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**BITS &
PIECES
e-news**



Special Edition August, 2012



This edition of Bits & Pieces focuses on the resources and services available to those living with a genetic condition, disability or special needs, their carers, their families and the support groups who help them. We hope this edition will provide some practical tips on some of the resources and services that are available and how to access them. We have also included a small selection of 'unique' services offered by support groups.

This Special Edition corresponds with the announcement of the GSNV Small Grants 2012 program. Perhaps you and your group might like to consider whether the development and use of any of these resources would be beneficial for your members, and apply for a grant to assist in implementing the idea.

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From the Committee and Team



A Note from the GSNV Team

We hope this latest edition of the GSNV's Bits & Pieces e-news bulletin contains some useful information. The GSNV often receives requests for information on community, government and health services. This edition of Bits & Pieces highlights some of the most practical services we often refer to. For further information, please also go to the [GSNV website](#) which also contains a comprehensive list of support group and links to services.

Thank you for your feedback!

Our last Bits & Pieces called for some feedback on how the GSNV can improve its' services to better support you and/or your group. The response and feedback was excellent and very useful! The GSNV will consider all suggestions made and advise on how we may use your feedback and suggestions to inform our planning and programs.

Congratulations to our competition winner - Kathryn Ward. We hope you enjoy watching Brave with your son.

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Genetic Testing and National Priority... the GSNV seeks your feedback!

Medical genetic testing in Australia is a hot topic at the moment! There is currently significant review on improving national standards for the funding and conducting of medical genetic testing. There are a number of issues to consider: services and resources, education, training and research, workforce planning, funding, communications between clinical and laboratory services, the utility of investigations, the quality of investigations, and ethical and legal matters to name a few!

The GSNV is interested in your feedback and your priorities in order to be prepared for any consumer contribution to this review process on national genetic testing.

Please tell us your top 3 issues (in order of priority) on establishing an effective and well funded national genetic testing plan in Australia **for your chance to win a double pass to the Royal Melbourne Show**. If you are from interstate, the GSNV will award a movie gift card for two people.

To enter, email your responses to info@gsnv.org.au with **FEEDBACK** in the subject line. Competition closes **22nd August, 2012**. Please also include your contact details.

Brochures

The GSNV encourage our support groups to send in copies of your most recent brochures so that we can assist in raising awareness for your groups as well as referring on relevant individuals.

If you have a recent brochure and would like to send us copies, please post them to:

The Genetic Support Network of Victoria

South Building, Level 9, MCRI

Royal Children's Hospital

Flemington Road

Parkville, VIC 3052 (Australia)



Special Event



The [Friends of Sammy Joe Foundation](#) are holding a Trivia Night on Saturday the 15th of September at the Hadfield Sporting Club.

Entry is \$20 per person and in addition to trivia, the night will include an auction and the chance to win some amazing prizes in the raffle and through door prizes. Tables can seat 10 or 12 or you are welcome to join another table. The Night will start at 7pm, BYO nibbles and drinks will be available at bar prices.

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Date & Time: Saturday, 15th September at 7pm

Venue: Hadfield Sporting Club, Martin Reserve, 85 Box Forest Road, Hadfield, 3046 (Map 17 E2)

For more information, please see the [Friends of Sammy Joe website](#).



Small Grants



Applications for the GSNV Small Grants Scheme 2012 are now open! Apply Now!

Every year the GSNV offers Small Grants to members for projects that support the work of a support group. In previous years Small Grants have only been available to paid, financial members of the GSNV. However, thanks to an injection of donations last financial year we are opening the opportunity to all groups listed on our database. If your support group is listed on the GSNV database but you have not paid a membership in the last 12 – 24 months *you are eligible* to apply this year.

If your group receives the GSNV e-news Bulletin, the GSNV newsletter or has been listed on the links page of our website, you are also eligible to apply for a Small Grant in 2012. All grants are between \$50 and \$500.

To apply for a small grant for your support group or organisation, visit our [website](#) to view our Small Grants Terms and Conditions and Application Form, contact our office on (03) 8341 6315 or email info@gsnv.org.au.

Applications close 5pm Monday, 10th September.

