



February, 2013



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### From the Team



Welcome to the latest edition of the GSNV Bits and Pieces. We commence this bulletin with an important reminder of the vital work of support groups in Victoria and nationally. Whether they are kitchen table or board room orientated, support groups provide immense support to the community, raise awareness on genetic and rare conditions and advocate for improvements in therapeutics and clinical services. The GSNV team have recently met with passionate and motivated people rallying behind Neurofibromatosis (NF) in Victoria and Primary Ciliary Dyskinesia (PCD). Both groups are working hard to provide representation on behalf of those affected by NF and PCD and are broadening their networks, communities and messages this year.

As 2013 speeds past us, please remember to pass on your support group news, events and topical issues to the GSNV in order that we can spread the messages on your behalf. This bulletin also includes some important diary dates and invitations from the GSNV to get involved in some of our work and help us, help you.

With the dedication of support groups in mind, the GSNV reminds all our community that Rare Disease Day 2013 is fast approaching and it is time to support and celebrate rare disease and the rare disease community globally. ***“There are over one hundred million people living with a rare disease around the world. Take down borders, for rare disorders.” Show your solidarity with the GSNV and all support groups working hard to make a difference at the local, National and International level.***



28 FEBRUARY 2013

## Celebrate Rare Disease Day and the Launch of PCD Australia

*There are over one hundred million people living with a rare disease around the world.*

In recognition of rare disease awareness, treatment and research we are pleased to bring together the Primary Ciliary Dyskinesia (PCD) community, the Genetic Support Network of Victoria community, health professionals and researchers to facilitate important discussions and an awakening of public and government opinion on rare diseases.

Please join us in marking the day with the official launch of a new support group, PCD Australia Association.

The GSNV encourages everyone to join us on this international day of recognition and help put the spot light on PCD, all rare diseases and the rare diseases community.

Date: Thursday February 28<sup>th</sup>  
Time: 10.00-11.30am  
Venue: Meeting Room 2  
Adjacent to the Ella Latham Theatre  
Ground Floor, Royal Children's Hospital, VIC



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**genetic support network of victoria**

**RARE DISEASE DAY**  
**FEBRUARY 28<sup>th</sup>, 2013**

Please join the GSNV to mark Rare Disease Day 2013 and launch PCD Australia Association

**10 am – 11.30 am**  
**Meeting Room 2**  
Ground floor, adjacent to the Ella Latham Theatre  
Royal Children's Hospital  
Flemington Rd, Parkville, VIC  
RSVP by February 22<sup>nd</sup> to [info@gsnv.org.au](mailto:info@gsnv.org.au)



## Support Group News



### Marfan Syndrome Awareness DVD Launch

Marfan Association Victoria Inc. is launching their DVD – Marfan Syndrome Awareness. This DVD aims to create better understanding and recognition of Marfan among the medical professionals to improve diagnoses and the chance of survival for individuals with Marfan syndrome.

For more details on the launch, please click on the flyer (right).



**JOIN US:**  
2pm, Sunday, 24 February  
Building 8, RMIT University  
360 Swanston St, Melbourne  
RSVP: E00 691164 or  
[info@marfanvic.org.au](mailto:info@marfanvic.org.au)  
by Monday, 18 February  
*Light refreshments will be served*

**THE PREMIERE:**  
There are too many tragic stories of undiagnosed Marfan syndrome. The Marfan Association of Victoria has produced a DVD that aims to create better understanding and recognition of Marfan among medical professionals to improve diagnoses and the chance of survival for individuals with Marfan syndrome. We would like to thank everyone who has helped raise funds over the years to realise this goal. We hope you can join us at the premiere of the DVD and celebrate this milestone in Marfan awareness!

**GETTING THERE:**  
Closest train station: Melbourne Central  
Trams run along Swanston Street: visit [www.ptv.vic.gov.au](http://www.ptv.vic.gov.au) for details  
Mel ref: 2f (parking available in multi level car parks in La Trobe Street)

**ADMI ONE**  
Bookings essential!

## Tourette Syndrome Family Fun Day – February 27<sup>th</sup>

Members of Tourette Syndrome Association of Victoria are invited to a Family Fun Day at Funfields, Whittlesea on Sunday February 17<sup>th</sup>. Please note, special discounts are available for members.

Contact the Tourette Syndrome Association of Victoria on [tourette.syndrome@msaustralia.org.au](mailto:tourette.syndrome@msaustralia.org.au) for more details.

## Purple Day – March 26<sup>th</sup>

Purple Day is a grassroots effort dedicated to increasing awareness about epilepsy worldwide. On 26 March, people from around the globe are asked to spread the word about epilepsy by wearing purple.



