

# GSNV UPDATE



June 03

*overcoming genetic challenges*

## ***Heard The Good News?***

### **The In's and Out's of Our Office**

The GSNV's Office has seen a couple of changes in the last few weeks. Everyone will be thrilled to hear the coordinator, Eilis Hughes is now full time in the office. (Yes this will have to do until we perfect cloning her!) She is still continuing her Masters, but will be in the office to service the GSNV five days a week. This change coincides with the move of our communications and administration officer, Emma-Kate Rickard to 1 day per week working from home. GSNV is also thrilled to welcome a volunteer to the office. Joanne Kelley will be in the office on Thursdays, so pick up the phone to say hello to Jo, another great member of our team.

## ***In The Limelight***

### **Saying goodbye...**

In his many years at Genetic Health Services Victoria, **Dr John Rogers** has touched the lives of many patients and their families. He has also been a supporter of a number of our support groups. John is retiring in July, so if you would like to send him a greeting, please send it to us at the GSNV and we will be sure to pass on the best wishes of all those families who have appreciated his service.

## **Outreach Dates –Important Changes**

Thanks for the enthusiastic response from all our rural and regional supporters for our outreach program this year. Unfortunately, due to limited resources, the Genetic Health Services Victoria clinics in regional and rural services have been reduced this year. This means that some of our visits with the clinics have been changed. The new dates for the GSNV visits are:



4 & 5 June - Warrnambool  
22 July - Sale  
23 July - Traralgon  
12 September - Mildura  
26 November - Bendigo  
10 December - Wodonga

If you're interested in meeting with other families with rare genetic conditions on any of these dates, contact me in the GSNV office on (03) 8341 6315 and we'll arrange a meeting. If you're a service provider in any of these towns and you think your colleagues would like to hear about the work we do, contact me and I'll arrange a visit.

## **What do you mean, cut back?**

This year some towns will have fewer genetics clinics, and some (like Frankston, Sale and Warragul) will have none at all. How do you feel about this? Does this affect you or your family or your support group members? Write us a letter or drop us an email at [ehughes@gsnv.org.au](mailto:ehughes@gsnv.org.au) and tell us what you think. When there are limited resources, the decision-makers need as much information as possible in order to make good decisions about how to distribute these resources. Send your comments to us and we will pass them on to both Genetic Health Services Victoria and to the Department of Human Services.

## ***Expand Your Mind***

Centre for Grief Education



The CGE is running a number of workshops aimed at helping people within the disability sector deal with grief. The half day workshops, *Exploring Dimensions of Grief Within Disability*, will be held in Clayton, July 18, Shepparton, October 9 and Bairnsdale, November 17. For further information contact Fiona Hughes, on 03 9545 6377 or 1800 642 066 or email [f.hughes@grief.org.au](mailto:f.hughes@grief.org.au)



## ***Surfing The Web***

I recently heard about an attractive medical ID bracelet for women that was designed by the mum of a young woman with diabetes. Even Halle Berry wears one! The site is <http://www.laurenshope.com> and they have several designs to choose from. They also have standard ones for men.

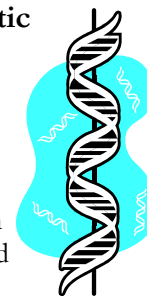
## ***Groups Activities***

### **Ehlers-Danlos Syndrome... ring a bell for you?**

Calling all families with Ehlers-Danlos Syndrome (or EDS) in Victoria. Are you interested in meeting other families? We've been speaking with a family whose daughter would love to meet other kids with EDS. If you're interested in contacting this family, or if you're interested in meeting a group of families for a social get-together, please contact the GSNV on (03) 8341-6315 or [info@gsnv.org.au](mailto:info@gsnv.org.au) to register your interest. Please pass this on to any families you know with EDS. Thanks.

## **Essentially Yours: The Protection of Human Genetic Information in Australia**

The Australian Law Reform Commission and the Australian Health Ethics Committee have been exploring the issues, laws, institutions and policies surrounding genetic testing in Australia. The GSNV had considerable input into this inquiry, with both a public meeting and a written submission and we are aware many members and supporters also offered submissions.



