



December 15 2011



May your world be filled with warmth and good cheer this Holy season and throughout the year ahead.

We Have Moved!

The GSNV has moved into new office accommodation as part of the general Murdoch Childrens Research Institute (MCRI) and the Royal Children's Hospital (RCH) move into a new building.

Please note our new address is:

Level 9, South Building, MCRI
Royal Children's Hospital
Flemington Road, Parkville Vic 3052

The GSNV is now accessible through the MCRI entrance of the new RCH which is also on Flemington Road. MCRI has its own ground floor reception where all visitors are required to report and obtain a visitors pass. 'Popping' in to the GSNV is no longer as easy as it once was. All visits to the GSNV office will now need to be pre-arranged. If we know you are coming we can arrange access. The GSNV office is located in one of the many restricted access administration areas in the new MCRI/RCH campus. The good news is that there are many more friendly and spacious areas where we can meet our members and supporters throughout the building.



After the move into our new office we were experiencing some IT issues including limited phone access. Please note our telephone is now working! We hope to respond to all our callers this week. We apologise for any inconvenience.



Our Committee

On the November 10 the GSNV held its 2011 Annual General Meeting and reported on the previous financial year. Thank you to the Executive and Committee for their commitment over that time and working through many agendas. If you are a current financial member of the GSNV and would like a copy of the 2011 Annual Report please contact us and we will be happy to pass it on.

Conferences/Seminars/Workshops

Art and Yoga Day

Especially for those feeling grief or aloneness at this traditionally family-oriented and festive period.

When: Friday 16 December 10am-3pm
Location : Highett
Cost : \$130 inclusive

This relaxing day will uplift the body and spirit! We start with a yoga/relaxation session with Jenni Newman, a very experienced and gentle teacher, enjoy a morning tea together then move into making artworks in clay with Anne. In the afternoon there will be a further immersion into art and yoga. Beginners and those with experience are invited. A delicious, home made lunch will be provided. This nurturing day will give you space and techniques to contemplate your feelings and will support you with purpose, enjoyment, companionship and good food.

GIFT VOUCHERS ARE AVAILABLE

Making for Mothers - an art group especially for mothers who have been affected by childhood sexual trauma and other trauma which is now affecting their ability to mother as they would like. In this clay class participants will look at artists whose work has expressed motherhood, and will be guided to express about their own feelings in response to their past, and how better to live in the present and future.

Please Contact::

Anne Riggs
PhD Artist
Centre for Art, Trauma Loss and Grief
Sterling Avenue, Highett
03 9532 5667 0417 526 636
www.anneriggs.com ariggs@alphalink.com.au



OzCleft & CleftPALS are proud to announce “Appearance Matters”.

A symposium on appearance research with emphasis on facial clefts, body image and psychology. Including interactive group workshops for young people with clefts, parents and clinicians.

Presenters Prof Nichola Rumsey, Dr Diana Harcourt, Dr Phillippa Diedrichs, Heidi Williamson. Centre for Appearance Research, University of West England, Bristol, UK.

<http://hls.uwe.ac.uk/research/car.aspx>

When: Saturday 11th February 2012, 9-5

Where: The Auditorium, The New RCH, Flemington Road, Parkville

Register Interest: contact-Supriya Raj email ozcleft@mcri.edu.au

Ph: +613 99366532

Community News

New Research to Look at the Experiences Of Students with Disability in Victorian Schools - Have Your Say!

The Victorian Equal Opportunity and Human Rights Commission is conducting research into the experiences of students with disability in Victorian schools.

This follows an increase in complaints to the Commission relating to disability discrimination in education, and concerns raised by parents of children with a disability, disability advocacy groups and members of the Commission’s Disability Reference Group about the provision of education services to students with a disability.

The purpose of the Commission’s research is to gather information about the issues and challenges experienced by students with disability in the Victorian school system and to identify potential solutions, consistent with Victoria’s equal opportunity and human rights framework, to improve access to education for students with disability.

The Commission is keen to hear from students, parents and educators about what works and what could be improved when it comes to the education of students with disability in Victoria. There are several ways you can have your say:

If you are a student with disability, parent of a student with disability, a principal or teacher or you work in a Victorian school, you can complete a confidential online survey available at:

http://www.humanrightscommission.vic.gov.au/index.php?option=com_k2&view=item&layout=item&id=1541&Itemid=7



If you work in a community organisation or otherwise provide support to families, children and young people with disability, tell us your views by sending an email which will be treated as a written submission to our research. The email address is:

research@veohrc.vic.gov.au

Call 1300 292 153 or (03) 9032 3583. Lines are open on Saturday 3 December from 10am to 4pm. If you need an interpreter, you can call the Commission using the interpreter service on 1300 152 494 or TTY at 1300 289 621.

