



May, 2013



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### From the Team



Welcome to the latest edition of Bits and Pieces. This bulletin contains important support group information, events and calendar dates and as in previous editions, highlights the importance of awareness raising for all genetic conditions.

#### ***You will notice some changes in the GSNV team:***

After sadly bidding Christine Chan and Lynley Donoghue farewell (and we will miss them terribly) four new faces now form a reinvigorated admin team under the continuing guidance of Louisa Di Pietro. We are pleased to introducing Marleen Susman, Catherine Beard, and casuals Emily Higgs and Emma Swain who will each have responsibilities with genetic support, administration, communications and development. Welcome ladies and good luck in your new roles.

#### ***We appreciate your feedback:***

"I would like to thank the Genetic Support Network of Victoria that provided the funding for me to fly from Brisbane to Melbourne to be able to attend the CleftStars event at BOUNCEinc. It was a unique opportunity to be able to meet up with the CleftStars as there isn't anything like it in Queensland that I'm aware of. It was a fantastic venue to have some fun and to meet some of the other cleft affected people and reassure myself



that I'm not the only one out there affected by it. It would be lovely to start something similar in Queensland, however in the meantime I hope to be able to attend another event in Melbourne to catch up with all the CleftStars again." – *Recipient of a GSNV grant*

### GSNV on Social Media

**GSNV is now on [facebook](#) and [twitter](#)!**

**'Like' and share our page or  
follow us on [@gsnv\\_info](#).**



Being a part of the conversation is a useful tool for interacting with the community. The GSNV wants to *listen* and *hear* how you think we can help or what we can do for you, rather than just updating you on our activities. Join in our conversation!



## GSNV Volunteer Program



The Genetic Support Network of Victoria is introducing a new Volunteer Program. This program is an opportunity for our support groups to source suitable volunteers to help them with various small tasks. The tasks may vary, but some examples are assisting with mail-outs, updating databases, creating a simple brochure, or assistance organising an upcoming event or fundraiser. The volunteers will be students in the Masters of Genetic Counselling program (the University of Melbourne), or students interesting in applying for the Masters and seeking some hands-on experience in the genetics community. The GSNV may also engage volunteers from its broader networks and community. We expect the program to be up and running in the coming weeks!

Please help us to help your support group by letting us know what you need. Further information about the progress of the Volunteer Program will be posted in coming editions of Bits and Pieces but in the meantime if you have a need for a volunteer or would like to volunteer, please let us know at [info@gsnv.org.au](mailto:info@gsnv.org.au).



## Support Group News



### Charcot-Marie-Tooth Association Australia

The Charcot-Marie-Tooth Association Australia (CMTAA) has been promoting the establishment of more support groups throughout Australia for those affected by CMT. If you are interested in joining a support group in your area please contact CMTAA on 02 9767 5105.

Source: Charcot-Marie-Tooth Association Australia

### Cystic Fibrosis Victoria 65 Roses Day

It is one of the biggest days for the CF community and we need your help to make it our biggest celebration and awareness campaign to date!



On Friday 31 May come down to the Melbourne City Square (corner Collins and Swanston Street) and join in Cystic Fibrosis Victoria's 65 Roses festivities. There will be bands, interviews with ambassadors, competitions and give-aways.

After a month of raising awareness of CF we will be finalising the 65 Roses Campaign by celebrating and selling beautiful roses, merchandise and tin rattling.

These much needed funds ensure CFV can continue our programs and support services for those with CF in the community. Festivities will run from 8.00am to 6.00pm.

If you can't join us on 65 Roses Day there is plenty of other ways to get involved like taking up a '65' themed challenge at home... let your imagination run wild!!



CF has beautiful 65 Roses themed lapel pins and pens available this year. Please contact [events@cfv.org.au](mailto:events@cfv.org.au) for more information or see the website, <http://www.65roses.org.au/event/65rosesvic13/65roses>.

Source: Cystic Fibrosis Victoria, [www.cysticfibrosis.org.au/vic/](http://www.cysticfibrosis.org.au/vic/)



### **Disability Action Southeast Calls for Members**

The Disability Resources Centre Inc. (DRC) in the outer southeast is seeking expressions of interest from people with disabilities to join Disability Action Southeast (DAS).

The purpose of Disability Action Southeast is to encourage local input into the southeast advocacy service and assist the Disability Resources Centre with community awareness and running local campaigns.