President of the ALRC Professor David Weisbrot, believes while genetic research can be of tremendous value it may have wide ranging effects on other aspects of life,

"The enormous promise of genetic research for improving human health is well known. However, it's also influencing many other aspects of Australian society, such as employment, insurance, law enforcement, family, immigration, sports and the delivery of clinical genetic services," he said.

"Australia has an opportunity to be an international leader in the protection of human genetic information. This inquiry has attracted significant interest overseas, and this report will be keenly studied by governments and policymakers around the world," Prof Weisbrot said.

The 1200-page report has 144 recommendations, but luckily, you don't need to read the whole thing as there's an executive summary available at [www.alrc.gov.au](http://www.alrc.gov.au) or contact the GSNV and we can send you a copy.

## ***Have A Say... Have A Go***

### **Communities in Control**

Did you miss the Communities in Control conference in early May? You can read speeches of some of the prominent speakers at the Our Community website, at [www.ourcommunity.com.au](http://www.ourcommunity.com.au). If you don't have internet access, you can contact Our Community by phone on (03) 9320-6800.

### **Women's Health Conference 2003**

The second annual statewide women's health conference will be held at the Whitehorse Centre. The conference will have a particular focus on the Eastern region. It will be held on July 2 and you can access more information at [www.whe.org.au](http://www.whe.org.au) or by calling (03) 9879 2199 or (03) 9845 8000.

### **Chronic Disease Self Management Workshop**

Sharing Health Care Initiative is holding a National Chronic Disease Self-Management Workshop on 12-14 November 2003 at Hilton on the Park in Melbourne. Purpose of the Workshop is to promote chronic disease self-management by examining the progress, lessons learnt and successes of the 12 National Sharing Health Care Initiative demonstration projects and other chronic condition self-management projects and research activity.

Papers are now being sought for this workshop. All nominations need to include a brief half page abstract. These should be emailed to Daphne Shakespear on [daphne.shakespear@health.gov.au](mailto:daphne.shakespear@health.gov.au) by 30 June 2003. For further details contact Daphne on (02) 6289 8689.

### **GP's – What Do You Think?**

The Victorian Medicare Action Group is keen to gather a range of people's experience of how they've used GP services recently. These stories will be used to inform media contacts, politicians and in submissions to Parliamentary Inquiries. The stories should be very brief and may record both the financial and health impacts of peoples access to GP's or related medical services. Confidentiality is assured and stories will only be used with the consent of the author. For further information please ring (03) 9429 1855 or email [mmurray@iechs.org.au](mailto:mmurray@iechs.org.au).

### **Your Genetics Congress**

Over two and a half thousand researchers from around the world will arrive in Melbourne. There will also be quite a few Nobel Prize winners and the man who actually discovered DNA all coming to the Congress. "Wow!" you might say, "but is there any room for me?" And the answer is a big fat Yes!

The public participation program gives an opportunity for Victorians to participate in informed debate about the many contemporary social and scientific issues surrounding genetics.

Below are some highlights from the PP Program. Many are at no cost, and many include participation by one or more of the 8 Nobel Laureates in attendance. More details can be found at <http://www.yourgeneticscongress.org/> or call the GSNV to have a program sent to you.

**July 1 - 3 - 'Sequence your own DNA' workshop** at Melbourne Uni Genetics Department. No cost, but booking essential.

**July 5 - Addiction – What if it's genetic?** 2-4pm at the Melbourne Exhibition Centre. No cost, book online or on (03) 9563 6922.

**July 7 - Melbourne Conversation – The Three Tenors of Genetic Research** 6-7.30pm at Melbourne Town Hall. No cost, bookings not required.

**July 9 - Who's Your Father? A Child's Right to Know** (Final of National Secondary Students Genetics Competition) 9.30-11am Melbourne Exhibition Centre. No cost, bookings essential on (03) 8341-6315.

