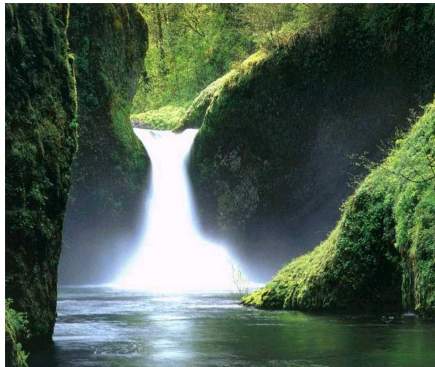




## Genetic Support Network of Victoria

### 'Bits and Pieces'

**June 1, 2011**



What lies behind us and what lies before us are tiny matters compared to what lies within us.

*Ralph Waldo Emerson*

### The GSNV Has Moved!!!!

The GSNV has moved into a temporary office until the official move into the new RCH building in November of this year. We are very pleased with our much larger and comfortable accommodation and are happy to report we have a window! Please inform the office if you are wishing to visit in order that we can instruct you how to find us. For those familiar with level 10 of the RCH building, we are located adjacent to Genetic Health Services.

### **OUR COMMITTEE**

The GSNV welcomes our newest committee member Ms Paula Forsyth, Social Worker, Adult Metabolic Clinic, Monash Medical Centre. Thank you to Paula for taking leave of private practice every third Thursday of the month to contribute to the work of the GSNV. We appreciate your time and expertise and look forward to working together.



## **PEER SUPPORT**

The GSNV works hard to connect individuals and families interested in sharing their experiences and insights with others. Persons interested in contacting others in the same boat can advertise their details through the GSNV and we will assist in making connections. Support group information sessions are also a fantastic way to connect people with shared experiences and prove to be an important networking opportunity, particularly for those travelling from rural and regional areas. The GSNV will be hosting a number of support groups and research sessions over the coming months so please watch this space!

## **CITY OF BOROONDARA FREE SERVICES EXPO**

A reminder that the City of Boroondara free services expo is still open to interested groups. Please contact the GSNV if you wish us to highlight your group on this day. The EXPO will be on **21 July, 10 - 2pm** in the Chandelier Room at Hawthorn Town Hall. If you are interested or you would like to send a representative, please feel free to contact us to discuss. Alternatively, if you wish to have your own stand, contact the City of Boroondara directly:

David Williams

Metro Access Project Officer

Telephone: (03) 9278 4777

Email: [David.Williams@boroondara.vic.gov.au](mailto:David.Williams@boroondara.vic.gov.au)

## **DISABILITY NEWS**

### **Nominations for the 2011 National Disability Awards are now open!**

The awards recognise people with disability who have achieved something remarkable or made a significant contribution to their community, and people or groups within the community who have contributed to the disability sector or improved access and inclusion.

## **SUPPORT GROUPS**



### **Fabry Support Group Australia Patient Information Session**

In 2008, Carla (CEM) Hollak has been appointed as full Professor of Internal Medicine, Inborn Errors of Metabolism in Adults at the University of Amsterdam at the Department of Internal Medicine, Division of Endocrinology and Metabolism, Academic Medical Center.

Hollak combined her PhD studies with her residency in internal medicine and completed her specialization as an internist in 1996. In the same year she

obtained her PhD degree at the University of Amsterdam. The title of her thesis is: "Gaucher disease: clinical and laboratory studies in relation to enzyme supplementation therapy". In 1995 Hollak received a research grant for the development of guidelines for treatment of Gaucher disease patients in the Netherlands with enzyme replacement therapy by the Ziekenfondsraad (CVZ) and in 2002 an identical grant to study treatment of Fabry disease.

