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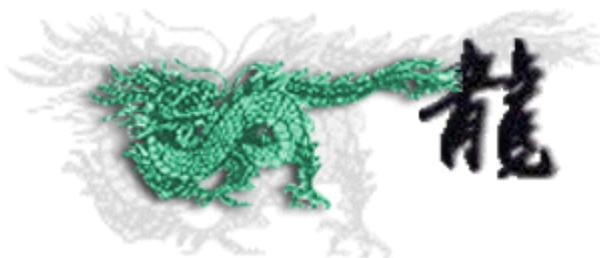
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January 31 2012

2012 The Year of the Dragon



This Edition

- * From the Committee
- * Community
- * Grants
- *
- * Conferences/Seminars/Workshops
- * In the News
- *

From the Committee

Happy New Year to the GSNV community and 'welcome back' to our Committee of Management. Our 2011 Annual General Meeting paved the way for another busy year and we thank our committee members who have re-nominating for their commitment to another term. We thank Paula Forsyth for joining us for a brief but valued time and wish her well in the future. The GSNV committee has a number of vacancies and we welcome new members to join us. If you are interested in joining the committee please contact the GSNV Office on 8341 6315 or email to info@gsnv.org.au

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Conferences/Seminars/Workshops

Experiences of Students with Disability in Victorian Schools

Recently the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) announced it was conducting research into the experiences of students with disability in Victorian schools. As part of the research, VEOHRC are holding a series of “have a say” days over the next few months to hear from students with disability and parents in regional Victoria. These regional “have a say” days will be held in Bendigo, Traralgon, Ballarat, Shepparton and Geelong.

Additional forums are also being held in Melbourne to hear from parents and students with specific disabilities. The first of these forums will be held on 14 February 2012 and will be for students with intellectual disability and their parents.

For more information about these forums please contact VEOHRC on (03) 9032 3430 or email research@veohrc.vic.gov.au.

Source: Children with Disability Australia [info@cda.org.au] E-News Bulletin January 2012

Our Community Training Programs

Our Community has recently released our training program for community organisations for the next 6 months. With short courses in grant application writing, fundraising, boards & governance and women's leadership, as well as nationally recognised Certificate and Diploma level courses, we're sure there's something for everybody.

So we thought now would be a good time to let you know about some of the training that we have coming up in the near future.

Upcoming short courses include:

2 March Morning: Strategies for Sustainable Funding Seminar (9.30am to 1.00pm)

Afternoon: Introduction to Writing Winning Grant Applications (1.30am to 4.30pm)

Venue: Angliss Conference Centre, Building A, Level 5, 555 La Trobe Street, MELBOURNE VIC 3000 Cost: \$145 per session

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9 March Course: Advanced Grant Writing Seminar (10.00am to 3.00pm)

Venue: Karstens, Level 11, 123 Queen Street, MELBOURNE VIC 3000

Cost: \$245

16 March Course: Secrets of Successful Boards Seminar (10.00am to 3.00pm)

Venue: Angliss Conference Centre, Building A, Level 5, 555 La Trobe Street, MELBOURNE VIC 3000 Cost: \$245

1 May Course: Women Achieving And Flourishing (9.30am to 1.00pm)

Venue: Karstens, Level 12, 123 Queen Street, MELBOURNE VIC 3000 Cost: \$145

2 May Course: Women Leaders - Taking the Next Steps (9.30am to 1.00pm)

Venue: Karstens, Level 12, 123 Queen Street, MELBOURNE VIC 3000 Cost: \$145

In addition to the above short courses, you may also be interested in attending and completing one of our nationally recognised qualifications:

20 to 23 February Course: Certificate IV in Governance

Venue: Karstens, Level 11, 123 Queen Street, MELBOURNE VIC 3000 Cost: \$1995

19 to 23 March Course: Diploma of Management

Venue: Karstens, Level 11, 123 Queen Street, MELBOURNE VIC 3000 Cost: \$2995

If you don't see a date that suits your needs, you may want to check out our scheduled training calendar.

If you have any questions, please contact Alan Matic by telephone 03 9320 6805 or email alanm@ourcommunity.com.au.

Our Community Grantmaking in Australia Conference 2012

Friday 24 February – Melbourne, Australia

The Australian Institute of Grants Management best/next practice conference for Australian Government grantmakers. For more information and to register on-line go to

www.grantsmanagement.com.au/conference2012

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Chronic Illness Alliance

National Disability Insurance Scheme

FORUM: Who are the winners and who are the losers?