Disability Action Southeast has been running for over 6 years and during this time has advocated on many issues including improvements to public transport; various issues around access to the built environment, and recently assistance animals on public transport. We have also run successful forums including one in the City of Casey on Accessible Housing. Members benefit from regular Self-Advocacy training opportunities.

The DRC provides an outreach advocacy service to adults with disabilities living in the regions of Casey, Cardinia, Dandenong, Frankston, Kingston and the Mornington Peninsula. People with disabilities living in these regions are encouraged to participate on DAS. Currently we are looking for new members from the regions of Frankston and Kingston, however if you are outside these areas and are keen on making a contribution please give us a call.

The membership of Disability Action Southeast is comprised of up to 15 people with disabilities living in the outer southeast growth corridor, and meets once every two months. The next meeting is scheduled for Monday 8<sup>th</sup> April 2013.

If you are interested in joining the group please give Katrina a call on 9791 4870 Monday, Tuesday and Wednesday 9:30am – 4:30pm or email [Katrina@drc.org.au](mailto:Katrina@drc.org.au).

Source: Disability Resources Centre Inc.



## Prader-Willi Awareness Month May 1<sup>st</sup>-31<sup>st</sup>



Prader-Willi Awareness Month is helping to spread the word about Prader-Willi Syndrome (PWS). To promote awareness, the PWS Association of Australia is inviting schools, workplaces and our families and friends to GO Orange for PWS on 30th May 2013. The colour orange represents appetite and hunger - something a person with PWS has to live with everyday, the feeling of constant hunger. So wear something orange or buy a PWS Orange Ribbon to raise awareness and support the PWS Association of Australia.

For some fantastic ideas about how you can spread the word, such as changing your Facebook profile picture, blogging, or requesting a casual day at your school, see the PWS Association of Australia website, <http://www.pws.asn.au/awareness.html>.

Source: Prader-Willi Syndrome Association of Australia [www.pws.asn.au](http://www.pws.asn.au)

## Self Help Queensland: Of interest to Australia-wide support groups

Self Help Queensland is producing a comprehensive database of support groups in Queensland. There will be no charge to search for or to register a self help or support group. Self Help Queensland welcomes contact from any newly formed groups that we may not be aware of yet, so that we can send out a letter and registration form to them also. They also welcome newsletter articles of relevance to their readers.

See their latest newsletter on their website, <http://www.selfhelpqld.org.au/>, or email [info@selfhelpqld.org.au](mailto:info@selfhelpqld.org.au)

Source: <http://www.selfhelpqld.org.au/>



## In the Media



### Counting down to the launch of the National Disability Insurance Scheme

Finally we can count down to the launch of the National Disability Insurance Scheme (NDIS) in less than two months. The scheme will be named 'DisabilityCare Australia', and will be launched on 1<sup>st</sup> July this year in South Australia, Tasmania, the Barwon region of Victoria and the Hunter in New South Wales. The ACT launch will start in July 2014. The NDIS will roll out in full across NSW by July 2018. The NDIS is continuing to work with other state and territory governments toward agreement with them to roll out the scheme nationally.

The NDIS has already provided \$1 billion and is celebrating the passage of the landmark piece of legislation, the National Disability Insurance Scheme Bill, through Parliament. The legislation also establishes the NDIS Launch Transition Agency as an independent body, to work with people with disability to identify their goals and aspirations, and provide them with the support they need to help them reach their full potential.

It's vital that people with disability, their families and carers continue to provide their input during this final stages before the scheme is launched. The NDIS has opened a [new online Your Say forum](#) to seek your views on how best to support people with disability who are from culturally and linguistically diverse (CALD) backgrounds. Don't forget to have your say by visiting the website, <http://yoursay.ndis.gov.au/cald>!

There is still much to be done but DisabilityCare Australia is well on the way. The NDIS will continue to work closely with people with disability, their families, carers and service providers as DisabilityCare Australia develops. *"Australians have been calling for this fundamental reform for a long time and we've heard their calls"* Jenny Macklin MP.

Sources:

<http://www.ndis.gov.au/>

<http://www.ndis.gov.au/talking-about-ndis/sign-up/previous-ndis-updates/>



### **Parents ignore speech problems: study**

The Murdoch Children's Research Institute recently studied communication issues in pre-school aged children. They found that half of the children with delays in communication skills were not receiving professional help. Although early intervention can prevent ongoing problems with school performance and behaviour, the study points out that it is not always easy to notice a language delay. The researchers urge parents to have their child assessed if they have any concerns.