*Show your support for Epilepsy on March 26<sup>th</sup> by wearing purple!*

## New Brochures for Teens and Parents- Australian Alopecia Areata Foundation

The Australian Alopecia Areata Foundation has just published two new brochures: '[Teenagers Talking About Alopecia Areata](#)' and '[Parents Talking to Other Parents](#)'. This is a great resource to assist and facilitate discussions for both teenagers and parents of children with alopecia areata.

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

## IDFA Picnic – March 3<sup>rd</sup>

The Immune Deficiencies Foundation Australia (IDFA) is holding a picnic for people who have Primary Immune Deficiency. Join IDFA at the beautiful Gasworks Art Park in Albert Park on March 3<sup>rd</sup>. This community arts centre has a lovely park area with BBQ facilities and a playground set amongst two theatres and three gallery spaces, including rare public art sculptures. This park is very central and has quite good parking available. Bring your own picnic lunch, drinks, chairs/picnic blanket.

Date: March 3<sup>rd</sup>  
Time: 12.30pm  
Venue: Gasworks Art Park  
Foote St  
Albert Park, VIC  
Contact: Jackie Murphy on 1800 100 198  
for more information



## In the Media



## Institute welcomes new Director

Murdoch Childrens Research Institute recently welcomed Professor Kathryn North AM as the new director, succeeding Professor Terry Dwyer. Professor North has exceptional qualifications and awards to her name and most recently, awarded Member of the Order of Australia (AM) for service to medicine in the field of neuromuscular and neurogenetics.

[Read more](#) about Professor North and her vision for the Murdoch Childrens Research Institute.

## **Crown Princess Mary of Denmark announced as Patron of Australian and Danish Twin Registries**

Her Royal Highness Crown Princess Mary of Denmark has become a patron of the Australian Twin Registry, based at the University of Melbourne.

Crown Princess Mary became the International Patron of the Australian Twin Registry and the Danish Twin Registry at a ceremony in Denmark on 16 January.

Director of the Australian Twin Registry and University Professor John Hopper said he was extremely grateful for the Crown Princess's patronage and, as a mother of twins, she was a fantastic ambassador for twin research.

To read full article, <http://musse.unimelb.edu.au/january-13-102/crown-princess-mary-denmark-announced-patron-australian-and-danish-twin-registries>

## **Fearnley highlights 'damning' disability inequality**

Paralympic triple gold medallist Kurt Fearnley has made an impassioned plea for Australia to end the inequality suffered by people with disabilities.

In an Australia Day speech held in Sydney, Fearnley also urged politicians to stop bickering over who will pay for the National Disability Insurance Scheme (NDIS).

To read the full article and to watch Kurt Fearnley's full Australia Day Address, <http://www.abc.net.au/news/2013-01-23/fearnley-calls-for-end-to-disability-inequality/4479716>.

## **Mother's BMI can predict children will develop Type 2 diabetes**

A mother's body mass index (BMI) can be used as a predictor for the later development of type 2 diabetes in her children, and is a stronger predictor than genetic data, a recent study has found.

A team of international researchers, including Doctor Matt Sabin from Murdoch Childrens Research Institute, studied over 1800 children for over 20 years, and found not only did maternal BMI predict the later development of type 2 diabetes in offspring, but that the association was independent of other childhood factors, including genetics.

To read full article, <http://www.mcri.edu.au/news/2013/january/maternal-bmi-more-accurate-than-genetics-at-predicting-type-2-diabetes-in-children/>



## **Conferences / Seminars / Workshops**



### **Peer Support Group Workshops for Chronic Illness**

The Royal Children Hospital runs Chronic Illness Peer Support (ChIPS) program for young people with a chronic illness. The topics explored related to how chronic illness affects them emotionally and

physically and in their daily life. Additional topics discussed include schooling, friendships, relationships and the future.

There are two programs available:

- 8-week Peer Support Group. This group is run during school term 1, beginning Feb 19<sup>th</sup> from 5-6.30pm and is aimed at young children aged 14-16.
- 2 Day Intensive Peer Support program. This program is aimed at young people living with a chronic illness who are isolated in rural areas or unable to participate in the 8-week program due to access barriers such as lack of transport.

For more information or to participate in the ChIPS program, contact the ChIPS office on (03) 9345 6616.

### **Forum for Young People Living with Rare Diseases: The challenges of the many transitions to adulthood!**

The Australian Paediatric Surveillance Unit is holding a forum for young people aged between 15 to 20 years old who have a rare disease or condition. It's not just about transitioning from child to adult health services but also other transitions you might be going through: final exams, higher education, employment, relationships...

