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March 22, 2012

To exist is to change, to change is to mature, to mature is to go on creating oneself endlessly. ~ Henri Bergson



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From the Committee

Hard to believe we are already at the end of March and the cooler months are already fast approaching. The GSNV committee has convened twice this year and set a list of priorities and actions for 2012. As for many non-profits, the GSNV is working through organisational change and the impact of the current political environment. The GSNV President Moira Rayner states that "The political and economic climate in Victoria is one of uncertainty and it's a vulnerable time for any not for profit organisation especially one as small as ours. The only way to manage such uncertainty is to step forward briskly, doing what we have to, which is make sure your voice is heard. We need to keep the

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conversation going between you, who are affected by genetic disorders, with others who are as lost and concerned. One way of doing this is to deliver the facts of your lives to researchers and administrators”.

Coming up to Easter the GSNV committee and staff wish you a safe and restful break.

Conferences/Seminars/Workshops

Disability Advocacy and the Legal System: You Be The Judge

When: 26 & 27 March 2012

Where: Melbourne Park Function Centre, Batman Ave, Melbourne

Register: Go online to: <http://youbethejudge.eventbrite.com/>

Why are people with disabilities so over-represented in our prisons?

How do we make sure people with disabilities have a say in what happens to them?

Are we living up to our responsibilities under international law in Victoria and Australia?

What are the challenges and opportunities for us in a changing legal environment?

This conference will explore the major issues and challenges facing disability advocates at a time of profound change. Don't miss our exciting speakers, including:

- Johnny Crescendo (UK/USA) – singer-songwriter, activist and founder of the Direct Action Network
- Cindy Johns and Michael Aldridge (NZ) – from New Zealand's leading disability advocacy movement People First and its ground-breaking 'Nothing about us without us' campaign
- Ian Gray – Chief Magistrate of Victoria
- The Hon. Andrea Coote – Victorian Parliamentary Secretary for Family and Community Services
- Sarah Barton – Award-winning documentary-maker, with her new film
- Richard Coverdale (Centre for Rural Regional Law and Justice)
- John Chesterman (Office of the Public Advocate),
- Anne Coghlan (Victorian Civil and Administrative Tribunal)

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Who should attend?

Disability advocates, self advocates, people with disability, legal workers, government and non-government officers, community workers and allied health professionals.

For more information, visit the conference website at:

<http://daru.tysonarmstrong.com/strengthening-disability-advocacy-conference>

Download a flyer at: <http://www.daru.org.au/webpage/items/398751-upload-00001.pdf>

Women with Disabilities Victoria Focus Groups

Women with Disabilities Victoria are running an exciting project this year focusing on improving access to health care for women with disabilities. Thanks to the Telematics Trust, we have received funding to film a DVD which will be used to inform and educate health practitioners and students about providing accessible and relevant health care for women with disabilities.

We're very excited to welcome Sarah Barton on board, who will be working jointly with Grit Media and Fertile Films to produce the DVD.

Now we need your help to begin developing the content and script for the DVD.

At the beginning of April we'll be running 3 focus groups to inform you about the project and get your feedback and ideas. The focus groups will be held on the following days at our offices in Bourke St:

- Monday, April 2: 10:30Am-1:30PM
- Wednesday, April 4: 1:00-4:00PM
- Thursday, April 5: 10:30AM-1:30 PM

Refreshments will be provided.

We'd particularly love to hear from you if you are aged between 18-35.

If you are unable to attend a focus group but would like to contribute, a teleconference may be organised, numbers permitting. The date and time of the teleconference is yet to be confirmed.

Please RSVP by Wednesday, March 28. Let us know which focus group you'll be attending, and whether you have any special requirements.

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To register your interest, please contact me on 9664-9342, or email lauren.hayes@wdv.org.au.



Connecting Up: Unleashing the Power of Your Non-Profits

When: 1 - 3 May 2012

Where: Dalton House, Darling Island Wharf, Sydney

Topics include social media/online, marketing/communications or technology.

