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BITS & PIECES e-news



September, 2012



In this edition

- * Message from the Team
- * Community
- * Events
- * Grants
- * Seeking Contact
- * In the Media
- * Support Group News
- * Conferences/Seminars/Workshops
- * Research
- * Calendar



From the Team



A Note from the GSNV Team

We hope this edition of e-news bulletin Bits & Pieces finds the GSNV community well. It has been a busy couple of few weeks with GSNV attendance at the Human Genetics Society of Australasia Annual Conference in Canberra and contribution to the Federal Department of Health and Ageing's Genetic Working Party (GWP), which is currently reviewing medical genetic testing nationally. The GSNV will continue to keep our members informed of developments in relation to the GWP and the development of discussion documents.

Save the Date **GSNV AGM**

The GSNV are getting in early and advising that the GSNV's Annual General Meeting will be held on Thursday, 18th October, 2012. A formal notice of the meeting will be circulated in late September. Please save this date as participation from GSNV members is very important to us.

Amendment

In our previous edition of Bits & Pieces, there was an incorrect contact number listed under Thalassaemia Australia. The correct contact details are (03) 9888 2211. Our apologies for any confusion.

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Feedback Competition – Winner!

Congratulations to our winner of GSNV's feedback competition featured in the last edition of Bits & Pieces. The winner has been notified by email.

Feedback competition for this week

We would love your feedback on GSNV's quarterly newsletter. Our last edition (Winter 2012) featured articles on Pre-Implantation Genetic Diagnosis and genetic technology. If you would like the chance to win a movie pass (Admit 4) to the 3D release of Finding Nemo, please write 'a letter to the editor' with your comments and feedback and we will publish in our next newsletter. We hope to include Letter to the Editor as a regular feature in the GSNV newsletters.

Please email your letters by mid-September to info@gsnv.org.au or via post to:

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



Community



National Disability Insurance Scheme

We have come a long way since the Government released the Productivity Commission's report into disability care and support one year ago, which recommended the establishment of a National Disability Insurance Scheme (NDIS).

The latest update from the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) has announced that a NDIS will launch in mid-2013 in the Barwon region of Victoria, including Geelong. This means that from next year, a NDIS will be launched in five states and territories across Australia.

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The launches in the Hunter region of New South Wales, Geelong in Victoria and across the ACT will be location-based, while the South Australian and Tasmanian launches will be for groups of people within these states – in South Australia for children under 15 and in Tasmania for young people between 15 and 24.

People with disability, their families and carers must be at the centre of this reform.

The National Disability and Carer Alliance is holding forums across the country and has just released its schedule of forums for 2012. You can go to the [Alliance's website](#) to register to participate in one of their important engagement activities.

To help this work and to provide another way for you to have your say on the big questions, FaHCSIA is pleased to launch "[NDIS Your Say](#)".

NDIS Your Say is an online forum to give you -- the real experts in disability -- a chance to have your say, and for FaHCSIA to hear your views and get your input on some of these key questions.

Register, get involved and share this with others who may also want to join in on the discussions. Your thoughts and opinions will help shape details of the NDIS.

Visit www.ndis.gov.au to sign up to updates on the progress of a NDIS and to register for Your Say to be kept up to date when new discussion forums open.

Source: <http://www.fahcsia.gov.au/>

Are You Caring for a Child with a Severe Disability?

The SBS Insight program is looking closely at the needs of families and carers with a child with a severe disability. They are focusing on respite needs.

*"We understand this is a sensitive, personal area but we feel it's an important discussion to have. We will do our best to explore everyone's stories in a sensitive and meaningful way."
– Hannah Meagher, Associate Producer, Insight SBS Television*



If you are interested in having a confidential conversation to assist in the research and possibly join the show in a couple of weeks, please contact Hannah Meagher at: hannahm@sbs.com.au.