As Principal investigator, Hollak is in charge of the research theme "natural history, pathophysiology and treatment of lysosomal storage disorders". Together with Aerts, Poorthuis, Wijburg, and Maas she is co-founder of SPHINX, the Amsterdam Lysosome Center. Hollak is involved in many international collaborations and activities, including participation in supervising boards for Governmental studies in Canada and the UK and drug Registries. She is member of the board of the European Working Group on Gaucher Disease, treasurer of the European Study Group on Lysosomal Diseases and Chairman of the Gaucher Stichting. She acts repeatedly as expert for regulatory agencies both at a national and international level. Hollak has been (co) promoter of 5 completed PhD thesis works and has published over 120 papers in peer-reviewed scientific journals.

### **Saturday 23 July 2011**

Observatory Hotel  
89-113 Kent Street,  
Sydney, NSW 2000

#### **Program:** 2.00 pm Registration

2.15 pm Welcome

2.30 - 3.15 Dr Carla Hollak

3.15 - 3.30 Q&A

3.30 - 4.00 Afternoon Tea

4.00 - 5.30 FSGA Meeting

6.30 pm Dinner - Venue TBA

***RSVP BY FRIDAY 1ST JULY*** this will ensure the session will proceed and will assist with catering. If you have any questions regarding this event please do not hesitate to contact:

*Megan Fookes: 02 9967 4395 Lea Chant: 02 9772 1346 or Email: president@fabry.com.au*

*Travel Grants are available to FSGA Members, please contact us for details.*

### **Collective of Self Help Groups COSH**

#### **Words, Heart, Art and Music WHAM!**

Are you interested in sharing and learning some creative and fun support group ideas? Then **WHAM** is for you!

Presented by BrainPower Self Help Group and Featuring performance by 'Lotus'

WHAM is an interactive fun forum for people who use, or would like to use, words, heart, art and music in their self help group activities. At this event presenters and participants will come together to share their experience and knowledge.

When: Friday 24 June, 10.30am to 3.00pm (registrations start 10.00am)



Where: Ross House, Hayden Raysmith Room, 4th Floor, 247 Flinders Lane, Melbourne (between Swanston and Elizabeth Streets). Accessible venue.

Cost: \$20.00 per person / group member or \$15.00 each for 2 or more group members. Concession \$15.00. Carers Free. \$50.00 per organisation / worker.

Registration is essential by Wednesday June 22. (Participation not denied due to financial hardship) Registration: Phone COSHG: 9650 2005 or email: [info@coshg.org.au](mailto:info@coshg.org.au)

Website for registration form and program: <http://www.coshg.org.au/news.html>

Phone or SMS Lyn Macdonald BrainPower, for conference information 0457 038 834

### **Rubinstein-Taybi – Better Start Initiative Petition**

RT support the Petition to help all Disabled Children in Australia have Equal Opportunity to the Governments Better Start Initiative . To re- fresh your memories or if you have not heard of the Better Start Initiative please watch the link to a video about Better Start .

#### **Video**

<http://www.youtube.com/watch?v=cHsvYqJyi5U>

#### **Petition**

<http://www.gopetition.com/petitions/better-start-equality.html>

## **IN THE NEWS**

The lead up to the Federal budget was a tense time for the Australian research community with cuts to the NHMRC funding on the budget hit list. Today, the GSNV celebrates that research dollars are safe, and the Australian Federal government has chosen not to compromise the very sector that contributes greatly to better health outcomes and benefits for all Australians.

The GSNV applauds those who participated in the 'Discovery Needs Dollars' campaign and continues to encourage moves to keep medical research high on the political agenda. Wherever possible, the GSNV contributes position statements and feedback on the consumer perspective toward research, gene technology and developments in diagnosis and treatment. Our most recent attention has been focused on Whole Genome Sequencing (WGS) and the integration of WGS technology and related technologies into health care and clinical service delivery.



