

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
eNews**

## July , 2012

### This Edition

- \* From the Committee and Team
- \* Conferences/Seminars/Workshops
- \* Community
- \* Grants
- \* Research
- \* Thank You
- \* Support Group News
- \* Seeking Contact
- \* Government
- \* Calendar

## From the Committee and Team

### A Note from the GSNV Team

Welcome to the latest edition of the GSNV e-News Bulletin. It has been a little while since we last communicated with members and networks as we have been undergoing some changes.

The GSNV has a new team! We welcome Christine Chan as the Administration Assistant and Lynley Donoghue as the Genetic Support Coordinator. As the Group Leader I will be working with Lynley and Christine to meet our objectives and continue our important work in Victoria.

We take this opportunity to extend our goodbyes and sincere thankyou's to outgoing GSNV staff. We thank Stephanie Shepley, Penny Dodds and Tarli Bogtstra for their tireless contribution and work with the GSNV. We wish Stephanie and Penny all the very best in their careers and futures and wish Tarli all the very best with her new born baby and family life. We also thank Alice Weeks who is retiring from the GSNV as joint-Secretary. All the best in Europe Alice! Thank you to all of you for your commitment and dedication.

Lynley, Christine and I are available to all support groups, members and our networks at

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

any time to answer questions and/or assist with any support group needs. Our website is a great place to start if you are looking for something from the GSNV and we also encourage you to phone the GSNV office on (03) 8341 6315 or send us an email at [info@gsnv.org.au](mailto:info@gsnv.org.au) with your request.

In the coming months, the GSNV Team and Committee will continue to work towards efficient processes and effective governance but above all, seek to improve on how we deliver support to individuals, families and support groups. Once again, we encourage you to send us any important information you wish us to pass on, on your behalf and to use the GSNV as a portal to link support groups, advocacy and the community.

We are continuing to update our website and support group links and have been contacting groups individually in order to update and confirm contact information. If you have been contacted by our office in recent weeks and have not spoken to one of our staff or volunteers, please do contact us if your support group or contact information has changed. We are also using this opportunity to remind support groups and our members that the GSNV is happy to list important events and promote activities via our newsletter, website and e-bulletin. The GSNV is more than happy to assist with your communications at any time.

We look forward to working with all our support groups and families in the coming months.

**Louisa Di Pietro, Christine Chan and Lynley Donoghue**

## **Free Movie Tickets**

In order to encourage feedback and ensure that the GSNV is responding to support groups' needs, we are offering the chance to win a double pass to Disney's movie Brave.

To enter, please tell us in 50 words or less, how the GSNV can improve its services to better support you and/ or your group. Tell us what we can do for you!

Please email responses to [info@gsnv.org.au](mailto:info@gsnv.org.au) with the subject title **'Feedback'**.

Entries close by 5pm Friday 27<sup>th</sup> July 2012. Winners will be notified by email. Movie pass is valid throughout theatrical season.

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

## Thank You

The GSNV is pleased to announce that we have received an injection of funding of over \$8,000 from the MotorOne group. The MotorOne Group held a very successful fundraiser called 'Stop Drop and Bowl' as a team building exercise and as part of a management project conducted by a number of staff to bring the all the MotorOne business units together. 'Stop Drop and Bowl' was dedicated to the GSNV and Louisa Di Pietro attended, representing the GSNV Committee, staff and community. We had anticipated around \$3,000 to \$5,000 dollars and were ecstatic to receive a very large cheque for over \$8,000!

Sales of raffle tickets, donations of prize packs from motor vehicle dealerships and service providers, and generous donations from business owners exceeded our expectations. It was wonderful to see how an industry group rallied together, embraced the GSNV vision, and message and raised money for us! The evening was spectacular and as a charity event and team building exercise – it could not have gone better.

The GSNV specifically thanks John Weekley (WorldMark), Greg Lewis (MotorOne), Warren Koopmans (Tint A Car), David Lowrie (Sewells), George Mariotto (MEP), Tim Thorne and all who participated from High Performance Corporation, TCB Car Tinting, Top Edge Tinting, GWPM and VM Smiley. We particularly congratulate and thank Sylvia Smiley, Marcia Yianni, Natasha Olive and Marcus Modoo from MotorOne, for their commitment, dedication and incredible negotiating skills in getting this project off the ground and making it such a success. Thank you to all involved for providing an opportunity for the GSNV to give back to our support groups, community and in helping them conduct their important work.

Proceeds from this event will be dedicated to the GSNV Small Grants Scheme 2012 and Special Grants 2012.

**genetic support**  
network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

## Conferences/Seminars/Workshops

### **Strategies for Sustainable Funding – Friday 27 July, 9.30am - 1.00pm**

The Strategies for Sustainable Funding seminar provides an overview of the strategies every community organisation should consider putting in place to provide for a practical, workable, integrated, sustainable fundraising strategy. Learn how the sources of funding other than grants - donations, grants, community-business partnerships, alumni/membership, special events - can build a sustainable future for your group.

