/inquiry/disability-support> to keep up to date with the latest developments.

## **Every Australian Counts**

**The Government has just announced that they share the vision for a National Disability Insurance Scheme and will begin laying the foundations for its introduction.**

They also released the final report by the Productivity Commission into the NDIS.



[See the Government's announcement at:: <http://www.pm.gov.au/press-office/productivity-commissions-final-report-disability-care-and-support>](http://www.pm.gov.au/press-office/productivity-commissions-final-report-disability-care-and-support)

**You made this happen. By coming together, supporting the campaign and taking action, you showed our politicians that Every Australian Counts.**

The Government's announcement today shows that when we speak up, they are prepared to listen. But as the Government has made clear, there is more to do. We are waiting for the opposition to come out in strong support of the Productivity Commission's recommendations. And over the coming weeks and months we will all want to work to ensure the government gets the details right. But first let's take some time to celebrate this colossal win for people with disabilities, their families and carers.

*Source: John Della Bosca and the Every Australian Counts team*  
[www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)

## **Community**

### **Disability Sport & Recreation (DSR)**

Disability Sport & Recreation (DSR) invites you to help celebrate International Day of People with Disability by exhibiting at our 2011 Disability Sport and Recreation festival on 2 December 2011.

The theme of this year's festival is '*Diversity in Disability*'.

This unique, interactive public event brings together the health and disability sector and the wider community to promote and celebrate physically active lifestyles through participation in accessible and inclusive sport and recreation initiatives. We would like your organisation to be a part of this great event.

Expressions of interest are due by Wednesday 31 August 2011.

**For more info please go to: <http://www.dsr.org.au/>**

## **Books**

Two recently published books give thought-provoking accounts of the authors' personal journeys towards better health through attention to spiritual, mental and emotional wellbeing. Trevor and Corinne Waller are brother and sister and have each approached the challenge of living with Hereditary Sensory Neuropathy, a degenerative neurological disorder, in their own way.

Trevor Waller's book, "Know Thyself, Vice or Virtue. My Eightfold Path to Health" is based on an eight step guide relating his own development of personal awareness in order to maintain optimal health and well-being of mind, body and spirit.



**Know Thyself. My Eightfold Path to Health**

**Trevor Waller**

**Trafford Publishing, 2010**

To contact author: [nibbanalotus@westnet.com.au](mailto:nibbanalotus@westnet.com.au)

Corinne Waller's book, "Heal Thyself, One Mind - One Truth - One Solution", charts her personal journey to improved health through resolution of "inherited and personal psychological issues" and puts forward her own theory as to the origins of disease.

**Heal Thyself. One-Mind-One Truth- One Solution**

**Corinne Waller**

**Trafford Publishing, 2010**

To contact author: [adminHSN@westnet.com.au](mailto:adminHSN@westnet.com.au)

## **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 are working on an exciting web-site and CRM upgrade so until we launch, please bear with us as we make the updates.

## **Memberships/Members Survey**

GSNV memberships now fall due and thank you to those who are up to date. Please contact the GSNV office to renew your membership if you have not already done so.

## **GSNV Calendar 2011**

<b>Huntington's Disease Seminar</b>	<b>Friday September 2nd</b>	<b>9 am</b>
<b>GSNV Support Group Afternoon Tea</b>	<b>Friday September 16th</b>	<b>1.30pm - 3pm</b>
<b>GSNV AGM</b>	<b>October – TBC</b>	
<b>GSNV Moves Office</b>	<b>Friday November 18th</b>	



## **Genetic Support Network of Victoria**

Is an umbrella organisation representing and supporting some 130 organisations and many more families and individuals across Victoria.

10th Floor, Royal Children's Hospital, Flemington Road,  
Parkville Vic 3052

Postal address: PO Box 1100, Parkville Vic 3052

Ph: (03) 8341 6315 Fax: (03) 8341 6399

Email: [info@gsnv.org.au](mailto:info@gsnv.org.au) Web: [www.gsnv.org.au](http://www.gsnv.org.au)

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