Source: <http://www.daru.org.au/resource/sbs-insight-are-you-caring-for-a-child-with-a-severe-disability>

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Support Group News



Spina Bifida Foundation Victoria (SBFV) has an exciting month coming up in September. Spina Bifida Awareness Week, from 1st – 7th September, is being launched with a fundraising promotional walk. The SBFV team will be participating in the 6km walk in the Yarra Valley Water Grape Run on Saturday 1st September. All

donations will go directly to helping people with spina bifida and their families. Join the SBFV as a participant or cheer squad – or promote, sponsor or donate.

Details on SBFV awareness walk can be found via the link:

<http://makingadifference.gofundraise.com.au/page/LoganE>

“What Are You Doing?” Autism Awareness DVD

"What are you doing?" is a short film created by Autism Awareness which aims to help school aged children learn about their peers with Autism Spectrum Disorder (ASD).



This film aims to send out the message that acceptance, encouragement and support from the community and peers is very important to children with ASD.

"What are you doing?" will be screened at primary schools across Australia later this year and will be available for purchase at the end of 2012.

Watch the trailer for “What are you doing?” [here](#).

Source: <http://www.whatareyoudoingfilm.com/>

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Cancer Screening for Women with Intellectual Disabilities

Cancer screening is an important service available to Australian women. The Cancer Council of Victoria is rolling out a program available to Victorian women with an intellectual disability, to encourage the benefits of cancer screening.

For more information, go to www.cancervic.org.au.

Source: <http://www.daru.org.au/resource/cancer-screening-for-women-with-intellectual-disabilities>



Events



GSNV Genetic Health Seminar – Supporting Victorians with Cancer

The GSNV is hosting a Genetic Health Services Victoria Friday seminar focusing on support for Victorians with Cancer. The session will be presented by guest speaker Janet Phillips and Cancer Information and Support Services (CISS).

Date: Friday 7th September 2012
Time: 9am – 9.50am
Venue: Vernon Collins Theatre
HELP Precinct, Level 1, West Building
Royal Children's Hospital
Flemington Rd, Parkville, VIC

For more information, please visit the [GSNV events page on the website](#) or contact the GSNV office on (03) 8341 6315.



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VCGS Friday Morning Seminar

**'Supporting Victorians
with Cancer'**

*Presented by Janet Phillips,
Cancer Information and Support
Services*

9.00am – 9.45am
September 7, 2012
Vernon Collins Lecture Theatre
HELP Precinct, Level 1,
West Building, RCH



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Huntington's Victoria – Huntington's Disease Charity Gala Ball

On Friday 12th of October, Huntington's Victoria in conjunction with community member Jess Wood will be hosting the Inaugural Huntington's Disease Charity Gala Ball to help raise awareness of this condition. Funds raised will go directly to supporting those living with this condition.

Date: Friday 12th October 2012
Time: 7pm – 12am
Tickets: \$130 pp
Venue: The International – Ballroom
81 Bay St
Brighton, VIC

Don't miss out on this special event, [book your ticket now!](#)

*The Huntington's Disease
Charity Gala Ball*

THE INTERNATIONAL
-BALLROOM
81 BAY STREET
BRIGHTON VIC

FRIDAY OCTOBER 12, 2012
7PM TILL 12AM
CANAPES ON ARRIVAL, FOLLOWED BY 3 COURSE MEAL,
DRINKS, ENTERTAINMENT AND MORE!
KEYNOTE SPEAKER: HON. BILL SHORTEN MP

TICKET PRICE: \$130 PP
BLACK TIE EVENT
FOR TICKET PURCHASE OR ENQUIRIES PLEASE CALL:
JESS WOOD - 0412 216 793
GLENYS AT HUNTINGTON'S VIC - (03) 9818 6333

hope dignity awareness

Haemophilia Awareness Week and Red Cake Day

Haemophilia Awareness Week is designed to raise awareness about haemophilia and related bleeding disorders.

'Achieve Your Dreams'

During the week of 7-13th October, you can support the Haemophilia Foundation in a number of ways.

- Red Cake Day
- Organise you own awareness activity at your work place, school or local community

The Haemophilia Foundation has stickers, posters and various promotional ideas that can be ordered to assist in your activity. Stocks are limited.