Source: <http://news.ninemsn.com.au/health/2013/04/29/17/40/parents-ignore-speech-problems-study>

### **Study reveals learning disabilities affect up to 10 per cent of children and co-occur at higher than expected rates**

A University of Melbourne study has revealed that up to 10 % of our population is affected by a specific learning disability, such as dyslexia, dyscalculia and autism. This means two or three students in a class of twenty five. The study also found that children may have more than one learning disability. The researchers encourage the need for specialised learning support tailored to each child's individual learning needs.

Source: <http://newsroom.melbourne.edu/news/study-reveals-learning-disabilities-affect-10-cent-children-and%2%A0co-occur-higher-expected-rates>

### **Australia helps world cancer breakthrough**

**Australian scientists have played a key role in a collaborative international study that has shed more light on the genetic alterations involved in certain cancers.**

"To work out how to prevent or treat cancers, we need to understand what causes them in the first place. This research has found about 80 genes that underlie the risk of breast, ovarian or prostate cancer," says Prof Chenevix-Trench, head of the Queensland Institute of Medical Research Cancer Program. It is hoped that in the next five years the results of this research can be used to give individuals a more accurate assessment of their risk of developing certain cancers.

Source: <http://www.heraldsun.com.au/news/breaking-news/australia-helps-world-cancer-breakthrough/story-e6frf7kf-1226608295409>



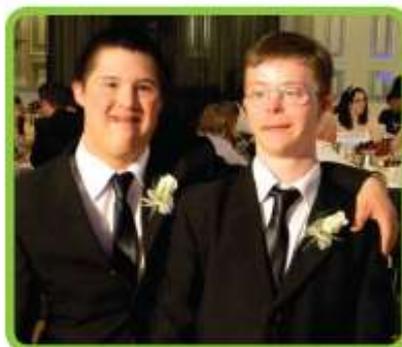
## Conferences /Seminars/Workshops



Association for Children with a Disability 'Making it *Possible*' Parent Workshop in Barwon region

### Making it *Possible!*

A WORKSHOP FOR PARENTS



#### Details:

**Date:** Friday 24th May 2013

**Time:** 9.30am – 2.45pm

**Venue:** Vines Road Community Centre  
49 Vines Road, Hamlyn Heights VIC 3215

**Cost:** \$20 per person – members\*

\$40 per person – non-members

Morning tea & light lunch included

#### Barwon Region:

##### Warrambrook

**Date:** Thursday 23 May 2013  
**Time:** 9.30am – 2.45pm  
**Venue:** Southern Way Direct Care  
Conference Centre,  
181 Fairy Street, Warrambrook VIC 3200  
**To Book:** <http://www.trybooking.com/44596>  
or contact our office

##### Geelong

**Date:** Friday 24 May 2013  
**Time:** 9.30am – 2.45pm  
**Venue:** Vines Road Community Centre  
49 Vines Road, Hamlyn Heights VIC 3215  
**To Book:** <http://www.trybooking.com/44596>  
or contact our office

**Cost:** \$20 per person – members\*  
\$40 per person – non-members  
Morning tea & light lunch included

\*Membership is free for the first 12 months,  
so ring the office to apply

Build on the  
strengths and  
skills you already  
have as a parent to  
create a fulfilling  
life with choices,  
purpose, friendship  
and happiness!

Our presenters are parents  
themselves, so they  
understand the issues  
families face



#### Association for Children with a Disability

For more information phone 9818 2000 or 1800 654 013 (rural callers)  
Email [mail@acd.org.au](mailto:mail@acd.org.au) or visit our website [www.acd.org.au](http://www.acd.org.au)

Places are limited so be quick to book at: <http://trybooking.com/44596> or phone the ACD office on 9818 2000.

**genetic support**  
network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**



## **Immune Deficiencies Foundation Australia National Patient & Carer Conference**

IDFA is hosting a National Patient & Carer Conference for people living with and people caring for those with primary immune deficiency (PID).

### **"You, Me and PID"**

1st & 2nd June  
Mantra Legends Hotel  
Surfers Paradise

For more information contact Christine by email, [christine.jeffery@idfa.org.au](mailto:christine.jeffery@idfa.org.au), or phone 1800 100 198.