For more information please go to: <http://www.connectingup.org/events>

Call for Papers - 3rd Annual National Disability Summit 2012

When: 27 & 28 June 2012

Where: Novotel Melbourne on Collins

This event has become a premier meeting place for information sharing and networking. Preparations for the 2012 event have begun and expressions of interest to present papers in the conference program are now being called for. As with previous years, the event will focus on the future direction for disability policy reform in Australia and include updates from those states and territories willing to share their approach to disability support and models for disability reform.

Any feedback or suggestions you have for this year's program are welcome to help make the agenda as relevant and useful to you and your organisation as possible.

For more information, phone the conference organisers on (02) 9080 4003.

Source: DARU Update 13 February 2012

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ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA, Inc

Triple X Syndrome Seminar

When: Sunday 25th March 2012

Where: AGSA, 66 Albion Street, (Cnr Commonwealth & Albion Streets), Surry Hills NSW 2010

For more information and to register please go to: www.agsa-geneticsupport.org.au

Social Action Workshop with Johnny Crescendo

Join other young people with and without disabilities to learn about making change on the issues you care about and take part in some social action!

Where: Melbourne Multicultural Hub, 506 Elizabeth St

When: Saturday 31st of March 2012

Cost: Free (but you are required to register and places are limited!)

Hosted by: YDAS, Grit Media and proudly supported by the City of Melbourne

RSVP: Monday 26th of March 2012

For more info, to discuss your support needs and to register: contact Bec at YDAS on 9267 3712 or ydasprojects@yacvic.org.au

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Support Group News

World Autism Day

World Autism Awareness Day is 2 April each year, and once again, we will be promoting awareness of ASD with a short walk and a balloon release - the Melbourne event will be on Sunday 1 April.

Declan Sykes to count down!

X Factor contestant, and an individual with Asperger's Syndrome, Declan is going to be walking with us on the day and counting down for the balloon release - we are delighted to have him with us.

Please put it in your diary - it is completely free to attend so bring all your friends and family.

The more people we have, the more attention we can draw to ASD and the more likely we are to have an impact on the community and the reception that individuals with ASD receive: we are aiming to have over 3000 people there.

[More information](#)

More Volunteers Needed

Being near the river, we want to make sure that nobody goes for an unintended swim, so if you can volunteer your time on the day as a balloon handler or marshall, please get in touch - email volunteering@amaze.org.au or call 9657 1601 and speak to Caetlyn.



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FSHD Footy Tipping Competition 2012

Join the AFL Footy Tipping 2012 Competition and support the Foundation in finding a cure for FSHD.

PRIZES

First Prize

5 nights' accommodation at "**Kabuki by the Sea**" in Swansea (Tasmania).

Second Prize

\$200 dinner voucher in the CBD or town near you.

Third Prize

\$100 dinner voucher in the CBD or town near you.

All proceeds go direct to the FSHD Global Research Foundation.

Please go to <http://www.footytips.com.au/> to register as a member.

Contact:

FSHD Global Research Foundation

E: admin@fshdglobal.org Ph: 02 8007 7037



CAHSGA Family Day 2012 (Congenital Adrenal Hyperplasia Support Group of Australia) Sunday 9th September in Randwick (Sydney)

Details regarding speakers and the program for the day will be available in the next newsletter.

This is a great opportunity to meet other families affected by CAH from all over Australia. We are hoping that with some generous support we will be able to make this event as low cost as possible.

For more information contact CAHSGA Inc. On (03) 9513 9255 or visit their website at www.cahsga.org.au

Cardiomyopathy Association of Australia Ltd.

Have you enrolled in the National Genetic Heart Disease Registry?

If you or a family member has an inherited Cardiomyopathy you may be eligible to take part in this Registry.

We are aiming to enrol every family with an inherited heart disease in Australia, which

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will assist Australian research groups learn more about these conditions. More information, including patient information sheets can be found at our website.

www.registry.centenary.org.au

To get an enrolment packs please contact Dr Jodie Ingles or Laura Yeates.

Molecular Cardiology Centenary Institute

Locked Bag No 6 Newtown NSW 2042

Phone 02 9565 6185 Wednesday – Friday.