## **YOUTH**

### **REVIEW OF THE VICTORIAN CHARTER OF HUMAN RIGHTS – WHAT'S YOUR EXPERIENCE?**

The Victorian Attorney - General has announced a review of the *Charter of Human Rights and Responsibilities Act 2006*. The review is being conducted by the Scrutiny of Acts and Regulations Committee, with public submissions by 10 June 2011. For more information please go to: <http://www.disabilityconnections.org.au/whats/nominations-2011-national-disability-awards-are-now-open>

YACVic is submitting a submission and would like to hear your views. In particular whether you have any personal stories and experiences working with the Victorian Charter – both positive and negative – will be crucial to provide evidence of the Charter's effectiveness.

If you wish to provide any stories, comments or views please contact Alice Tudehope at [policy@yacvic.org.au](mailto:policy@yacvic.org.au) or phone on 9637 3722 by Wednesday 1<sup>st</sup> June.

For information on the review, its Terms of Reference and the Submissions process, visit [www.parliament.vic.gov.au/sarc](http://www.parliament.vic.gov.au/sarc).  
Source: YACVic

## **CONFERENCES/SEMINARS/WORKSHOPS**

### **Girls and Women with Asperger's Syndrome**

**Saturday 18th June 9 am – 4:30 pm** at the **Karstens Conference Centre, 123 Queen Street Mall, Melbourne**, the cost is only \$100 parents and family members, this includes welcome tea/coffee, morning tea, lunch and afternoon tea.

Prof Tony Attwood is a world expert and leading authority on Asperger's Syndrome (AS) and autism. Dr Michelle Garnett devised the world's first screening tool for AS and is the Founder of Minds & Hearts, a specialist clinic in Brisbane for children and adults who have an autism spectrum disorder (ASD). Both are Internationally known presenters, having presented together around Australia and in the UK, Norway, Portugal, Slovenia and New Zealand, for numerous Universities, Societies, Colleges, Schools and Support Networks. Tony, Michelle, Louise and Danuta are clinical psychologists who have specialised in ASD and particularly in assisting girls and women on the autism spectrum. They are warm, inspiring engaging and knowledgeable presenters.

The female presentation of Asperger's syndrome has largely been ignored in research and in definitions of Asperger's syndrome. The sad result is that many



girls and women with Asperger's syndrome go undetected by health professionals or are misdiagnosed, which can lead to years of misdirected treatment.

This 1 day presentation will focus on and celebrate the unique presentation of girls and women on the autism spectrum. The seminar is designed to increase awareness and knowledge of the female presentation of Asperger's syndrome and share strategies and ideas found to be useful in clinical practice. Whilst paying careful attention to the many strengths that women on the autism spectrum share, the presenters will also explore the challenges that many of these women are faced with. The presenters will explore the difficulties associated with accurately diagnosing a female with an autism spectrum disorder due to females with AS commonly presenting with a unique profile. They will also discuss key areas of difficulty commonly reported by females with an ASD including self-understanding, adolescent issues, relationships, and expressing and managing emotions. The presenters will provide ideas and strategies that can maximize the possibility of successful outcomes for girls and women on the autism spectrum.

### **Consumers Reforming Health 2011 Conference**

Health Issues Centre will host the inaugural international conference for community engagement in health care. The conference will run from 18-20 July 2011 with a Public Forum on Sunday, 17 July 2011 at the Melbourne Convention and Exhibition Centre.

An impressive list of national and international keynote speakers will be presenting on a number of themes.

For more information please go to:

<http://consumersreformhealth.asnevents.com.au/>

## **NDIS UPDATE**

July this year the Productivity Commission will present its final report on a proposed National Disability Insurance Scheme to the Federal Government. The GSNV is closely watching the NDIS process and sees that it is good news for Victorians with the Victorian government offering to host the first stage of implementing an NDIS. Two recent news articles exploring recent updates can be found at:

ProBono News

<http://www.probonoaustralia.com.au/news/2011/05/victoria-trial-disability-insurance-scheme>

Canberra Times

<http://www.canberratimes.com.au/news/opinion/editorial/general/a-disability-insurance-scheme-offers-clear-benefits/2169742.aspx>