## **12<sup>th</sup> International Conference on Pre-implantation Genetic Diagnosis**

The Preimplantation Genetic Diagnosis International Society (PGDIS), would like to invite you to participate in the 12th International Conference on Preimplantation Genetic Diagnosis (PGD), which will be held in Swissotel The Bosphorus Istanbul, Turkey, 8<sup>th</sup> -11<sup>th</sup> May, 2013.

This is one year after the 11th PGD Conference in Bregenz, Austria, due to the growing need to review the recent dramatic progress in PGD technology and its expanding applications in reproductive medicine and genetic practices not only in Western countries, but all over the world.

For full details please visit the conference website, <http://www.pgdis2013.com/>.



## **Health issues Centre**

### **PATIENT AND FAMILY CENTRED CARE ONE DAY FORUM**

#### **Details:**

TUESDAY, 21 MAY 2013

9:00am-4:00pm

Victoria University Conference Centre

Lv12 300 Flinders St Melbourne

Patient and family centred care is an approach to health care aimed at drawing upon the strengths of patients, families and health care professionals. The aim is strong partnership that improves both the experience and outcomes of health care.

Four of the key principles of patient and family centred care are:

- \* Respect and dignity
- \* Information sharing
- \* Participation
- \* Collaboration

In this one day forum we will focus on practical applications of these and other key principles. We will hear from both consumers and health care professionals about the innovative and exciting ways they are working together to improve the experience and outcomes in the Australian health care system.

For a registration form or copy of the program, visit the Health Issues Centre website, <http://www.healthissuescentre.org.au/>

### **The International Porphyrin Patient Day**

The International Porphyrin Patient Day, organised by the Swiss Society for Porphyrin and the German EPP Patient Group, will be held on Saturday, May 18<sup>th</sup>, 2013 in Switzerland. For more details see the Porphyrin Patient Day website, <http://www.porphyrinsandporphyrias.org/patient-day>.



### **National Palliative Care Week 19th – 25th May 2013**

On 20<sup>th</sup> May as part of the National Palliative Care Week, Dr Ira Byock, an international leader in palliative care, uses his insights and inspiring stories to illustrate how, by practising four life affirming phrases in our day to day lives, we can experience a sense of wholeness even in the wake of personal tragedy or in the face of death.

This event is open to the general public as well as health professionals.

For more details of the event see the Palliative Care Victoria website,  
<http://www.pallcarevic.asn.au/more-info/events/>.

Places are limited so please remember to register online as early as possible.

### **Chromosome 18 Registry & Research Society**

The 2013 Australasian Registry Conference will be held in Sydney this August. This is a special event that is held only every several years. Guest speakers including international leaders in researchers will present their research. The program will also include special events such as a panel discussion for Chromosome 18 and a Parent Speaker session.

For more information please see the website, [www.chromosome18.org](http://www.chromosome18.org), or contact Marlene from the Chromosome 18 Registry & Research Society by email on [chromosome18@optusnet.com.au](mailto:chromosome18@optusnet.com.au) or by phone on (02)9580-5707 or 0400-809-366

## Community

### **Australia Alopecia Areata Foundation wig sale**



AAAF has been fortunate enough to be provided some very high quality products from an Australian wig provider that they can sell to our Alopecia Community. As funding for wigs



is extremely limited and they are very costly, you might be interested in getting some heavily discounted items.

The wigs retail for over \$200 each and are current styles. These prices are a **once off** and there are over 100 wigs that will be on display for **CASH** purchase on May 18<sup>th</sup>. The wigs are synthetic with a net weave cap and side ties. They are all female wigs and suitable for ages 12 upwards. We will also have other items for sale on the day.

All money raised from this day goes into the AAAF **research** fund.

**Details:**

Saturday May 18th 3pm - 5pm  
Temple Society Australia  
152 Tucker Rd, Bentleigh

**Here's what is on offer:**

Wig Short	\$45.00
Wig Long	\$60.00
Mannequin Head Stand - tall	\$40.00
Mannequin Head Stand - short	\$30.00
Mannequin Head Stand - scarf	\$30.00
Wig Cap	\$2.00
Wooden Wig Brush	\$15.00
Hair extensions	\$20.00
Travel Wig stand	\$8.00
Nammu Swim Hats	\$20.00
Scaaf's	\$20.00
Temporary Eyebrow Tattoos	\$10.00



Image provided by Chel Campbell, AAAF president

For more information please contact the AAAF president, Chel Campbell on 0412921013 or see the website, [www.aaaf.org.au](http://www.aaaf.org.au).