Muscular Dystrophy Australia

MD Education Seminar 2012

Friday 23 March 2012

MDA National Centre

111 Boundary Road, North Melbourne

MD Education Seminar 2012 is a comprehensive multidisciplinary seminar designed to present latest and up to date information for anyone involved with students in the education system who are affected by Muscular Dystrophy.

MD Education Seminar 2012 will bring together researchers, clinical specialists and health-care professionals including a Specialist Teacher Consultant and a former Vice Principal to share information and expertise in order to improve outcomes for individuals affected by MD in a school setting.

To register contact the MDA on 03 9320 9555 or visit the website at MDA.org.au

MDA's Free Counselling Service

MDA is pleased to announce that they are now able to offer six free counselling and support sessions a year for our members. The sessions are 1:1 with MDA Client Services Manager – Marie Fleming, who has completed her Masters in Counselling at Monash University and is registered with the Australian Counselling Association. Sessions can be in home (metropolitan region only) at the MDA in our new counselling room or over the phone. They may be of benefit to both people affected by MD as well as their family members.

For more information contact Marie on 03 9320 9555 or @ Marie.Fleming@mda.org.au

Turner Syndrome Association of Australia Albury/Wodonga

Christmas in July

Saturday 14th July

6.00pm for 6.30 meal

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The Seaton Arms Restaurant
Cnr Olive and Wilson St, Albury

RSVP: Friday 11th June to Di and Rob King 02 60 243442 or dirobking@bigpond.com

Marfan Association of Victoria The 5th Annual Walk for Marfan

When: Sunday April 22nd 2012

Where: Albert Park Lake Reserve, Swan Picnic Area, Melbourne

Melways Ref: Map 2K, G5

Registration: 10.30am Walk Begins: 11.30am

Sausage sizzle and activities: 12.30pm

GSNV Rare Disease Seminar



The last day in February is 'Rare Disease Day' and on February 29 I chaired a Genetic Support Network of Victoria (GSNV) seminar aimed at students, researchers, clinicians, genetic counsellors and GSNV members on rare diseases. We focused on our recent survey scoping our member's top 5 concerns regarding rare disease and how they may be addressed. GSNV members Anna Hickey and Tina Costanzo talked about the lived experience of someone who has a rare disease, and how important it was to not only have the services you need but the money to be able to pay for them, and to feel and be supported through that adjustment process.

Further to Tina's presentation please visit the following sites for more information about Prader-Willi:

http://www.youtube.com/watch?feature=player_detailpage&v=KvnBP02pX2g

<http://www.heraldsun.com.au/news/more-news/soon-of-a-guns-always-hungry/story-fn7x8me2-1226115491168>

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[New initiative – Australian Rare Disease Day website](#)

This year Australia has developed its own home for Rare Disease Day
www.rarediseasedayaaustralia.com.au

This website is designed to encourage the sharing of information and events around Rare Disease Day in Australia. Through this website individuals and families can come together and share their stories.

To receive more info about World Rare Disease Day Australia you can send an email to
info@rarediseasedayaaustralia.com.au

In the News

VICTORIAN geneticists have cracked two new genes causing potentially fatal inherited diseases, ending the agonising search many families endure for a diagnosis.

Brigid O'Connell, From: Sunday Herald Sun, March 04, 2012

See: <http://www.heraldsun.com.au/news/more-news/new-victories-in-war-on-inherited-disease/story-fn7x8me2-1226288194394>

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Community

[Victorian Equal Opportunity and Human Rights Commission Disability Reference Group: Call for Members](#)

The Victorian Equal Opportunity and Human Rights Commission is calling for expressions of interest for people to join our Disability Reference Group (DRG) for 2012 – 2014.

The DRG:

assists the Commission to identify priority human rights and systemic discrimination issues affecting people with a disability;

- provides advice and assistance to the Commission on the development of policies and procedures towards ensuring the delivery of appropriate and effective services to people with a disability;
- provides guidance to the Commission on the implementation of the United Nations Convention on the Rights of Persons with Disabilities and advice under the Victorian Charter of Human Rights and Responsibilities Act, and
- provides a user perspective on the ongoing implementation of the Commission's Strategic Plan.