Time: Tuesday 28 February 2012 from 2.00P.M. to 5.00 PM

Venue: Epilepsy Foundation Victoria, 818 Burke Rd Camberwell 3124

Host: Mr Graeme Shears EFV

Guest Speaker: Mr John Cain Special Projects Officer, Maurice Blackburn Lawyers

Have your say about how the NDIS will work for people with chronic illnesses and tell us what you think will work best for the people you know or represent.

RSVP: 21 February 2012 to Marion Wilde

Phone: 03 9882 4654 or mwilde@chronicillness.org.au

Chronic Disease Self-Management Special Interest Group

THURSDAY 16 February 10 am to 12 noon

Multicultural Hub

506 Elizabeth St, Melbourne (Opp Vic Market)

Parking at Vic Market, trains to Melbourne Central, trams along Elizabeth St

RSVP TO: mwilde@chronicillness.org.au or

Marion Wilde, Chronic Illness Alliance 03 9882 4654

Dr. Phyllis Lau, Pharmacist, Dept of General Practice, University of Melbourne

Integrating cultural respect into mainstream services to improve Chronic Disease Management for Aboriginal and Torres Strait Islander peoples.

Phyllis is an experienced researcher in the areas of quality use of medicines, medication adherence, and adverse drug reactions in the oncology setting. She is now engaged in research to address the appropriate care of Aboriginal and Torres Strait islander people with chronic disease

Who should attend?

- Health professionals from hospitals and community health services working with people with chronic illnesses
- Interested consumers with chronic illnesses
- and carers
- Researchers in self-management.

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Chronic Illness Alliance and Peer Support Network

Inaugural Peer Support Conference

When: Friday May 25th 2012 from 9.00 am to 4.30pm

Where: Multicultural Hub, 506 Elizabeth Street, Melbourne, (opposite Queen Vic Market)

Key Note Speaker: Doctor Craig Hassed, Senior Lecturer, Monash University, Dept of General Practice

Topic: Social Connectedness and the benefits of psychosocial supports

Contact for more information: Marion Wilde or Denise Sheard Ph: 9882 4654

Conference to be officially opened by: Andrea Coote. MLC; Member for Southern Metropolitan: Minister's Parliamentary Secretary for Families and Community Services.

Conscious Governance Nonprofit Masterclass

An intensive 1 day Masterclass that will shake long-held beliefs about strategy, innovation and creating revenue in a nonprofit environment. Would you and your board benefit from the renewal of energy and the skills to become even more strategic and innovative? Would you like the latest and most powerful strategies to get your board truly engaged and making the decisions that create the desired future for the community you serve? Presented by Steven Bowman, a leading international advisor in nonprofit conscious leadership, this Masterclass will include: "Developing a culture of leadership, strategic innovation and community engagement", "Strategic decision making: Creating a culture of strategic awareness", and "beyond the Bottom Line- Creating diverse funding and revenue streams that drive impact and sustainability".

For more info:

Contact: Leonie Gliddon

Phone: 03 9509 9529

Email: leonie@conscious-governance.com

Website: <http://www.conscious-governance.com/>

Source: VCOSS Clearinghouse: PIECES - February 1, 2012

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Support Group News

HeartKids

Beginning in February 2012, HeartKids will be holding a weekly afternoon tea on Wednesdays from 2pm – 4pm to support families with cardiac children at MonashHeart, Monash Medical Centre, Clayton.

Children with Disability Australia (CDA)

Next edition of Family Voices – Looking for Contributions

CDA is currently planning the next edition of its national publication 'Family Voices' and are looking for contributions from our members. One of the most popular sections of the magazine is "Our Children's Voices". This section provides an opportunity for children and young people with disability to share their views and opinions about their experience of disability. Some examples of the great contributions published can be found on the CDA website at www.cda.org.au.

Source: Children with Disability Australia [info@cda.org.au] E-News Bulletin January 2012

Down Syndrome Victoria

Join DSV for Family Fun Day on Sunday 25th March!!

Where: Ashwood School, Montpellier Rd 3147

Time: 11am – 3pm

What's planned: A fun family day...a chance to network, receive information on current issues, enjoy a range of activities, entertainment and a delicious BBQ

Cost – FREE to all current financial members or \$16 for non-member adults at the gate.

Not sure if you are a current financial member – contact the office.