**Disability Action Plan Community Consultation: Have your say about disability in Frankston City!**

What are the key issues affecting people with a disability, their family and carers living in Frankston?

Come along and share your ideas about how to make Frankston City a fairer and more inclusive place for people with a disability.

RSVP by **Thursday, 16 May 2013** to the Policy & Planning Officer on 9784 1721 or email [communitydevelopment@frankston.vic.gov.au](mailto:communitydevelopment@frankston.vic.gov.au)

Refreshments will be provided (*please mention any dietary or access requirements*)

**If you can't make it to the forum then you can still have your say by simply following the link below.**

[Disability Action Plan Community Consultation Online Participant Survey](#) - Survey Closes May 29, 2013

*This event and survey are open to people who live and/or work in Frankston*

**National Volunteer Week 13<sup>th</sup>-19<sup>th</sup> May**

**Public transport for people with disabilities in Victoria - have your say**

The Australian Government is currently reviewing the Disability Standards for Accessible Public Transport. Under Australian law, providers and operators of public transport must comply with these standards that set out the minimum requirements for access by people with disabilities, their families and carers.

You can find out more about the review of the Standards, including making your own submission to the government at:

<http://www.infrastructure.gov.au/transport/disabilities/review/2012.aspx>. Submissions to the Australian Government close on 31 May 2013.

The Victorian Equal Opportunity and Human Rights Commission (VEOHRC) is currently preparing its own submission to the review. The VEOHRC wants to use this opportunity to



inform the review of the real experience of Victorians with disability. They have set up a survey that gives people with disability the opportunity to say what is good and what is bad about the accessibility of public transport in Victoria.

To complete the survey go

to: [http://www.humanrightscommission.vic.gov.au/index.php?option=com\\_k2&view=item&id=615:public-transport-for-people-with-disabilities-in-victoria-have-your-say](http://www.humanrightscommission.vic.gov.au/index.php?option=com_k2&view=item&id=615:public-transport-for-people-with-disabilities-in-victoria-have-your-say) or you if you need to complete the survey over the phone please call 1300 292 153.

*The survey ends on 30 May 2013*



## Resources



### Haemophilia Foundation Australia: New Mild Haemophilia Fact Sheet



Haemophilia Foundation Australia (HFA) has developed a short fact sheet on mild haemophilia. The fact sheet includes tips on managing mild haemophilia and what your doctors need to know. Print copies of the fact sheet can be ordered by emailing [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or calling 1800 807 173 or the fact sheet can be downloaded from their website, <http://www.haemophilia.org.au/publications/living-with-mild-haemophilia>.



## 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.

- Atypical Haemolytic Uraemic Syndrome
- Osteogenesis Imperfecta
- Ring Chromosome 8
- Langer-Gideion syndrome
- Undiagnosed genetic conditions
- Hereditary Sensory Autonomic Neuropathy
- Incontinentia Pigmenti
- Palmar Plantar Keratoderma
- Carriers of Balanced Translocation
- Stickler syndrome
- Cloacal Anomalies
- Pitt Hopkins Syndrome
- Noonans Syndrome

If you would like to make contact with others in the same boat and share your experiences with the above conditions, please either contact the GSNV office by phoning (03) 8341 6315 or by emailing [info@gsnv.org.au](mailto:info@gsnv.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.



## GSNV Calendar

The International Porphyria Patient Day	18 <sup>th</sup> May	Switzerland
Australia Alopecia Areata Foundation wig sale	18 <sup>th</sup> May	VIC
Palliative Care Week Key Note Speaker	20 <sup>th</sup> May	VIC
Health Issues Centre: Patient and Family Centred Care Forum	21 <sup>st</sup> May	VIC
Association for Children with a Disability 'Making it Possible' Workshop	24 <sup>th</sup> May	VIC (Geelong)
Go Orange for PWS Day	30 <sup>th</sup> May	VIC
Cystic Fibrosis 65 Roses Day	31 <sup>st</sup> May	VIC
IDFA "You, Me and PID" Conference	1 <sup>st</sup> -2 <sup>nd</sup> June	QLD

For more events, please see our website:

[www.gsnv.org.au](http://www.gsnv.org.au)

### **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](mailto: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](http://www.gsnv.org.au)

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