For more information on haemophilia awareness week, Red Cake Day, or to place an order for promotional material, please visit the [Haemophilia Foundation website](#).

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FSHD Global – “I Believe in Miracles” ‘70s Gala

The Facioscapulohumeral Dystrophy (FSHD) Global Research Foundation is holding a ‘70s themed dinner dance – I Believe in Miracles, on October 27th 2012, to raise fund for FSHD Muscular Dystrophy. This is the third event held to support this cause in Victoria.

Date: Saturday 27th October 2012
Tickets: \$150 pp
Venue: Rydges on Swanston
701 Swanston St
Carlton, VIC

For more information, download the [event flyer](#) or visit the [FSHD website](#).

Leukaemia Foundation – Light the Night Walk

Leukaemia Foundation is holding a fundraising event – Light the Night Walk. Participate and help raise funds for in support of leukaemia, lymphoma and myeloma research.

For more information, visit www.communitynews.infoxchange.net.au



Connecting Up

If you are not-for-profit organisation and struggling to set up or improve your website, take a look at Connecting Up. Connecting Up is currently offering free webinars and tips to help you on your way.

Free webinars: managing your content with Drupal and Content,
go to <http://www.connectingup.org/events/webinars>

5 Tips for Visually Enticing Nonprofit Websites,
go to <http://www.connectingup.org/learn/articles/5-tips-visually-enticing-nonprofit-websites>

For more ideas and information, please visit the [Connecting Up website](#).

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Down Syndrome Victoria – Stepping into the School Years

On September 13th, Down Syndrome Victoria is presenting a workshop designed to inform, discuss and prepare families who have a child with Down Syndrome and are starting school.

For more information, please visit the [Down Syndrome website](#).



GSNV Small Grants Scheme 2012 – applications are open!

As previously mentioned in the last edition of Bits & Pieces, applications for the GSNV Small Grants Scheme 2012 are now open. If your support group or organisation is listed on the GSNV directory, but have not paid a membership in the last 12-24 months, or if your group receives Bits & Pieces and/ or the GSNV Newsletter, you are *eligible* to apply this year. We encourage all support groups and organisations to apply.

Visit our [website](#) to download the Application Form and to view our Small Grants Terms and Condition.

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.

Foundation for Children Grants

The Foundation for Children is currently offering grants for projects that improve the health, welfare and wellbeing of Australian children. Projects focusing on children aged 14 and under are preferred.

Visit the [Foundation of Children website](#) to download the application form and to view the Expression of Interest guidelines.

Applications close on 30th September, 2012. Please note that applications will only be accepted via email, sent to foundationforchildren@afma.com.au.

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Stillbirth Foundation Australia – Research Grants

The Stillbirth Foundation Australia is calling for applications for clinical research and project funding in 2013.

Visit the [Stillbirth Foundation Australia website](#) to download the 2012-2013 Research Grant Application Form and to view application guidelines.

Applications close on 14th September, 2012.



Research



The Australian Nonprofit Leadership and Fundraising Survey

Queensland University of Technology is conducting a survey about the importance of fundraising leadership in the not-for-profit sector.

“This major study examines perceptions of leadership in fundraising from two perspectives – those in organisational leadership positions (board chairs, board members and CEOs) in nonprofit organisations where a dedicated fundraising function currently exists; and fundraising/development team members. The experiences and opinions of both groups will be analysed and compared to reveal leadership issues, challenges and success factors of fundraising.” - Dr Wendy Scaife from the Australian Centre for Philanthropy and Nonprofit Studies

Further details on the study and how to participate can be found by clicking on the following link: [Australian Nonprofit Leadership and Fundraising Survey](#).

Source: Lord Mayor’s Charitable Foundation, Thursday 16th August 2012

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RMIT University, School of Health Sciences, Honours Research – Meaning Making and Family Quality of Life

This project focuses on understanding families' experiences of quality of life and how they give meaning to their lives when experiencing stressful parenting.

To participate in this study, all you need to do is complete an 'Expression of Interest for Parent Participants' and a very quick questionnaire.

For full details, please contact Amanda Yee at s3359448@student.rmit.edu.au.