Come to one of our 'have a say' days in regional Victoria which will be held in February 2012. More details will be available soon.

If these options are not convenient, please feel free to tell us your story by sending us an email to research@veohrc.vic.gov.au

In participating in the research, you will be providing your consent on the basis that your information will be kept private. No individual, family or student will be identified in the research. [Source – DARU Update 28th November](#)

Support Groups



FSHD

The FSHD Global Research Foundation announces the last chance before Christmas to purchase a Bill Moss – Still Walking. All profits from this book go to the FSHD Global Research Foundation and Fighting Chance Australia. Please visit www.stillwalking.com.au to purchase your copy of the book. Please see www.fshdglobal.org for more information.

[Immune Deficiencies Foundation Australia](#)

The new Immune Deficiencies Foundation Australia website has arrived and can be viewed at: www.idfaustralia.org

[The Australian Pain Society](#)

The Australian Pain Society is a multidisciplinary body that aims to reduce pain and related suffering through leadership in clinical practice, education, research, and public advocacy. The main focus is ensuring that all members of the community receive adequate and timely



pain management. Developments in this area relating to clinical practice, hospital admissions, Emergency Department procedures and general attitudes toward pain management for those living with genetic conditions (that present complex and ongoing pain issues) are of direct interest to the GSNV and its members.

The Australian Pain Society will hold its National Conference in April 2012 and is currently calling for submissions. Please go to: <http://www.dconferences.com.au/aps2012/home> for more information.

Autism Victoria - AMAZE

Autism Victoria now trades under the name of AMAZE. Please take a look at their new branding and website which can be viewed at www.amaze.org.au

Australian Gorlin Syndrome Support

The address for the Australian Gorlin Syndrome Support is:

<http://home.vicnet.net.au/~gorlinsyndromesupport/LightNEasy.php?page=Home>

This is a newly established group and one which the GSNV will endeavour to support as it grows.

Consumer Groups

Having a Say on Pharmacy Agreement

The GSNV has followed the debate surrounding the Pharmacy Agreement negotiated between the Commonwealth Government and the Pharmacy Guild this year. There are a number of issues that directly impact on consumers and as a stakeholder, the GSNV is concerned with how decisions and legislation might affect our members. Through our membership of the Consumer Health Forum and the Chronic Illness Alliance the GSNV has offered comment and opinion on some of the issues. We will continue to follow this issue.

Grants

Department of Premier Cabinet – Community Grants

Multicultural Community Grants for 2012 are currently open. You only have until December 16 to submit. Please go to <http://omac.smartgrants.com.au> to view the five categories of funding aimed at supporting Victoria's culturally and linguistically diverse communities.



Resources

[NPS – Better Choices, Better Health](#)

Christmas is coming and it is worthwhile reminding all the people we work with to ensure they continue caring for themselves. Medicines Talk is a very useful resource and the latest edition provides contact details of where to get help when someone is concerned about medicines they take. The NPS website has a full list of Medicines Talk editions with information written in plain but very accurate English: http://www.nps.org.au/consumers/publications/medicines_talk

NDIS Update

[NDIS: The Facts](#)

A National Disability Insurance Scheme (NDIS) would provide insurance cover to fund long-term high quality care for all Australians who have a significant disability.

- The cost is estimated at \$13.6 billion a year, \$6.5 billion more than is currently allocated to disability services by states, territories and the Commonwealth.
- All states and territories support the introduction of a NDIS
- Commonwealth Government support and funding is required to get the system up and running.

An NDIS could see an additional 220,000 people with disability working by 2050. When coupled with reductions in disability pension, this could deliver \$32 billion in additional GDP in that year alone. [Source: Made You Look No.5 Nov-Dec 2011, Don't Dis myABILITY, Page 17](#)

[Disability Research Agenda to Focus on NDIS](#)

Friday, 02 December 2011

From the Minister for Community Services

The Victorian Coalition Government has committed \$1.18 million to research on national disability reform, with a focus on what is required to establish a National Disability Insurance Scheme (NDIS), Community Services Minister Mary Wooldridge announced today.

Ms Wooldridge said the NDIS has the potential to revolutionise the lives of many thousands of people with a disability, their families and carers.

“Our participation with other States and Territories in the National Research and Development Agenda will help take us another step closer to an NDIS,” Ms Wooldridge said.