This forum aims to:

- Connect with other young people with similar experiences
- Share views and focus attention on issues that matter to you
- Give you an opportunity to contribute to advocacy for better health and community services for young people living with rare diseases
- Share and listen to inspirational young people living with a rare condition

A limited number of support packages will be available to off-set the costs of attending for young people from rural areas of NSW and from interstate.

Date: 23<sup>rd</sup> February, 2013  
Time: 8.30 – 2.30pm  
Venue: The University of Sydney  
New Law Building  
Camperdown, NSW

For more information or to register your interest, please contact the APSU.

Phone: 02 9845 3005

Email: [apsu@chw.edu.au](mailto:apsu@chw.edu.au)

### **4th Annual National Dementia Congress**

The Federal Government already recognises dementia as a national health priority. Now, more than ever, there is a need to share findings and discuss the progress of dementia care initiatives to allow for greater understanding and collaboration of ideas. The event will delve into a broad range of topics from diagnosis through to palliation across the continuum of care. Topics include early detection and diagnosis of dementia, the difficulties of acute care, partnering with disability services, developing a person-centred care approach, younger onset dementia, the use of psychotropic medications,

environmental design, pain relief and palliative care. The conference also features a number of real-world examples of innovative practice, exploring the theme of doing things differently in dementia care.

Date: 21-22<sup>nd</sup> February, 2013  
Venue: Novotel Melbourne on Collins  
Melbourne, VIC

For more information, [http://www.iir.com.au/conferences/government/national-dementia-congress?utm\\_source=Carers+Victoria&utm\\_campaign=213e90a099-VOICE10\\_01\\_20131\\_10\\_2013&utm\\_medium=email](http://www.iir.com.au/conferences/government/national-dementia-congress?utm_source=Carers+Victoria&utm_campaign=213e90a099-VOICE10_01_20131_10_2013&utm_medium=email)

## Free Health Literacy Forum

According to the Australian Bureau of Statistics, 41% of Australians are health literate. The remaining 59% of the Australian population struggle with understanding what is important in maintaining good health and wellbeing. The Centre for Culture, Ethnicity & Health (CEH) is holding a free health literacy forum *Curing the Cultural Barrier: health literacy forum* on February 28<sup>th</sup> at the Fitzroy Town Hall.

Date: Thursday 28<sup>th</sup> February, 2013-02-07  
Time: 8.45 am – 9.15 am Registration  
9.15 am – 1.30 Forum (includes morning tea and light lunch)  
Venue: Fitzroy Town Hall  
201 Napier Street  
Fitzroy, VIC

Please note, entry is free but registrations are essential.

For more information on this forum, please visit the [CEH website](#) or contact CEH on (03) 9418 9929.

## Carer Support Group Facilitation Workshop

Carers Victoria is offering a one-day, introductory program for new carer support group facilitators, a refresher for current facilitators, or for those wanting to start up a carer support group.

This workshop is FREE for family carers and \$80 for workers. Lunch, morning and afternoon tea will be provided for participants. Bookings are essential: Tel – 03 9396 9560 or email [judith.oliver@carersvictoria.org.au](mailto:judith.oliver@carersvictoria.org.au).

Please note: If workers are able to bring along two carers (per worker), the workshop is free for both workers and carers.

Date: Tuesday 12<sup>th</sup> March, 2013  
Time: 10am – 2.30pm  
Venue: Footscray

For more information, please contact [Carers Victoria](#).

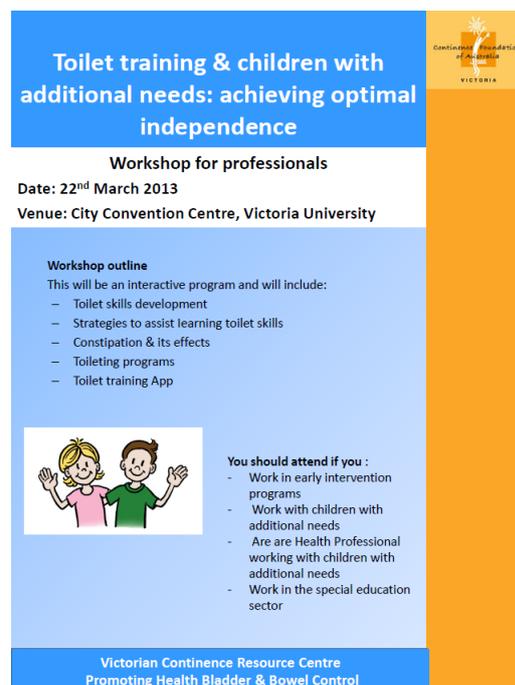
## Toilet Training & Children with Addition Needs: Achieving Optimal Independence

Continence Foundation of Australia is holding an interactive workshop for health professionals who work in early intervention programs, children with special needs and work in the special education sector. This professional workshop will address common issues around learning toilet skills and emphasis skills development required throughout toilet training.