Further information: [www.ourcommunity.com.au/fundraisingseminar](http://www.ourcommunity.com.au/fundraisingseminar)

Source: [www.ourcommunity.com.au](http://www.ourcommunity.com.au)



### **Victorian Autism Conference – August 9 & 10**

The Victorian Autism Conference is held every second year in Melbourne and is an important event in raising awareness, sharing knowledge and seeking understanding of Autism Spectrum Disorder. The conference engages regional partners and will this year stream team to 8 regional centers via live link up. With hundreds of delegates and a full program it is an important date to save!

Please go to <http://www.amaze.org.au/events-info/vac/> for more information

### **Pathways Australia Training - Management, Difficult Conversations and More!**

Pathways Australia training programs are specifically designed to meet the needs of Not-For-Profit organisations. Facilitators are experienced in the sector.

For the August training calendar please go to:

<http://www.pathwaysaustralia.com.au/SeminarCategories.aspx>

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**



*A Fun Challenge Away from Home.....*

## **CMTAA Inaugural Youth Weekend – September 7, 8 & 9**

The GSNV supports the inaugural CMTAA Youth Weekend and will work towards sponsorship of this exciting event. Stay tuned for more details.

For more information please go to:

[http://www.cmt.org.au/index.php/site/seminars/inaugural\\_youth\\_weekend\\_friday\\_september\\_7\\_to\\_sunday\\_september\\_9/](http://www.cmt.org.au/index.php/site/seminars/inaugural_youth_weekend_friday_september_7_to_sunday_september_9/)



## **Epilepsy Free Sessions**

If you have epilepsy, or a family member or friend has epilepsy, these **FREE** sessions will help you gain a greater understanding of the condition and how to manage it.

Topics covered include:

- What is Epilepsy?
- Different seizure types
- Triggers & causes
- Diagnosis & treatment
- First Aid for seizures
- Living with Epilepsy

The next session is:

Wednesday 19 September, 2012

Time: 12pm – 2pm

Where: Epilepsy Foundation of Victoria

818 Bourke Rd, Camberwell VIC

For information and to register, phone 1300 852 853 or email [mgreen@epilepsy.asn.au](mailto:mgreen@epilepsy.asn.au)

Or go to <http://www.epinet.org.au/>

**genetic support**  
network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

## Support Group News



### Peer Support Contact

Maria Wallace who is the Victorian representative for the O.I. (BRITTLE BONES) Society of Australia, welcomes new families who are in need of assistance to contact her. Maria can be emailed at: [tm.wallace@optusnet.com.au](mailto:tm.wallace@optusnet.com.au) if you wish to start a discussion.

### ALDS 20<sup>th</sup> Anniversary Conference

The ALDS 20<sup>th</sup> Anniversary Conference is taking place on August 18<sup>th</sup> and 19<sup>th</sup> 2012 at the Novotel St Kilda, 16 Esplanade St Kilda Vic 3182.

For more information, do to: <http://alds.org.au/wp-content/uploads/2012/04/ALDS-20th-Anniversary-Leukodystrophy-Conference.pdf>

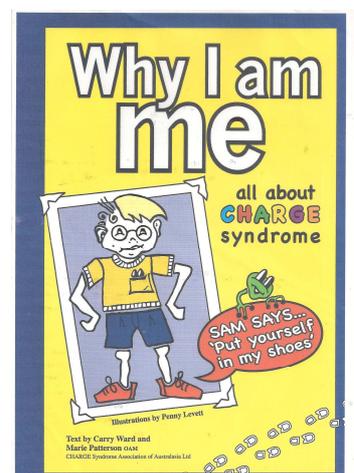
### CHARGE-Ability Conference 2012

The CHARGE Syndrome Association of Australasia is holding their 2012 Conference. The program covers a wide range of topics ranging from medical to non-medical issues. The day closes with a presentation by Rob Last on how well CHARGE children develop over the years.

For more information, please go to:

<http://www.chargesyndrome.org.au/home/conferences>

Parents or professionals wishing to attend should contact Trudy Smith at: [trudy.smith@ridbc.org.au](mailto:trudy.smith@ridbc.org.au) for details including cost of attending.



Source: CHARGE Syndrome Association, reproduced with permission.

## genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

## Community

### Every Australian Counts Campaign

The National Disability Insurance Scheme (NDIS) will make it easier for people to access essential care, support, therapy, equipment, early intervention and training. To make the NDIS real for every Australian, go to <http://everyaustraliancounts.com.au/home/> to leave a message to the Prime Minister, Premiers and Chief Ministers at COAG.

Source: <http://everyaustraliancounts.com.au/home/>

### Equal Pay For Community & Disability Sector Workers

The Australian Services Union (ASU) is providing education and information sessions for employees and all community sector workers. These sessions are designed to assist with an understanding of changes in this sector.

Find out more visit [www.disabilitynews.infoxchange.net.au](http://www.disabilitynews.infoxchange.net.au)

Source: Infoxchange Australia's Community Infocast, Friday July 13<sup>th</sup>, 2012

## Seeking Contact

- Do you have a family member affected by Pallister-Killeen syndrome?  
If you are interested in talking to Victorian families also affected by this condition contact [info@gsnv.org.au](mailto:info@gsnv.org.au) or phone (03) 8341 6315.
- An 11 year old girl with Osteogenesis Imperfecta would like to meet another young person who also has this condition. Contact [info@gsnv.org.au](mailto:info@gsnv.org.au) or phone (03) 8341 6315.