Ms Wooldridge announced the funding at a function to celebrate International Day of People with Disability.



The Victorian Government is playing a leading role in advocating for an NDIS to replace an existing funding and services system that the Productivity Commission described as “inequitable, underfunded, fragmented and inefficient”.

The \$1.18 million represents Victoria’s contribution to the \$10 million National Disability Research and Development Agenda.

Due to the intervention of the Victorian Government, this funding will now be prioritised towards research that helps prepare for an NDIS.

“With such fundamental reform, robust research and development will be central to sustaining and supporting the reform process,” Ms Wooldridge said.

Ms Wooldridge also acknowledged the importance of International Day of People with Disability (IDPWD), which seeks to increase awareness of the benefits of the integration of people with disabilities in every aspect of political, social, economic and cultural life.

“It provides a great opportunity to acknowledge and celebrate the contribution and achievements of people with disabilities,” Ms Wooldridge said.

The Victorian Government is supporting a number of IDPWD activities, including the Disability Sport and Recreation Festival at Federation Square and associated regional activities.

[Progressing a National Disability Insurance Scheme - Media Release 6/12/2011](#)

The Minister for Families, Housing, Community Services and Indigenous Affairs, Jenny Macklin and the Member for Fraser, Andrew Leigh, recently provided joint statements in relation to the Government’s commitment to a National Disability Insurance Scheme (NDIS).

“We know that people in Canberra strongly support reform of disability care and support. They support our work to lay the foundations for a National Disability Insurance Scheme,”

“The Commonwealth, states and territories are putting our shoulders to the wheel on this one. We’ve all agreed to deliver the foundations we need for a scheme by mid-2013.” Ms Macklin said.

Foundation reforms need to be delivered to make disability services “NDIS-ready”. They include a common assessment tool to determine eligibility for support, national quality standards and a strategy to boost the disability workforce.

“An NDIS will mean better support for people with disability, their families and carers here in my electorate and right across my electorate,” “It means people with disability will have more



control over the support they receive, and are able to access care that meets their needs – so they can participate in school, work and the community to their full potential. Mr Leigh said.

The GSNV will continue to follow the progression and any activities around the NDIS in 2012.

Source: The Hon Jenny Macklin MP – Media Release 6/12/2011

http://www.jennymacklin.fahcsia.gov.au/mediareleases/2011/Pages/progressing_ndis_061211.aspx

Chronic Illness Alliance (CIA) - To Run Forum on National Disability Insurance Scheme

Under the latest incarnation of the National Disability Insurance Scheme (NDIS), many people disabled by their chronic illnesses may not be eligible for funding. The Chronic Illness Alliance will run a forum on 28 February 2012 to discuss issues regarding the benefits of the NDIS as well as the gaps the NDIS does not fill. It will take place at Epilepsy Foundation of Victoria, 818 Burke

Road, Camberwell on the afternoon of the 28th February.

CIA members and others interested in putting forward their views and ideas are invited to join Dr Christine Walker and guest speaker, John Cain, ex-Solicitor-General of Victoria.

Mr Cain will have the opportunity to present findings from our forum to a COAG committee later in the year. Pencil this in your diaries.

Source – Chronic Illness Alliance December Newsletter

<http://www.chronicillness.org.au/new.htm>

Research

Genetics in Primary Care

Have you ever talked to your GP about genetics?

A new research project is being conducted through the Murdoch Childrens Research Institute and the University of Melbourne. This project aims to understand how genetics is part of primary care, and if there are any changes that could be made in the future. If you would be interested in taking part we would like to invite you to take part in an interview (30-60 minutes of your time). After the interview you will also be offered the opportunity to take part in a focus group at a later date where we will bring together our findings from the initial round of interviews for all participants to comment on. You will be given a \$20 voucher for participating.

Please contact Alice Weeks either by phone on 8341 6331 or email at alice.weeks@mcri.edu.au if you are interested in further information or participating in the project. This study has ethics approval from the University of Melbourne: HREC 1034301.1



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

GSNV Calendar 2011

Early Intervention Education	December 15	Bundoora
GSNV Office Closes	December 22	
GSNV Office Re-Opens	December 10	
GSNV Committee Meeting	January 24	RCH
Rare Disease Day	February 28	TBC
Early Intervention Education	December 15	Bundoora



GSNV Office Closure: December 22 until January 10, 2012

Thank you for your support and dedication this year and we look forward to a fantastic 2012.
We wish you a wonderful festive season and joyous year ahead.



Genetic Support Network of Victoria

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

Level 9, South Building, MCRI
Royal Children's Hospital
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