

GSNV UPDATE

October ~ November 2003

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10th floor RCH Flemington Rd Parkville



Heard The Good News?

GSNV's New Committee – Old and New Working For You

After another successful Annual General Meeting, the GSNV is proud to unveil their new committee. It is a vibrant mix of familiar faces returning to continue their good work, and new blood, bringing fresh ideas and enthusiasm to our organisation. Tony Briffa has been elected as the new GSNV president. The former GSNV treasurer has been a strong and active advocate not only for the GSNV but also for the Androgen Insensitivity Support Group Australia. He has been involved in support, advocacy and human rights for 15 years and believes it is important to educate society in regards to genetic conditions.

The new committee:

Tony Briffa (President)

Androgen Insensitivity Syndrome Support Group Aus.

Marjorie Cresp

Porphyria Association

Deborah Dalton (Vice President)

Melanie Forsyth

Muscular Dystrophy Association

Stephanie Hamer

Susi Hendricks

Metabolic Dietary Disorders Association

Marie Karamesinis (Treasurer)

Victorian Turner's Syndrome Association

John McKenna

Sandra Timbrell

Jeff Craig

Murdoch Childrens Research Institute

Tanya Files

Unique in Australia

Matt Doyle (Vice-President)

Margaret Harris

DHS, Specialist Children Services

Ray Hee

Andie Hider (Secretary)

Androgen Insensitivity Syndrome Support Group Aus.

Tony McDonald

Down Syndrome Association Victoria

Margaret Sahhar

Genetic Health Services Victoria

To read a full profile of each committee member, or to contact a committee member please see the GSNV web site www.gsnv.org.au

In The Limelight

Lift Your Profile In The White Pages

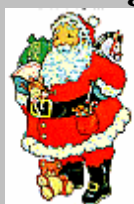
Is your group listed in the White Pages? It's easy to get your association listed - just send a fax (preferably on letterhead) to White Pages Customer Service on 1800 639 169 giving your association name and phone number. Charges apply for further details such as fax numbers and websites - call 1800 810 211 for full details about charges.

Say What You Want With The National Relay

The majority of people take telephones for granted. We cannot imagine our lives without the convenience of that line to the outside world. But for people who have trouble with their speech or hearing, the telephone is often a difficult or completely inaccessible machine. However the National Relay Service is a way for everyone to communicate in an easy and inexpensive way.

Run by the Australian Communication Exchange (ACE), the service enables people who can type to

Christmas Is Coming!



Royal Children's Hospital –Christmas Card Collection

For Christmas 2003, why not send a Christmas card that brings double the happiness? The Royal Children's Hospital has released a series of beautiful Christmas cards, which will not only bring happiness to your friends and family but will raise much needed funds for the hospital. Packs of 10 start from as little as five dollars and have been produced in 20 varied styles. You can call the RCH Auxiliaries on (03) 9345 6513 or call in to the Auxiliary which is open 9.00am to 7.00pm weekdays and 9.00am to 5.00pm weekends.



Surfing The Web

<http://www.erni.asn.au> or Equipment Recycling Network Inc is a site run by the Maroondah City Council and offers a range of services for people with a disability . The services are available to anyone in Victoria and include a discounted computer recycling program and online classifieds to buy and sell second-hand equipment.



What do you think? We'd be interested in your feedback on this story...

[communicate with a relay officer who 'relays' the message to the person using a telephone. This allows people who are limited to typing to access services and information previously inaccessible.](#)

[Customer Service Hotlines are attended from 8am to 7pm Monday to Friday and can tell you about all the services NRS supplies. For more information contact 1800 555 660 \(voice\) 1800 555 630 \(TTY\) 1800 555 690 \(fax\) email \[feedback@accinfo.net.au\]\(mailto:feedback@accinfo.net.au\) or go to the web \[www.accinfo.net.au\]\(http://www.accinfo.net.au\)](#)

GSNV Online Forum

[Every day I receive emails from families and support groups asking me excellent questions about genetic conditions and running support groups. I often think that some of you out there will know the answers even better than I do. So I've set up an online forum where you can post questions and answers and get in touch with people in other support groups. You can also post notices about special events you want people to know about.](#)

[Here's how to get into our online community - it takes less than ten minutes to join up:](#)

1. In your internet browser, go to the site: <http://mc2.vicnet.net.au> (My Connected Community - run by Vicnet)
2. Look at the New Users section on the left hand side of the screen and click on "Join Us - It's FREE!"
3. Fill in the form and click "I Agree" (after reading the Code of Conduct).
4. You will be sent an email. To activate your account, you must check your email, then follow the instructions provided.

Once you have registered,

1. Go to <http://mc2.vicnet.net.au/home/gsnv> click on "Join this group" and log in with your username and password.
2. Click on "Forum" to ask and answer questions. Click on "Noticeboard" to make announcements.

Get online and get involved! There's already some great questions on the forum - come and check them out!

