



**September 27, 2011**



**“When one door closes, another opens; but we often look so long and so regretfully upon the closed door that we do not see the one which has opened for us.” – Alexander Graham Bell**

## **GSNV Office Update**

Only one month to go until the GSNV moves into our new office space! There is a flurry of activity occurring around the move and although it is business as usual, there will be some changes to technical and service capabilities over the next little while so we will get to all requests as soon as possible.

## **Our Committee**

The GSNV welcomes back to the fold our newest (but seasoned) committee member, Ms Amy Herlihy. Amy has previously sat on the GSNV committee and acted as Treasurer. We are delighted to have Amy back with us and look forward to working with her once again.

## **Disability News**

### **Event Registrations for 2011 International Day of People with Disability**

Communities from around Australia can now register their 2011 events for International Day of People with Disability (IDPwD).

**IDPwD** is celebrated on **3<sup>rd</sup> December** each year to recognise people with disability, their achievements and contributions to our communities. To register an event, order your promotional products or to see what events are happening in your community, phone 1800 440 385 or visit: <http://www.idpwd.com.au/events/> Event registrations close on **25 November 2011**.

IDPwD is supported by Australian of the Year and IDPwD Patron Simon McKeon. The Australian Government is working with Nican, a national disability community organisation, to coordinate community events for the Day for 2011.

*Source: Disability Advocacy Resource Unit (DARU) newsletter update Sept 12<sup>th</sup>*



### **Disability Employment Advisory Service at Randstad**

The Disability Employment and Advisory Service (DEAS) at Randstad is a partnership between Randstad and the State Government Departments, to support the employment and retention of people with a disability in the public service, across metropolitan and regional Victoria. The aim is to provide a pathway for job seekers with a disability to access Victorian State Government positions.

What are the benefits of working with DEAS?

- DEAS is designed to provide a pathway for job seekers with a disability to access Victorian State Government positions
- We adopt a supportive and personalised approach to ensure your job seekers are able to compete fairly for Victorian Government jobs
- Job Seekers are treated differently according to their needs, not just equally, so that they are able to participate in all aspects of their employment
- Direct access to decision makers and hiring managers in the Victorian Government
- Assistance to meet organizational objectives regarding job placement and post employment support.

For more information, visit the website at [www.randstad.com.au](http://www.randstad.com.au)

*Source: Disability Employment Advisory Service at Randstad.*

### **Children with a Disability Australia (CDA)**

CDA is pleased to announce the launch of its new website. The website has been redesigned with a fresh new look and has been updated with information about the organisation as well as providing essential links and information relevant to children and young people with disability in Australia.

Visit them on line at [www.cda.org.au](http://www.cda.org.au) and then know what you think.

*Source: CDA online news bulletin*

### **Conferences/Seminars/Workshops**

#### **World Congress on Huntington's Disease**

Last was the World Congress on Huntington's disease (Sept 11 -14). Visit the website for information at: [www.worldcongress-hd2011.org](http://www.worldcongress-hd2011.org)



### **“Scooter Etiquette Forum” presented by City of Boroondara**

Come along to collect information and hear presentations on community safety, pedestrian walk-ability and accessibility requirements for people with limited mobility.

All participants receive a **free 10 minute safety check** of their device by Scooters Australia.  
**\*Bookings Essential\***

**Location:** Ashburton Baptist Church, Y Street, Ashburton  
**Date:** Tuesday 4<sup>th</sup> October, 2011  
**Time:** 10am – 1pm  
**RSVP:** David Williams on 9278 4777 or [metroaccess@boroondara.vic.gov.au](mailto:metroaccess@boroondara.vic.gov.au)

## **Government**

### **High Court decision confirms importance of the Victorian Charter of Human Rights**

Acting Victorian Equal Opportunity and Human Rights Commissioner Karen Toohey has welcomed a High Court decision dealing with the operation of the *Charter of Human Rights and Responsibilities Act 2006*.

Ms Toohey said the Court’s decision in *Momcilovic v The Queen & Ors* on 8 September upholds the validity, operation and importance of the Charter.

“The Charter plays an important role in protecting and promoting human rights in Victoria and this judgement comes at a critical time to provide guidance to the Scrutiny of Acts and Regulations Committee (SARC) as it considers the future direction of the Charter in the four-year review,” Ms Toohey said.

Ms Toohey said the majority of the Court found that section 32 of the Charter, which requires that Victorian laws must be interpreted consistently with human rights, is valid and operates as an ordinary tool of statutory interpretation.