Decisions will be made by Monday, 17th September 2012 and successful applicants will be notified in writing and via email by Thursday, 20th September 2012.

**LORD
MAYOR'S
CHARITABLE
FOUNDATION**



Lord Mayor's Charitable Foundation – 2012 Direct Aid and Equipment Grants

The Lord Mayor's Charitable Foundation is currently accepting applications for their 2012 Direct Aid and Equipment Grant. Grants are up to \$10,000. Applications are online. Please go to their [website](#) for more information on grants guidelines and criteria, and about the 2012 Grants Program. Applications are online and you can [apply here](#).

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Resources for Carers



Commonwealth Respite and Carelink Centres

Commonwealth Respite and Carelink Centres are information centres for older people, people with disabilities and those who provide care and services. Centres provide free and confidential information on community aged care, disability and other support services available locally, interstate or anywhere within Australia.

For further information, call 1800 052 222 (free call from land lines only).



Carers Victoria provides support for family members and friends across Victoria who supports someone with special needs. They offer a range of resources and services that may be helpful for carers, including a free counselling service, assistance organising respite care, and educational workshops.

The role of a carer can be stressful and demanding. Your GP, case manager or support worker can refer you to a free counselling service. To find out more about how counselling may help you, visit the [Carers Victoria website](http://www.carersvic.org.au) or freecall 1800 242 636.

Carers Victoria Respite Connections can also assist with providing respite care to families in the Western Metropolitan region. For assistance organising a break, freecall 1800 052 or go to <http://www.carersvic.org.au/respite-connections>. There is also useful information for helping people with a disability or special needs live independently in their own home, and helping service providers to understand your needs.

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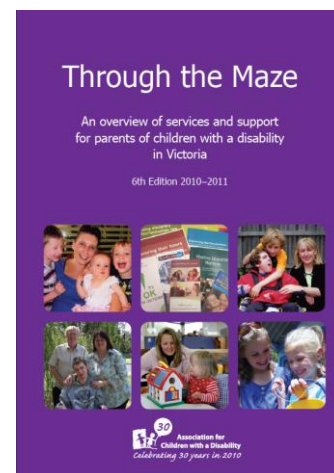


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Through the Maze

[Through the Maze](#) is a valuable resource produced by the Association for Children with a Disability (ACD). This booklet provides a comprehensive overview of services and support available for parents of children with a disability in Victoria. The booklet is currently in its 6th edition.

For a copy of this helpful booklet, please see our [website](#).



Life Circle provides a number of services to both those living with a life-limiting condition and their carers. Their HOPELINE®, which can be reached by calling 1300 364 673, provides people with access to professionally-trained counsellors who themselves have lived with a life-threatening illness or have cared for someone with a life-threatening illness.

Life Circle also provides a mentoring program for carers which aims to match carers with an individual they can contact for guidance, information and support. Mentors are also people who have personally cared for a loved one themselves and meetings with them can be arranged face-to-face or via telephone. For information about this mentoring service call 1800 132 229.

Additional information is available through help sheets which can be found [here](#). Sheets contain information about how to care for somebody coming to the end of their life, taking care of yourself as a carer, grief, community support and much more.

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Resources for Support Groups and Volunteers



GSNV Peer Support Training

Professional Counsellors are helpful, but there is nothing more powerful than talking to someone who has been 'in the same boat' as you. Peer support training is available for all individuals, including staff from support groups. It is a half day workshop and our aim is to help you feel empowered to listen and talk to others who are in a similar position, and share your wisdom and experience.

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

You will receive a certificate upon completion as well as a Peer Support contract with the Genetic Support Network of Victoria. Please contact us for further information.

Our next Peer Support Training Day is being held on Monday, 10th December 2012.

Places are limited, [book now](#) to avoid disappointment.



CHRONIC ILLNESS ALLIANCE

Peers are not health professionals or medical experts. They are volunteers who have been diagnosed with the same or a similar illness, and who are willing to share their time and experiences to offer hope, encouragement and a positive role model to others, especially the newly diagnosed.

The **Chronic Illness Peer Support Network** is made up of health-based organisations that offer peer support programs to their clients and members. The Network's [Member's Directory](#) offers a listing of all their current members, including links to their websites. The Network provides a forum for members to

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support each other, to share current ideas and knowledge, and to explore new ideas and knowledge.