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

- A young boy with Ring Chromosome 8 and his family would like to meet another child with the same condition. Contact [info@gsnv.org.au](mailto:info@gsnv.org.au) or phone (03) 8341 6315.
- A young adult with Langer-Giedion syndrome is looking to meet with a similarly aged person who also has the condition. Contact [info@gsnv.org.au](mailto:info@gsnv.org.au) or phone (03) 8341 6315.
- Do you have a family member with an undiagnosed genetic condition? If you would like to meet with a Melbourne family whose child also has no diagnosis, contact Heather on 0400 447 801.

## Grants

### GSNV Small Grants 2012

Every year the GSNV offers Small Grants to members for projects that support the work of a support group. In 2012, the GSNV is reviewing its membership's policy and has not issued membership renewals as yet. However, in September /October of this year, the GSNV will allocate Small Grants and continue to support important projects. All grants are between \$50 and \$500. We encourage you to start considering small projects you may wish to be funded and be ready for our applications process which will begin in August 2012. Stay tuned for further communications on Small Grants.

## Government

### Victorian Associations Incorporation Act

Changes to the Victorian Associations Incorporation Act began in 2010 but full amendments are occurring from July 2012. The amendments to the Act place higher levels of accountability and obligation to Boards and Committees of management and require that all Committees governed by the Victorian Associations Incorporation Act review

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

articles of association and accompanying constitutions/ rules. Public Interest Law Clearing House (PILCH) is a great place to start finding out information and means of navigating these changes.

## **NDIS CEO Appointed**

David Bowen has been appointed by the Australian Government to head up the coordination of the NDIS. By 2013 we will see the first stage of the NDIS with support going to approximately 10, 000 people with significant disability. It is expected that by mid-2014, there will be an expansion of up to 20, 000 eligible people receiving support.

Source: <http://www.jennymacklin.fahcsia.gov.au/node/1997>

## **Research**

### **Seeking 19-26 year olds with Impairments**

Dear GSNV member,

You are invited to participate in a research project that is looking at how young people (19-26yrs) with impairments make the move into adulthood.

What's the Study About?

Compared to their able-bodied peers, young people with impairments have an increased risk of negative social, physical and mental health outcomes. Yet, of all people with impairments, we know the least about adolescents and young adults. In particular, little is known about how they make the transition to adulthood.

Based on the stories of young people with impairments, this study seeks to produce new knowledge which can be used to help more people with impairments meet the challenges of transitioning to adulthood in order to become fully-functioning, well-adjusted, socially and economically included members of society.

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

The project aims to provide information to assist young people with various impairments meet the challenges of transitioning to adulthood.

Participants will be interviewed once a year for 3yrs (1-2 hours per interview). Topics that will be covered include: Family Background; Family Relationships; Impairment; Adolescence to Adulthood; Peer Acceptance; Leisure Activities; Career/Future.

For more information:

- Visit [http://sydney.edu.au/health\\_sciences/afdsrsrc/young\\_adults/underway/transitions\\_adulthood.shtml](http://sydney.edu.au/health_sciences/afdsrsrc/young_adults/underway/transitions_adulthood.shtml)
- Contact the team email: [transition.study@sydney.edu.au](mailto:transition.study@sydney.edu.au)



This project is being conducted by researchers in the Faculty of Health Sciences, University of Sydney and Deakin University and has Human Research Ethics Committee approval – No. 13386.

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**



## GSNV Calendar

<b>Fragile X Awareness Day</b>	<b>July 22<sup>nd</sup></b>	<b>International</b>
<b>MDA Trivia Night</b>	<b>July 25<sup>th</sup></b>	<b>Victoria</b>
<b>Strategies for Sustainable Funding</b>	<b>July 27<sup>th</sup></b>	<b>National</b>
<b>Victorian Autism Conference</b>	<b>August 9-10<sup>th</sup></b>	<b>Victoria</b>
<b>Haemochromatosis Awareness Week</b>	<b>August 13-19<sup>th</sup></b>	<b>National</b>
<b>ALDS 20<sup>th</sup> Anniversary Conference</b>	<b>August 18<sup>th</sup></b>	<b>Victoria</b>
<b>CMTAA Youth Weekend</b>	<b>September 7-9<sup>th</sup></b>	<b>Victoria</b>
<b>Pathways Australia Training</b>	<b>September 19<sup>th</sup></b>	<b>National</b>

# genetic support network of victoria

*empowering \* connecting \* supporting*



**BITS &  
PIECES  
enews**

## **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 web-site and database but still finalising the upgrade. Please bear with us as we make the updates.

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

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)

The information and material presented in Bits and Pieces is intended for educational/information purposes only. The contents express the opinions of the authors who alone are responsible for the views expressed. GSNV does accept any legal responsibility for their contents.

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