To read the Equal Opportunity and Human Rights Commission submission to the Productivity Commission, please go to:

[http://humanrightscommission.vic.gov.au/index.php?option=com\\_k2&view=item&id=1393:article-title&Itemid=385\News%20from%20the%20Commission](http://humanrightscommission.vic.gov.au/index.php?option=com_k2&view=item&id=1393:article-title&Itemid=385\News%20from%20the%20Commission)

### **Have you seen the GSNV submission yet?**

If you have not seen our submission yet, please go to:

[www.pc.gov.au/data/assets/pdf\\_file/0016/103192/sub0593.pdf](http://www.pc.gov.au/data/assets/pdf_file/0016/103192/sub0593.pdf)

## **GOVERNMENT**

### **State Health Plan**

Health Issues Centre encourages you to submit a written submission on the State Health Plan. The closing dates for submissions is 13 June.

Chair of Health Issues Centre Mary Draper is sitting on the Advisory Committee and we were pleased with the retention of a focus on issues such as health literacy and prevention in the documents. Health Issues Centre will continue through the Advisory Committee to promote the importance of:

- Resourcing consumer engagement beyond the 20 largest health services into community and rural health services
- Ensuring a strong consumer voice and focus as the health reform initiative such as Medicare Locals are rolled out
- Addressing inequity in access to health care for disadvantaged groups

Your feedback through a submission will help keep consumers central in the planning process.

Health Issues Centre would also welcome being informed of your views on this matter. Responses can be forwarded to Souzi Markos at [s.markos@healthissuescentre.org.au](mailto:s.markos@healthissuescentre.org.au)

The State Health Plan and the supporting Technical paper can be sourced at this site <http://www.health.vic.gov.au/healthplan2022/>

**Source:** HEALTH ISSUES CENTRE - eNews Bulletin - 24 May 2011

## **DID YOU KNOW?**

*It's World Environment Day on Sunday 5<sup>th</sup> June, 2011.*

### **Volunteerism**

Organisations working with volunteers need to know that they have responsibilities under the *Equal Opportunity Act 2010*, and volunteers need to know that they have protection from discrimination and sexual harassment.





To understand the issues facing volunteers and organisations, the Commission ran an online survey earlier this year and received over 500 responses. Informed by the survey responses, the Commission has developed an issues paper.

Volunteers and organisations working with volunteers are invited to respond to the questions and issues raised in the paper by 10 June 2011.

## **Victorian Equal Opportunity and Human Rights Commission**

### **New location! Commission now in Carlton**

The Commission has moved. We are now located at Level 3, 204 Lygon Street, Carlton. [Read more](#)

### **Charter review resources available**

Submissions to the Review of the Victorian Charter of Human Rights and Responsibilities are due on Friday 10 June 2011.

To help individuals and organisations who wish to make a submission, the Commission has put together a Charter Resources Kit. To read more go to: [http://humanrightscormission.vic.gov.au/index.php?option=com\\_k2&view=item&id=1393:article-title&Itemid=385\News%20from%20the%20Commission](http://humanrightscormission.vic.gov.au/index.php?option=com_k2&view=item&id=1393:article-title&Itemid=385\News%20from%20the%20Commission)

### **Genetic Alliance – USA**

#### **Some tips and pointers**

For many people, the process of drafting and passing legislation is confusing and out of their comfort zone. When you hear about actions that impact issues or programs you are passionate about, do you know how to reach out to your elected officials and effectively voice your opinion?

Here are ten tips to consider:

1. Get involved
2. Learn about your elected officials
3. Build a relationship with your elected officials
4. Identify a specific issue you are passionate about
5. Choose your method of contact
6. Share your story
7. Make an ask
8. Leave them with a one-page handout
9. Follow up
10. Encourage others to join you

These tips are further elaborated on in Genetic Alliance's May monthly column in Exceptional Parent magazine.