The DRG has up to 16 members. It meets four times a year. Members are appointed for two years. Members' travel, accommodation, meal and support costs are covered by the Commission. The DRG expenses policy is available on request.

The Commission is keen to ensure representation of:

- people with disability
- disability advocates, service providers and family carers of people with disability
- young people with disability
- older people with disability
- Indigenous people with disability
- people from culturally and linguistically diverse backgrounds with disability
- gay, lesbian, bisexual, transgender, intersex and queer people with disability

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- people with disability living in rural and regional Victoria.

People are asked to apply in writing via email or mail, however you are also welcome to apply over the phone. If you are applying in writing, please send a short letter outlining:

- why you are interested in joining the DRG
- your experience of disability and any other attributes detailed above
- any organisations and/or networks in which you are involved.
- a daytime phone number and an email or postal address.

The closing date for applications is 24 February 2012. Short-listed applicants will be invited to interview in March. All applicants will be notified in writing of the outcome of their application.

For more information or to submit an application please contact Priscilla White, Administration Assistant -

- Phone: (03) 9032 3430
- Email: priscilla.white@veohrc.vic.gov.au
- Mail: 3/204 Lygon Street Melbourne Victoria 3053

For more information about the Commission, visit:

<http://www.humanrightscommission.vic.gov.au/>
February 2012

Source: DARU Update 13

[Auditing the Victorian Charter - People with Disability and Applied Human Rights](#)

This study involves an interview and tests a human rights audit tool developed by Disability Rights Promotion International (DRPI). The tool has already been used in a number of countries worldwide and it is hoped that people with disability in Australia will take part to give the Australian experience of human rights.

The DRPI tool has been adapted for Australia by holding focus groups with people with disabilities. This means the results of the research will provide feedback to services at state and national level in Australia, as well as an international comparison.

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This research gives people with a disability the chance to have their voices heard.

For more information and to arrange an interview contact Paul Ramcharan on phone 0431 377 914 or email paul.ramcharan@rmit.edu.au

This project is funded by the ARC and Helen MacPherson Smith Trust and supported by VCOSS, Australian Bureau of Statistics, Human Rights Resource Centre

Source: DARU Update 13 February 2012

The Joan Kirner Social Justice Award

The Joan Kirner Social Justice Award all Social Justice Champions: \$5000 award NOW OPEN!

The Joan Kirner Social Justice Award recognises those people who are working to bridge the gap between the “haves” and the “have nots” in a way that ensures that everyone, and every community, has the confidence and power to shape their own future.

Everybody in this life is entitled to equal respect. Everybody can have autonomy. Everybody has rights. Everybody should get a fair go. In this world, though, there's often a gap between people's rights and entitlements and the reality of people's lives.

Social justice is about closing that gap in ways that are inclusive and empowering. Such work is relentless; it's sometimes slow to bear fruit. But when it works, and it often does, it's life-changing to all those involved.

Through the Joan Kirner Social Justice Award, we want to identify those people who are shaping the social justice agenda, and acknowledge and share their achievements.

Who's eligible?

The award is open to anyone who is working to build social justice in Australia. We expect and encourage applications from:

- Individuals (unpaid or paid; amateur or professional)
- People working as a team
- Community-centred groups, such as community residents' associations or community committees (whether incorporated or not).

What's the prize?

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The winner of the Joan Kirner Social Justice Award will receive a \$5000 cash prize thanks to the Trawalla Foundation.

Only one prize is available. In the eventuality that a team or group of people wins the award, the money will be provided to an identified group leader for appropriate distribution.

While awards necessarily involve the selection of a winner, we are aware that many highly worthy nominations are likely to be made for this award. Recognition of all worthy nominations will be made in the form of a certificate and other forms of public acknowledgement where possible and appropriate.

What's the deadline?

All entries must be received by 5pm on Friday, April 27, 2012.

The winner will be notified by telephone in May 2012 and announced at Communities in Control on May 28/29. All nominators and nominees will be advised of the outcome via email.