**July 9 - Hands Off My Genes!** A Discussion of Genetic Privacy in Science, Forensics and Law 11.30am-1pm Melbourne Exhibition Centre. No cost, bookings essential on (03) 8341-6319.

**July 10 - Melbourne Conversation – Jesse's Journey: Living with a Genetic Disorder** 6 – 7.30pm Melbourne Town Hall. No cost, bookings not required.

## **Grants Up For Grabs**

## **GSNV News**

### **Dear GSNV Members,**

As we approach the end of the financial year, we also approach the time when your GSNV membership should be renewed. Membership costs are still \$22 for an individual, a family, or a support group, and \$11 concession.

Benefits of being a member of the GSNV include:

- \* A united voice to decision-makers.
- \* Opportunities to interact with other families, groups and professionals.
- \* Cash grants to support groups for special projects.
- \* Access to information about genetics and about support and services available.
- \* Free access to venues for meetings and seminars (including free tea and coffee).
- \* Participation in seminars and other activities at reduced prices.
- \* Voting rights and key involvement in decisions made.

We will be sending out invoices soon and we hope you will keep your membership current. Those of you who are not yet members, we look forward to you coming on board. Membership fees are put towards the Special Projects Grants distributed annually.

Many thanks,  
Tony Briffa  
Treasurer

### **Banking On a Brighter Future**

ANZ Charitable Trusts has funding available for programs which assist families with complex needs. More information, call 1800 808 910 or go to <http://www.anz.com.au/australia/charitabletrusts/Guidelines.asp>

### **Equity Mate Equity**

Equity Trustees offer similar grants to the ANZ, and you can find out about those at <http://www.equitytrustees.com.au/charities/grants.asp> or by calling (03) 8623 5379.

### **Trust Its Worth a Call**

Although we can not provide a lot of details, we can tell you the Trust Company of Australia also has grants up on offer. Find out more information by calling Richard on (03) 9639 0100.

### **Are you a Quiet Achiever? Get loud to the tune of \$50000**

The BHP Billiton Corporate Community Program offers grants in the range of \$50,000 to \$100,000 for community projects that are of significant benefit to the Australian or International community. If your project aims at sustainably solving problems rather than providing short term relief you may be eligible. For more information about these significant grants, visit [www.bhpbilliton.com/bb/sustainableDevelopment/community/supportGuidelinesFoundations.jsp](http://www.bhpbilliton.com/bb/sustainableDevelopment/community/supportGuidelinesFoundations.jsp) or telephone Helen Lomen on (03) 9609 3596.

### **Change Not Charity**

The Reichstein Foundation has grants for community groups and developments which promote social change by assisting people to take greater responsibility for their own well-being and for the critical social issues currently facing our society. The Foundation supports projects which effect structural change to benefit disadvantaged communities. For more information, please contact Christa Momot on (03) 9650 4400 or visit the website at [www.reichstein.org.au](http://www.reichstein.org.au)

### **St George Foundation**

The St George Foundation supports projects which enable children with disabilities to participate in innovative programs that provide life experiences or daily comforts. Find out more at their website [http://www.stgeorge.com.au/about/foundation/about\\_foundation/](http://www.stgeorge.com.au/about/foundation/about_foundation/) or by calling Selina on (02) 9952 2298.

### **Sunshine Foundation**

The Sunshine Foundation has grants for projects to help alleviate human suffering, attend to matters of social need, advance the frontiers of knowledge and enhance quality of life. In the main, projects that are supported by voluntary labour or which are low cost tend to be favoured. Find out more at <http://www.mgg.com.au/> or call Jane on (03) 9419 5133.

## ***We'll Meet Again...***

<p style="text-align: center;"><b>REMINDER</b> <b>Executive Committee Meeting</b> July 16 6pm Conference Room B 10<sup>th</sup> Floor RCH, Flemington Rd Parkville</p>
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**For more information on anything you've read here, please contact Eilís or Emma in the GSNV office on (03) 8341-6315 or email [info@gsnv.org.au](mailto:info@gsnv.org.au)**