For more information refer to <http://www.humanrightscommission.vic.gov.au>

Source: Victorian Equal Opportunity and Human Rights Commission

## **Support Groups**

### **10<sup>th</sup> Autism Spectrum Disorder Research Forum**

The forum will focus on research matters and participants should have a reasonable knowledge of Autism Spectrum Disorders and research methodology: Suitable for autism researchers (including students), clinicians, autism educators as well as parents interested in research.

**Venue:** Grevillea Room  
Darebin Arts and Entertainment Centre, Bell St, Preston  
**Date:** Thursday 3<sup>rd</sup> November, 2011



**Time:** 9am – 5pm  
**Register:** [www.autismvictoria.org.au](http://www.autismvictoria.org.au) (from October 10<sup>th</sup>) or contact Lia Castorina on [lia.castorina@autismvictoria.org.au](mailto:lia.castorina@autismvictoria.org.au)

**Autism Victoria AGM**

23<sup>rd</sup> November: Details still to come.

**D.A.T.A. (Dialysis and Transplant Association of Victoria)**  
**D.A.T.A 2011 Annual General Meeting**

**Location:** Café Vanilli, 89 Railway Rd, Blackburn  
**Date:** Sunday 23<sup>rd</sup> October, 2011 at  
**Time:** 2pm  
**RSVP:** 4<sup>th</sup> October ([editor.shoestring@gmail.com](mailto:editor.shoestring@gmail.com))  
Guest Speaker: Karen Manly, Renal Dietician (Austin Hospital)

**CLEFTPALS**

**National Conference, 2011**

**Location:** Ella Latham Meeting Room,  
Royal Children's Hospital, 1<sup>st</sup> floor, Main Building,  
Flemington Rd, Parkville  
**Date:** Saturday 17<sup>th</sup> September, 2011  
**Time:** 12.00pm – 3.30pm  
**Info:** Evelyn Culnane at [evelyn.culnane@rch.org.au](mailto:evelyn.culnane@rch.org.au)

**CMTAA (Charcot-Marie-Tooth Association Australia)**  
**CMT Awareness Month, September, 2011**

Check the website at <http://www.cmt.org.au> for suggestions on how to get involved.

**HeartKids Victoria**

**Box Hill Miniature Train Day**

Free family fun day thanks to Kiwanis Club of Waverley and Box Hill Miniature Train Society.  
Event includes free sausage sizzle starting at 11am and free train rides between 12pm - 1pm  
(no open-toed shoes on train)

**Location:** Corner Elgar and Belmore Roads, Boxhill North (Mel Ref: 47 B4)  
**Date:** Saturday 22<sup>nd</sup> October, 2011  
**Time:** from 11am  
**Register:** by October 8<sup>th</sup> at [www.trybooking.com/STC](http://www.trybooking.com/STC)  
**Info:** Lynette on 9333 1586 or 0418 548 879 or [lmccoullough@heartkids.org.au](mailto:lmccoullough@heartkids.org.au)



### **Myuna Farm Day**

Sponsored by the Kiwanis Club of Sunbury: Come along to enjoy free train and pony rides and a free BBQ.

**Location:** Myuna Farm, 182 Kidds Rd, Doveton (gold coin donation entry)  
**Date:** Sunday 6<sup>th</sup> November, 2011  
**Time:** 10am – 2pm  
**Register:** by October 8<sup>th</sup> at [www.trybooking.com/STF](http://www.trybooking.com/STF)

source: *Heartkids Vic Quarterly newsletter, Vol21 Issue 3*

### **FSGA (Fabry Support Group Australia)**

#### **FSGA National Fabry Patient Meeting and Dinner**

**Location:** Murdoch Institute/ GSNV  
Conference Rooms A and B,  
Level 10 at the Royal Children's Hospital  
Flemington Rd, Parkville.

**Date:** Saturday October 22<sup>nd</sup>  
**Time:** 10am – 5pm

Speakers include: Dr Kathy Nicholls, Dr Drago Bratkovic, Carers Victoria, GSNV exploring innovative therapies, services available to patients and carers, Fabry Emergency Card Project and much more!

**RSVP:** September 22nd  
**Contact:** Lea Chant [leachant@yahoo.com](mailto:leachant@yahoo.com) or Megan Fookes([president@fabry.com.au](mailto:president@fabry.com.au)).  
(for further details and information regarding the Dinner)

### **Marfan Association Victoria** **2011 Annual General Meeting**

November 2011  
Details still to come.