You can see it by going to

<http://www.eparentdigital.com/nxtbooks/exceptionalparent/201105/index.php?star tid=26#/28> and clicking on the 'Preview' button at the bottom.

The GSNV has received a number of enquiries regarding funding for early intervention, education and access to aids and equipment. We validate and understand the difficulties related to accessing funding and therefore encourage all families and individuals to let government know how you feel. The above tips provided by the Genetic Alliance USA are general in nature and can be applied to the Australian context.

As an umbrella organisation the GSNV researches and produces position statements and comment on systemic issues and reforms. We are committed to representing the voice of our members and offering the Victorian 'genetic' perspective on overall health policy and changes.

## GRANTS

Please see here below information on the City of Melbourne's 2012 Community grants program. A range of grant opportunities are available including the International Day of people with a disability grants.

### **About International Day of People with Disability 2012 grants**

International Day of People with Disability 2012 grants are awarded to programs designed to celebrate International Day of People with Disability in December 2012. On this day, the Melbourne community has the opportunity to acknowledge the integral and valuable contribution people of all abilities make in our community.

The City of Melbourne's Our Melbourne-Disability Action Plan 2010-13 details the different ways in which the City of Melbourne endeavours to make Melbourne a barrier free municipality, where people with a disability can access and participate in all aspects of life with dignity and independence. This plan includes a commitment to support International Day of People with Disability. International Day of People with Disability will be held on 3 December 2012.

Your project must support one or more of the following themes:

- promoting the diversity and talent of people with disabilities
- raising positive community awareness of disability
- providing learning and development opportunities for people with disabilities
- creating sustainable and positive outcomes for people with disabilities.

**Contact:** Shawn Neilsen MetroAccess Project Officer on 9658 8587 or 0413 011 832 for further information.

### **City of Melbourne Community Grants**

Currently open are three City of Melbourne grants and sponsorship opportunities. The City of Melbourne is calling on individuals, groups and organisations to apply for a wide range of grants on offer in 2012. Grants are available in the following programs:

**Active Melbourne** grants to help individuals and community groups to easily access and participate in sport and recreation.

[http://www.Melbourne.vic.go.au/About\\_Council/grants\\_sponsorship/ActiveMelbourne/Pages/ActiveMelbourneGrants.aspx](http://www.Melbourne.vic.go.au/About_Council/grants_sponsorship/ActiveMelbourne/Pages/ActiveMelbourneGrants.aspx)

**Arts grants** to help individuals, groups and organisations enliven the city with diverse art and cultural activities that challenge and engage the community.

<http://www.melbourne.vic.gov.au/AboutCouncil/grantssponsorship/ArtsGrants/Pages/Artsgrants.aspx>

**Community services grants** to support not-for-profit community organisations create a safe, inclusive and engaged local community.

<http://www.melbourne.vic.gov.au/AboutCouncil/grantssponsorship/CommunityServicesGrants/Pages/CommunityServices.aspx>

Full details of all the programs on the City of Melbourne website:  
[www.melbourne.vic.gov.au/grantsandsponsorship](http://www.melbourne.vic.gov.au/grantsandsponsorship)

## COMMUNITY

### **Australia's Biggest Morning Tea**

Like Having a Cuppa with Friends?

Why not hold a morning tea and help us fight cancer! This May, Australia's Biggest Morning Tea aims to raise \$2.2 million to help the 76 Victorians diagnosed with cancer every day.

For more information please go to:

<http://www.biggestmorningtea.com.au/>

## 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 so until we launch, please bear with us as we make the updates.

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

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

10<sup>th</sup> 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)

The information and material presented in Bits and Pieces is intended for general information only. The contents reflect the opinions of the authors who are alone responsible for the views expressed. GSNV does not hold any responsibility for the accuracy of material supplied and or sourced from external entities.

**To unsubscribe from Bits and Pieces please email [info@gsnv.org.au](mailto:info@gsnv.org.au)**