How can I find out more?

Go to www.ourcommunity.com.au/joankirneraward

Volunteer Awards

Call for nominations for the 2012 Minister for Health Volunteer Awards. More information is available at: www.health.vic.gov.au/volunteerawards

Smarty Grants

The Australian Institute of Grant's Management's Grantmaking Manifesto is a free tool to help organisations obtain maximum value from grants programs.

As well as laying out a framework for reform of the Australian grantmaking process, the Grantmaking Manifesto includes a Code of Practice for Professional Grantmakers, as well as a Code of Practice for Grantmaking Agencies – invaluable instructional and inspirational tools for your grants and staff.

More information about The Grantmaking Toolkit is available at www.grantsmanagement.com.au/toolkit



Research

Wheelchair-seating Service: Research Project

Rachael Schmidt, from the Occupational Science & Therapy School of Health & Social Development at Deakin University is undertaking a research project aimed at exploring the experience of those who receive a wheelchair-seating service and those who provide a specialised wheelchair seating service (in all forms) within an Australian context.

Many service providers have already been contacted. To balance the data, Rachel is now seeking participants who:

- Live in their wheelchair-seating system
- Support a person who lives in their wheelchair-seating system
- Have received a wheelchair-seating service in the past three years
- Is over 18 years of age

Participants will be required to take part in an in-depth interview of 1 to 1 and a half hours, conducted in English, where experiences will be shared and discussed. Participant's identity and seating service will be coded to ensure anonymity.

To register your interest in participating, or to find out more about the project, contact Rachel Schmitt on phone 03 5227 8352 email rachaels@deakin.edu.au

Source: DARU Update 13 February 2012

Three-year study into 'cotton wool kids' phenomenon launched

VicHealth and the Parenting Research Centre have announced a three-year study into parental fear as a barrier to children's physical activity, to pinpoint causes and find solutions.

To find out more go to: <http://www.vichealth.vic.gov.au/Media-Centre/Media->

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[Releases-by-Topic/Walking-and-cycling/Three-year-study-into-cotton-wool-kids-launched.aspx](#)

Source: VicHealth Update - 20 February 2012

Essential Medical equipment and Energy Use

This important research for the Department of Human Services will also comprise Medicare Australia, Centrelink and the Child Support Agency. The purpose of the research is to speak to in-home users of essential medical equipment regarding their energy use and their response to proposed financial support to assist them with the cost of running such equipment.

The research will involve interviewing users of the equipment in their homes for up to 90-minutes on the 28th and 29th of February around Melbourne, and on the 1st of March in Ballarat. The participants will be paid \$80 to compensate them for their time.

We are looking to speak to a fairly specific group of people who reside in Melbourne or Ballarat. In particular, we are interested in talking to people who use any of the following types of electrical equipment in their homes:

- Home Dialysis Machine
- Home Ventilator
- Home Respirator
- Home Parental or Enteral Feeding Device
- Oxygen Concentrator
- Heart Pump
- Suction Pump
- Infant Apnoea Monitor
- Nebuliser
- Positive Airways Pressure Device
- Airbed Vibrator
- Phototherapy Equipment

If you know of anyone who might be eligible and would be willing to hear more about

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the research, please either forward their contact details (with their consent) via return email or calling the number below or pass on our contact details to them via the attached handout. Our office is open between the hours of 9.00am and 5.30pm on weekdays.

If contacting our offices via phone, please ask to speak to Jonathan Scanlan or Anna Lethborg. We can be reached on (03) 9372 8400 or via email at:

Anna:

alethborg@marketsolutions.com.au<mailto:alethborg@marketsolutions.com.au>

Jonathan: admin@marketsolutions.com.au<mailto:admin@marketsolutions.com.au>

[Neurofibromatosis Type 1 \(NF1\) – A Message from Washington University](#)

The Washington University NF Center is committed to raising awareness about NF1 and conducting research that will ultimately help improve the quality of life of individuals with this condition. We are currently recruiting individuals with NF1 to an online patient registry.