Dear Parents,
Hi! Our team from the School of Health Sciences at RMIT University are seeking your participation in a research project to assist us in understanding families' experiences of quality of life and how they give meaning to their lives when experiencing stressful parenting situations. Your opinions and experiences are important to us and they will help us to identify the best way to support families of children with disabilities and enhance their overall quality of life.

Parents, we hope you choose to participate in this research and fill out a questionnaire. The information that is obtained will remain confidential and no names or identifying information will be recorded. We will be providing families with a brief report of the findings at the completion of the study.

We would love to hear from families of children with disabilities aged between 3 to 12 years.

Please return the slip below with your details in the reply paid envelope. Alternatively, please feel welcome to call 9925-7710, or email susana.gavida-payne@rmit.edu.au to express your interest to participate.

THANK YOU FOR YOUR INTEREST!

A/Prof Susana Gavida Payne and Amanda Yee

Yes, I would like to participate in the study about meaning making and family quality of life

Parents' Names: _____

Name of your Child: _____ Date of Birth: _____

Telephone: (h) _____ (m) _____

A follow up study may also be conducted in the future. Would you like to be contacted at this time?

Yes No

NEW RESEARCH PROJECT

A WALK IN
YOUR FAMILY'S
SHOES
"Meaning Making and
Family Quality of Life"
Project



Seeking Contact

The GSNV works hard to connect individuals and families interested in sharing their experiences and insights with others. People interested in contacting others "in the same boat" can contact the GSNV to provide details and we will assist in making connections.

- **Carriers of balanced translocations** are looking to meet with others to share experiences, including coming to terms with the reproductive implications
- 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

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- 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

We are committed to your privacy

No details will be published without your consent, and those that are published will not include personal contact details. We will obtain consent from both parties before connecting individuals and families.

Disclaimer

The GSNV works to support contact between individuals and families to share experiences. However, in individual cases, there may be differences in approach and opinion. Those placed in contact are alone responsible for the views and opinion shared.

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GSNV Calendar

| | | |
|--|-------------------------------------|-----------------|
| Spina Bifida Awareness Week | September 1-7th | National |
| AGSA Official Launch Event Genetic Awareness Week | September 5th | NSW |
| GSNV Genetic Health Seminar – Supporting Victorians with Cancer | September 7th | VIC |
| COSHG Self Help and Support Group Awareness Day Forum | September 13th | VIC |
| NF Australia 11th Annual Family Cup | September 14-16th | NSW |
| Friends of Sammy Joe Foundation Trivia Night | September 15th | VIC |
| GSNV Genetic Health Seminar – Kleinfelter Syndrome | October 5th | VIC |
| Haemophilia Awareness Week and Red Cup Day | October 7-13th | National |
| Huntington’s Disease Charity Gala Ball | October 12th | VIC |
| National Carers Week | October 14-20th | National |
| FSDH – “I Believe in Miracles” Gala | October 27th | VIC |

For more events, please see our website.

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About the GSNV

The Genetic Support Network Victoria (GSNV) is a vibrant and active organisation committed to promoting the interests and well-being of people affected by genetic conditions. We assist individuals and families with the 'human', non clinical side of genetic diagnosis, living with a genetic condition, and gaining access to supports and services. The GSNV assists in the set up of new support groups and for those already established, helps to broaden awareness and assist in their activities. The GSNV is committed to improving the sense of isolation the community may feel in dealing with genetic conditions.

The GSNV is closely associated with a wide range of support groups, clinical genetic services and peak professional bodies.

Keeping up to Date

Please continue to notify GSNV of your change of contact details either by calling the GSNV office, or via email to info@gsnv.org.au. We have launched an exciting new website and database but are still finalising the upgrade. Please bear with us as we make the updates.

Contacting the GSNV

South Building, Level 9, Murdoch Children's Research Institute
Royal Children's Hospital
Flemington Road
Parkville, Vic 3052 (Australia)
Ph: (03) 8341 6315
Fax: (03) 8341 6390
Web: www.gsnv.org.au

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