Date: Friday 22<sup>nd</sup> March, 2013

Venue: City Convention Centre  
Victoria University

For more information and to register your attendance, please [download the event flyer](#).



**Toilet training & children with additional needs: achieving optimal independence**

**Workshop for professionals**

Date: 22<sup>nd</sup> March 2013  
Venue: City Convention Centre, Victoria University

**Workshop outline**  
This will be an interactive program and will include:

- Toilet skills development
- Strategies to assist learning toilet skills
- Constipation & its effects
- Toileting programs
- Toilet training App



**You should attend if you :**

- Work in early intervention programs
- Work with children with additional needs
- Are are Health Professional working with children with additional needs
- Work in the special education sector

Victorian Continence Resource Centre  
Promoting Health Bladder & Bowel Control

## Child Language Research Seminar

The Centre for Research Excellence in Child Language invites you to a seminar '*Child Language Research: Discovery, intervention and Policy Implications*'. This seminar is designed for early years services, schools, allied health professionals, local government, policy makers and researchers, focusing on:

- New discoveries in understanding what can go wrong in a child language development
- The latest in evidence based interventions for childhood language impairment
- Practice and policy implications of the above

For details on speakers and to register your attendance, visit the [MCRI website](#).



## Run For Strength – Sunday February 24

The 4<sup>th</sup> Run For Strength event will be held on 24<sup>th</sup> February to raise funds for research into Muscular Dystrophy at the National Muscular Dystrophy Research Centre. The event is held at Albert Lake Park and event options are a 5km walk, a 5km run or a 10km run.

For more information, contact the Muscular Dystrophy Australia office on (03) 9320 9555.

## 65kms for Cystic Fibrosis – Saturday March 2



Living with cystic fibrosis is no walk in the park.  
Help us change this.

Take the challenge of 65kms to help raise funds for Cystic Fibrosis. 65kms for Cystic Fibrosis is an endurance walk around a 19.8km track in the beautiful Royal Park Gardens and Princess Park in central Melbourne. Either take on the challenge and go for the full 65kms yourself or register as a team and share distance.

For more information, please visit the [65kms for Cystic Fibrosis website](#).

## MCRI's Discovery Day – Sunday March 3

The Murdoch family is again opening up Cruden Farm for Discovery Day. Bring your family down and be entertained by celebrities, musical guests and an exciting range of activities including face painting, rides, cooking show and sporting clinics.

Kids attend for free and tickets can be pre-purchased or available on the door. All proceeds raised on Discovery Day will directed to continuing kids research at MCRI.

**DISCOVERY  
DAY 2013**

For more information or to pre-purchase tickets, please visit [www.mcri.edu.au/discoveryday2013](http://www.mcri.edu.au/discoveryday2013).

## Run for the Kids – Sunday March 24

Join over 35, 000 Melbournians in 2013's *Herald Sun/CityLink* Run for the Kids, to raise money for the Royal Children's Hospital Good Friday Appeal.

Entries are now open for the 8<sup>th</sup> annual event. Register for Victoria's largest fundraising fun run in either the long super course or the family friendly short course and contribute to raising money for a cause that touches all Victorians.

Visit [Run for the Kids](#) to register.

# 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

Tourette syndrome Family Fun Day	17 Feb	VIC
ChIPS 8-week program begins	19 Feb	VIC
4 <sup>th</sup> Annual National Dementia Conference	21-22 Feb	VIC
Forum for Young People Living with Rare Disease: The challenges of the many transitions to adulthood!	23 Feb	NSW
Marfan syndrome DVD Launch	24 Feb	VIC
Run for Strength	24 Feb	VIC
Rare Disease Day 2013	28 Feb	International
Health Literacy Forum – FREE	28 Feb	VIC
65kms for Cystic Fibrosis	2 March	VIC
Discovery Day	3 March	VIC
IDFA Picnic	3 March	VIC
Carers Support Group Facilitation Workshop	12 March	VIC
Toilet Training & Children with Addition Needs Workshop	22 March	VIC
Run for the Kids	24 March	VIC
Purple Day	26 March	International

## **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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