For more information email: kijohnson@brownschool.wustl.edu or take a look at their website: <http://brownschool.wustl.edu/Faculty/FullTime/Pages/KimberlyJohson.aspx>

Source: Genetic Support Council of WA

Grants

[Multicultural Festivals and Events Grants Now Open](#)

Applications close Friday 13 April at 4pm. The Victorian Government aims to promote the social, cultural and economic benefits of cultural diversity to all Victorians. The Multicultural Festival and Events Grants are designed to encourage the participation of the whole community in celebrating and

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valuing cultural diversity.

The grants are awarded to encourage cross cultural awareness as well as foster intercultural relationships, community contributions, mutual respect, understanding and community unity

Who can apply?

Community organisations, non-profit organisations and schools can apply for funding. Organisations must be incorporated under the Australian Corporations Act or as an Association under the Associations Incorporation Act and have an Australian Business Number (ABN).

Organisations wishing to apply for funding which are not registered as a formal organisation are able to apply in partnership with another organisation who will act as an auspice for your project. Organisations may submit multiple applications, although priority will only be given to one application. If you are applying for more than one project please fill out one application form for each project.

For more information please go to: www.multicultural.vic.gov.au

[Lord Mayors Charitable Foundation Grants 2012](#)

General Grants

Applications for General Grants close on Friday 30 March, 2012.

[Forest Hill Grants Fund](#)

Forest Hill Grants fund makes grants within Australia for:

- projects involving children from birth to eight years;
- innovative projects for young children which contribute to their education, care and well-being;
- provision of equipment and resources;
- development and publication of innovative resources and educational materials;
- research in early childhood development.

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To find out more visit www.communitynews.infoxchange.net.au

Green PC

GreenPC refurbished computers are thoroughly cleaned tested and updated by skilled technicians in our Melbourne workshop, before being offered for sale to community groups and low income individuals.

GreenPC computers are internet ready, come with Windows XP or Windows 7 installed and a 12-month back to base warranty. To find out more visit www.greenpc.com.au or call 03 9418 7400

Call to Action

Recently the Chronic Illness Alliance held a forum on the National Disability Insurance Scheme (NDIS) where it was discussed who was likely to benefit from the introduction of the NDIS and who would not.

During the discussion the point was made several times that if a person was diagnosed with a disability after the pensionable age that person was not eligible for the NDIS but had to rely on aged care services. Rod Harris of Motor Neurone Disease Australia pointed out that this was a serious gap for many people with MND who were diagnosed late in life. It is likely to be a gap for many other people with different conditions. Rod has provided CIA members with a letter MND prepared to alert its members.

If this is an issue you believe will impact on the people you work with or the people you know and care about you may like to use this letter as a template or you may consider joining with MND to work together. If you use the letter as a template please acknowledge that Rod Harris and MND provided you with the background.

Source; Chronic Illness Alliance

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Government

On the 16th of February 2012 the Department of Transport conducted a forum on Accessible Toilets, at Etihad Stadium.

A summary of discussions and findings at this important session can be viewed at:
Social.Transit@transport.vic.gov.au

Resources

Access Travel – Australia

Website: www.e-bility.com/travel/

This section of e-bility's website is currently being redeveloped but all Access Travel information, guides and wheelchair accessible accommodation directories can still be viewed using the link above.

This website provides travel information for seniors and people with disabilities. It is a gateway to service providers and offers an overview of accessibility features offered by providers and/or people with disabilities and carers who have recommended the service.

The website includes:

- accessible accommodation database
- articles on access travel
- state access travel guides and directories
- National access travel guides and directories
- Organised tours and accessible group holidays
- Special needs travel agents
- Travel insurers covering pre-existing medical conditions
- Overseas destinations

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GSNV Calendar

World Down Syndrome Day	March 21	International
Triple X Syndrome Seminar	March 25	NSW
Lord Mayors Charitable Foundation General Grants	March 30	Victoria
World Autism Day	April 2	International
Nominations for Vic Govt Volunteer Awards	April 10	Victoria
Multicultural Festivals and Events Grants	April 13	Victoria

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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 have launched an exciting new website and database but still finalising the upgrade. 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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