The Network's long-term goal is to build the capacity of members and the chronic illness sector in general, to improve existing peer support programs, and to provide new services and initiatives wherever people living with chronic illness need them.

See their [website](#), for useful links including a Best Practice Framework for managing a peer support group.

Source: www.chronicillness.org.au

Volunteering Victoria



Volunteering Victoria provides helpful information for support groups about recruiting and working with volunteers. [Fact sheets](#) are available and cover a wide range of useful covering issues for managing volunteers.

Volunteering Victoria also offers training programs such as 'Establishing a Volunteer Program', 'Managing Volunteers', and 'Standards and Best Practice Frameworks'. For more information about training programs, including fees and bookings, please call 03 8327 8500.

Volunteers also have free access to information through Volunteering Victoria about their rights and responsibilities as a volunteer and how to go about finding a volunteering position as well as being able to utilise a telephone and email advice line.

For more information about membership with Volunteering Victoria and the services and information they provide volunteers and not-for-profit organisations that work with volunteers, visit their [website](#).

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Resources for Siblings



Siblings Australia provides information on the types of support available to siblings of children and adults with chronic conditions. Their [website](#) contains a directory of services which lists programs by state and provides web links and contact details for the groups listed.

Siblings Australia also run workshops for parents, healthcare providers, educators and the like which aim to raise awareness of the difficulties faced by siblings and the supports they often require. For more information or to book a workshop, head to the [contact us](#) section on their website.

If running your own program for siblings sounds like something you or your support group might like to do, a manual and accompanying participant booklets for the SibworkS program are available for purchase [here](#). SibworkS outlines a program designed to help siblings learn ways of dealing with the challenges they may face in a supportive, group environment.

The website also lists a range of books for purchase targeted at varying age groups that talk about the sibling experience, see <http://siblingsaustralia.org.au/books.php>.



Community Resources



DISABILITY SPORT & RECREATION



Disability Sport and Recreation is an organisation that supports people with a range of limiting conditions, including physical, mental and sensory disabilities, to have the opportunity to be involved in sporting and recreational activities.

The [DSR website](#) allows you to search for appropriate activities for your age, gender, geographical

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location, and abilities. Some fun examples are the swim program, lawn bowls and table tennis. For assistance in linking a Victorian with a disability to an appropriate recreation opportunity, including overcoming financial or transport barriers or just nervousness, contact 1800 BE IN IT (1800 23 46 48) or sportrecaccess@dsr.org.au.

Disability Sport and Recreation also run various education programs, such as WheelTalk. This allows school students to take part in interactive activities such as wheelchair basketball to help them learn about the skills and abilities of people who use a wheelchair.

See <http://www.dsr.org.au/wheeltalk-program.aspx> for more details and bookings.

Also see www.dsr.org.au for other educational workshops for your school or workplace.



Bayley House supports adults with an intellectual disability in the Bayside community in various ways from day programs to supported residential accommodation. They commenced an exciting new program in 2011, 'Working to Potential', which is continuing to be a success. 'Working to Potential' is a program that enables clients to undertake work at a local business, where they are thoughtfully linked to a participating business based on their skill level and interests, type of tasks involved in the work. Most work is voluntary but may lead on to paid employment.

Working to Potential is proving a great success and is offering new experiences to our clients enabling them to contribute meaningfully to their community. Each participant is very enthusiastic and it is wonderful to hear them sharing their experiences with their peers.

For more information email contactus@bayleyhouse.org.au or call 03 9982 1500.

Source: www.bayleyhouse.org.au

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Resources Offered by our Support Groups



The Friends of Sammy Joe Foundation have a wonderful outdoor play centre complete with trampoline available for use by the families of and children living with conditions that prevent them from playing outside in the sunlight. The Sammy-Joe Liistro Delfin Lend Lease Pergola Structure is a play centre attached to the family home that does not allow any light to penetrate into the room. To make a visit to their play centre, please see their [website](#) for contact and booking details.