For more info got to:

http://www.downsyndromevictoria.org.au/DSAV/Get_Involved/Family_Fun_Day.aspx

Intimo Fundraiser for Turner Syndrome Associate of Australia Ltd

When: Saturday 25th February

Where: Playmaze Narellan – 5/4 George Hunter Drive, Narellan

Time: 6pm – 8.30pm **Cost:** \$5.00 per child

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Hosted by Kerrie Shearer (owner of Playmaze), mother of TS girl and Intimo presenter.
Assisted by Amanda Wheeler, NSW President.

RSVP to Kerrie Shearer on 043357594

Spina Bifida Foundation of Victoria

Family Adventure Camp at Phillip Island

When: 6pm Friday 10th February to 2pm Sunday 12th February 2012

What's On? Lots of activities for parents and children, wonderful food and lots of talking

How much? All for just \$25 per person or \$100 per family (children under 2 years free)

How to book? Book your place NOW as spaces are filling fast

Who do you contact? Please call the SBFV office on (03) 9663 0075 or email
info@sbfv.org.au



Rare Disease Day 2012

In Australia, Rare Disease Day is now celebrated every year on the last day in February in conjunction with many other people around the world.

A rare disease has been described as a disease with a prevalence of 1 in 2000 people or less affecting less than 200,000 people in the population. In Australia it is estimated that

There are 8000 known rare diseases, collectively affecting up to 10% of the population or over 2 million people including about 400,000 Australian children.

Rare diseases have the following common features:

- Most begin in childhood and continue throughout life;
- Obtaining a definitive diagnosis is often difficult and delayed;
- Many rare diseases have no cure but some can be prevented;
- Neurological and intellectual disabilities occur in about half of all cases regardless of disease type and lead to loss of independence and opportunities;

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- Families experience isolation, psychological and financial stress;
- Health professionals have inadequate access to information, education and resources;
- Of deaths in children aged <1 year 35% are due to rare diseases;
- Of deaths in children aged between 1 and 15 years, approx 10% are due to rare diseases; and
- Equity in access to health and community services is lacking for people affected by rare diseases

Source: Improving outcomes for rare diseases in Australia: A National Plan for Rare Diseases (Department of Health WA)

Characteristics of rare diseases

The 6000 to 8000 rare diseases are characterised by a broad diversity of disorders and symptoms that vary not only from disease to disease but also from patient to patient suffering from the same disease.

Relatively common symptoms can hide underlying rare diseases leading to misdiagnosis and delaying treatment. Quintessentially disabling, the patient's quality of life is affected by the lack or loss of autonomy due to the chronic, progressive, degenerative, and frequently life-threatening aspects of the disease.

The fact that there are often no existing effective cures adds to the high level of pain and suffering endured by patients and their families.

Common problems faced

The lack of scientific knowledge and quality information on the disease often results in a delay in diagnosis. Also the need for appropriate quality health care engenders inequalities and difficulties in access to treatment and care. This often results in heavy social and financial burdens on patients.

As mentioned, due to the broad diversity of disorders and relatively common symptoms which can hide underlying rare diseases, initial misdiagnosis is common. In addition symptoms differ not only from disease to disease, but also from patient to patient suffering from the same disease.

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How can things change?

Although rare disease patients and their families face many challenges, enormous progress is being made every day. The ongoing implementation of a better comprehensive approach to rare diseases has led to the development of appropriate public health policies. Important gains continue to be made with the increase of international cooperation in the field of clinical and scientific research as well as the sharing of scientific knowledge about all rare diseases, not only the most “recurrent” ones. Both of these advances have led to the development of new diagnostic and therapeutic procedures. However, the road ahead is long with much progress to be made. Why not get Involved? Get involved!

Source: <http://www.rarediseaseday.org/article/what-is-a-rare-disease>

GSNV Rare Disease Seminar



GSNV's Rare Disease Seminar

On Friday March 2nd GSNV will host a Rare Disease Seminar at the GHSV's (Genetic Health Services Victoria) Friday Morning Seminar held at the Royal Children's Hospital.

Time: 9.00am – 9.45am

Location: Vernon Collins Room, Royal Children's Hospital

Please join us afterwards for morning tea

More details to follow and **Look out for an invite and our Quick Survey in your email box soon.**

In the News

The GSNV congratulates Tony Briffa on his recent election as Mayor of Hobson's Bay Council. Tony was President elect for the GSNV for a number of years and has been very active in support of our work. We wish Tony all the very best.

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Community

Students with a Disability Have a Say!

The Victorian Equal Opportunity and Human Rights Commission is conducting an online survey to gather feedback on the experiences of Victorian students with disability at school. Students, parents and carers are invited to have their say! Go to www.humanrightscommission.vic.gov.au/disabilityinschools

Source: Victorian Equal Opportunity and Human Rights Commission ebulletin Jan 1 2012

National Blood Authority (NBA) - UNCLASSIFIED

The National Blood Authority (NBA) is conducting public consultation on the draft Medical module of the Patient Blood Management Guideline.