### **NODSS (Narcolepsy & Overwhelming Daytime Sleep Society of Australia)**

#### **2011 Annual General meeting**

**Location:** Ross House,  
4<sup>th</sup> Floor, Hayden Raysmith Room,  
247 -251 Flinders Lane, Melbourne

**Date:** Monday September 19<sup>th</sup>, 2011



**Time:** 7.45pm  
**Enquiries:** Judith (03) 9870 1950 or Elizabeth (03) 9432 9669  
**Guest:** Dr Ryan Hoy: "Consequences of Sleep Apnoea on Cardiovascular Disease and other medical conditions".

### [Spina Bifida Foundation of Victoria](#)

#### [2011 Annual General Meeting](#)

**Location:** Level 7, 468 St Kilda Rd, Melbourne (near Leopold St)  
**Date:** Friday 4<sup>th</sup> November, 2011-09-14  
**Time:** 7.00pm – 9.30pm  
**RSVP:** (03) 9663 0075 or [info@sbfv.org.au](mailto:info@sbfv.org.au)

### **Consumer Groups**

The Clinical Trials Action Group (CTAG) was established in October 2009 to identify and progress necessary reforms to secure Australia's competitiveness in the clinical trials sector. Its report, "Clinically competitive: boosting the business of clinical trials in Australia", was released in March 2011.

Following the release of the report, CHF was funded by the Department of Innovation, Industry, Science and Research to develop a factsheet to provide consumer-friendly information about clinical trials, in response to a recommendation for improved consumer access to information on clinical trials. CHF members were engaged in focus testing and many provided input into the content and development of the factsheet.

CHF CEO, Carol Bennett formally launched the factsheet at the Joint Medicines Policy Conference on 30 August 2011 in Canberra. The factsheet is available online, in both colour and print-friendly versions. You can access it here: <https://www.chf.org.au/clinical-trials-project.php>.

CTAG is seeking feedback from consumers on the factsheet and invite you to complete a short survey to provide your views. The survey will only take a few minutes and can be accessed here: <http://www.surveymonkey.com/s/GG36DKW>.

*Source: Consumer Health Forum Australia*

### **Grants**

#### [GSNV 2011 Small Grants](#)

Applications are now closed and all successful applicants will be notified by October 7.



## **Community**

### **2011 Disability Sport and Recreation Festival**

#### **“Diversity in Disability”**

**Location:** Federation Square, Melbourne  
**Date:** Friday 2nd December 2011  
**Time:** 7.00am – 2.00pm  
**Info:** [info@dsr.org.au](mailto:info@dsr.org.au) or (03) 9473 0133.

The Festival is a unique, interactive public event promoting healthy, physically active lifestyles through participation in accessible and inclusive sport and recreation opportunities. Supported by the Victorian Government, City of Melbourne and Federation Square.

Please visit the festival website at [www.dsrf.org.au](http://www.dsrf.org.au)

### **Soccer Development Program**

Blind Sports Victoria in partnership with Reclink is pleased to invite you to take part in a soccer development program. This activity is open to all, so come along and get involved in the last of these fun and friendly sessions.

No experience required, men and women of all ages welcome, Free!

**Venue:** MSAC (Melbourne Sports and Aquatic Centre) :1,Aughtie Drive Albert Park (Mel. Ref: 2K, D7)  
**Date:** September, 28<sup>th</sup>  
**Time:** 6:00pm – 7:00pm  
**Contact:** Kavar Singh at Reclink 03 9419 6672 / 0411 137 186 or Email: [kavar.singh@reclink.org](mailto:kavar.singh@reclink.org)  
Susan Marshall at Blind Sports Victoria 03 9822 8876 or Email: [blindsports@netspace.net.au](mailto:blindsports@netspace.net.au)

Source: “disAbility Connections”, Victoria

## **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 are working on an exciting web-site and CRM upgrade. Please bear with us as we make the updates.



## **GSNV Calendar 2011**

<b>International Congress of Human Genetics - Montreal, Canada</b>	<b>October 11 – 15, 2011</b>	<b>Canada</b>
<b>GSNV AGM</b>	<b>Thursday November 10</b>	<b>Conference Rooms A and B, Level 10 RCH</b>
<b>GSNV Moves Office</b>	<b>Friday November 18th</b>	<b>RCH Level 10, RPB Building</b>

### **Genetic Support Network of Victoria**

Is an umbrella organisation representing and supporting some 130 organisations and many more families and individuals across Victoria.

10th Floor, Royal Children's Hospital, Flemington Road,  
Parkville Vic 3052

Postal address: PO Box 1100, Parkville Vic 3052

Ph: (03) 8341 6315 Fax: (03) 8341 6399

Email: [info@gsnv.org.au](mailto:info@gsnv.org.au) Web: [www.gsnv.org.au](http://www.gsnv.org.au)

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