When a patient with a rare disease presents at a hospital or medical centre, it is often difficult for staff and doctors to understand or know about specific treatment and care for that patient. The **Australian Pompe's Association** have produced a patient care folder which they hope will prevent a patient or family member from having to explain the care required. Instead, the folder can be used to advise healthcare providers on the particular needs and treatment options for people living with Pompe's Disease.

Contact the [Australian Pompe's Association](#) for more information.

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Cleftstars is a dynamic group of young people aged between 9 and 20 who were born with clefts.

Come along and:

- Share experiences
- Learn from others
- Hear from a range of professionals
- Support other young people who are cleft-affected
- Participate in social activities



Contact Evelyn Culnane on 0409 512 855 or Jarrod Morrison on 0424 860 862 to find out more.

Awareness Aids

A difficult issue for parents of children with a genetic condition can be how and what to tell other people about their child's condition. They may need to educate school teachers, the affected child, sibling, extended family members and friends. GSNV supports the value of educational tools for this purpose.

Some examples are listed below:



[Albinism Fellowship of Australia](#)

A useful template for parents to give to teachers to explain the needs of a child with Albinism.



[Cleft Palate and Lip Society \(CleftPals\)](#)

Offering free information sessions to families, health professionals, or other interested people.



[Gastrostomy Information and Support Society](#)

Gastrostomy Information and Support Society staff run workshops for anyone supporting someone with a gastrostomy or jejunostomy tube, for example for school teachers.

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[Muscular Dystrophy Australia](#)

An informative document covering key issues for discussing Muscular Dystrophy with children and other interested adults.



[Thalassaemia Australia](#)

This website offers free education sessions to Victorian high school students to promote awareness and understanding of Thalassaemia.

(Support hotline 0425 784 130)

We continue to encourage support groups that wish to promote their resources in our newsletter to contact us. We'd love to hear from you!

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Seeking Contact



The GSNV are looking to connect the following individuals with the following genetic conditions in order to promote peer support and connectedness:

- A young adolescent with **Osteofibrous Dysplasia** is looking to connect with a similarly aged individual
- A young child with **Ring Chromosome 8** and his family would like to connect with others with a similar condition
- A young adult with **Langer-Giedion syndrome** is looking to connect with a similarly aged individual
- A family with **Hereditary Sensory Autonomic Neuropathy** would like to connect with another family
- The family of a young child with **Incontinentia Pigmenti** would like to connect with another family
- An individual with **Palmar Plantar Keratoderma** would like to connect with others who have the same condition
- A family with a child with an **Undiagnosed Genetic Condition** would like to connect with other families in a similar situation

If you would like to make contact with any of the above people, please either contact the GSNV office by phoning (03) 8341 6315 or by emailing lynley.donoghue@vcgs.org.au

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GSNV Calendar for August

Haemochromatosis Awareness Week	August 13-19 th	National
ALDS 20 th Anniversary Conference	August 18-19 th	Victoria
VCFS 22q11 Conference	August 19 th	Victoria
VCFS 22q11 Awareness Week	August 20–26 th	National
DSV Race Day	August 25 th	Victoria
MDA Short Break Shopping Day	August 25 th	Victoria
SMA Australia Annual Gala Dinner	August 25 th	Victoria
DSV Chromosome Matters	August 27 th	Victoria

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GSNV Calendar for September

Autism Angels 4 th Annual Fundraising Dinner Date	September 1 st	Victoria
MDA SWAP Night Out	September 1 st	Victoria
Kidsflix – Ice Age Continental Drift	September 1 st	Victoria
AGSA Official Launch Event Genetic Awareness Week	September 5 th	NSW
Myositis Social Lunch	September 6 th	Victoria
CAH Support Group Australia Family Conference Day	September 9 th	NSW
COSHG Self Help and Support Group Awareness Day Forum	September 13 th	Victoria
DSV Stepping into School Years	September 13 th	Victoria
NF Australia 11 th Annual Family Cup	September 14-16 th	NSW
Friends of Sammy Joe Foundation Trivia Night	September 15 th	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 are 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 Children's Research Institute
Royal Children's Hospital
Flemington Road
Parkville, Vic 3052 (Australia)
Ph: (03) 8341 6315
Fax: (03) 8341 6390
Web: www.gsnv.org.au

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