The draft Medical module and technical reports are available on the NBA's website at: <http://www.nba.gov.au/guidelines/consultation.html> along with instructions on how to make your submission. The closing date for submissions is **5pm Friday 16th March, 2012.**

NBA are using this opportunity to present the preliminary conclusions and draft recommendations to a wider clinical audience encompassing a broad range of expertise, and to invite interested groups, organisations and individuals to make submissions.

Source: PBM Clinical Guideline Mailbox

National Blood Authority, Australia

'APPEARANCE MATTERS'

CLEFT SYMPOSIUM

FEBRUARY 11, 2012

Don't miss out on being part of the first international cleft symposium of its kind, 'Appearance Matters', being held at The Ella Latham Auditorium, The Royal Children's Hospital (Melbourne) on 11 February 2012, bringing together medical and health professionals, cleft-affected families and young people.

This one-day symposium is being jointly promoted by *OzCleft* (an NHMRC funded genotype: phenotype study aimed at exploring the genetic aetiology of clefting) and

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CleftPALS Victoria.

In order to register your attendance, please contact:

Supriya Raj, OzCleft Project Manager on 9936 6532 or ozcleft@mcri.edu.au

Run for the Kids – Sunday April 1st

Entries open 1 February for this Fun run which supports the Good Friday Appeal and the Royal Children's Hospital.

Resources

Launch of Palliative Care Resource

Palliative Care Australia has launched a newly updated edition of *Journeys – Palliative Care for Children and Teenagers*. *Journeys* is an information resource which aims to better prepare and equip families and carers for the situations and issues they may face as they lived with their child's illness. It is a starting point in identifying where to look or who to go to for specific information and support which best meets their needs.

Journeys can be downloaded or ordered free of charge from the Palliative Care Australia website <http://www.palliativecare.org.au/Default.aspx?tabid=1122>

Subsidy reinstated for child restraints

Two years ago, the subsidy for child car seats for children with a disability, provided by the Victorian Aids and Equipment Program (A&EP), was temporarily suspended as many were found to not meet the relevant Australian Standard.

Since then, a reference group consisting of the Department of Human Services and Vic Roads has reviewed this decision. A report had now been produced that provides recommendations about which child car seats for children with a disability are available for subsidy through the A&EP and the subsidy has now been reinstated.

To apply for the subsidy, contact the Statewide Equipment Program (SWEP) at Ballarat Health Services on telephone 1300 747 937 or (03) 5333 8100 or visit

www.swep.bhs.org.au

Source: Contact 2011, Spina Bifida Foundation of Victoria

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Growing Together

After 12 months of research, discussion with siblings and parents, writing and editing the Association for Children with Disability has launched a new resource.

The publication entitled 'Growing Together: A Parent guide to supporting siblings with a disability' is a valuable tool for parents and highlights the experiences of siblings growing up with a brother or sister with a disability.

The booklet includes stories and quotes from siblings and parents and provides useful tips for dealing with different situations.

You can order your own copy by contacting the Association office on phone 9818 2000, 1800 654 013 (rural callers) by email at mail@acd.org.au or by downloading a Publication Order form from their website www.acd.org.au

Research

Have you had prenatal testing for a disability? Used PGD?

Have you had a child in neonatal intensive care? Do you have a child with a disability?

If any of these questions apply to you, researchers would like to hear about your experiences and, in particular, your thoughts and opinions about the management of potential disability before or during pregnancy, or after birth. This research is part of an Australian study examining the meaning of serious disability in prenatal and neonatal settings. Your thoughts and opinion are valuable and will inform their analysis of law and policy relating to these practices.

The study is being conducted by researchers at the University of Sydney and the University of Technology.

To share your thoughts in a confidential online survey, visit

<http://seriousdisabilityproject.blogspot.com>

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GSNV Calendar 2012

Melbourne Univ Principles of Clinical Practice Lecture	Tuesday Feb 7	Melbourne Uni
Rare Disease Day 2012	Wednesday February 29	Global
GSNV Rare Disease Day Seminar	Friday March 2	Murdoch Childrens Research Institute 9.30am
Chronic Illness Alliance National Disability Insurance Scheme (NDIS) Forum:	Tuesday 28 February	Epilepsy Foundation VIC

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

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

South Building, Level 9, Murdoch Childrens 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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