Eilís Hughes, GSNV Co-ordinator

In The Media

[This story was featured on SBS recently.](#)

Dealing with Disability

["First to the difficulties of coping with severely disabled children. For many families the stress is almost unbearable. And if breaking point is reached in families, it's often the father who walks away. In this report two couples talk with unusual frankness about the effect having a disabled child has had on their marriages. Some people may find some of the views expressed in this report distressing. Anthony Wright with the story."](#)

<http://www.sbs.com.au/insight/index.php3?daysum=2003-10-02>

Have A Say... Have A Go

Working with the Media Training Workshop

We all have a message to get across, whether it's the search for a cure, the need for funds, or just about how life is for us. The media can be a useful tool if we know how to work well with it. Our workshop will combine the professional public relations experience of Kate Longton (from the Murdoch Children's Research Institute) with the experiences and needs of our members, to provide an interactive experience, giving you the confidence to work with the media.

Thursday 27 November 2003

6pm - 8.30pm

10th Floor Conference Rooms, Royal Children's Hospital

Supper provided

Free for GSNV members, \$5 for non-members.

RSVP to Eilis on ehughes@gsnv.org.au

or (03) 8341-6315

Cleft Awareness Day - Saturday 8th November 2003

CleftPals are celebrating their first awareness day at Collingwood Children's Farm, where we will be launching our fabulous Christmas Cards as well.

Time: 10am - 2pm

BYO picnic lunch and seating (chairs / picnic rug).

Entry: \$16 per family (or \$8 per adult & \$4 per child)

Collingwood Children's Farm St. Heliers Street Abbotsford ph. (03)

9417-5806 Christmas cards: \$8.00 for a pack of 8 (4 designs - includes envelopes) CleftPals / Xmas Card enquiries: Allison (03) 9584-4154.

Autism Parent Support Workshop

Northern Autism Parent Support Group is holding workshops with

Donna Williams. The Workshops will be held on Monday

November 3 and December 1 from 7.30pm to 9.30pm. It will be

held in the Fountain View room, Whittlesea Shire offices, Ferres

Boulevard, South Morang. Cost is \$5.00 per family and for more

information or to enrol call Thea on (03) 9385 3235

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 by 30 June

2003. For further details contact Daphne on (02) 6289 8689.

Communications Resource Centre

The Communications Resource Centre provides information on

complex communication needs, eating drinking and swallowing,

communication aids and materials, person centred planning and

more. They are running a number of workshops through November.

Advanced boardmaker, Nov 5, AAC an option not a last resort Nov

10 and Meal Assistance – through a tube, gastrostomies, what to do?

Nov 11. For more information contact CRC on (03) 9843 2000 or

1800 888 824.

IN MEMORY OF DAVID MILES DANKS, JUNE 1931 ~ JULY 2003

David Danks trained in Medicine at the University of Melbourne, qualified in 1955 and became a paediatrician in 1962. Encouraged by Dame Elisabeth Murdoch, he studied clinical genetics in Baltimore with Victor McKusick, the world leader in the field. On his return David started the clinical genetics service at the RCH. In 1967 he set up the Genetics Research Unit, and from 1975 to 1982 was Stevenson Professor of Paediatrics. He began the Murdoch Institute for Research into Birth Defects and the Victorian Clinical Genetics Service, which still exist today. David Danks was totally committed to paediatrics and genetics, both research and clinical practice. David made key contributions to our understanding of copper metabolism and PKU. The MCRI today is still a very powerful force in medical genetics research and clinical care in Australia, with over 200 staff working directly in the genetics service or on human genetics research. It's a tribute to his bravery and foresight that a Unit he began with less than ten staff in 1967 continues to grow from strength to strength today. He was a man of the highest intellect, and for many years trained most practitioners in this field. At the same time, he was a committed family man, and our condolences go to his wife June and their five children.

Prof Bob Williamson,
Director of Murdoch Childrens
Research Institute.

Eat, Drink and Be Merry – Groups' Activities

Thalassaemia Society Conference

The Thalassaemia Society of Victoria is hosting a National Conference on the haemoglobinopathies (genetic blood disorders) on November 19-23, 2003 in Brisbane, Queensland. This conference aims to provide health professionals with a more holistic view of the care needed for those affected and to provide the latest information from the October 2003 international conference in Italy. More information can be found at www.tsv.org.au/ata.html

What Is A Seizure? Epilepsy Foundation of Victoria

Everyone is invited to attend an education program hosted by the Epilepsy Foundation of Victoria. To be held November 24, at 818 Burke Rd Camberwell, guest speaker is Neurologist, Assoc Prof Christine Kilpatrick. Cost is \$6 per person, \$3 concession or free to Epilepsy Foundation members. More information from Maree Robson (03) 9805 9111 or email mrobson@epilepsy.asn.au

Friendships – Social Inclusion and Stress Workshop

The ABIA is holding a full day workshop on October 31 dealing with Management Techniques for Children and Adolescents with an Autism Spectrum Disorder. Presented by Clinical Psychologist, Tony Attwood, the workshop will run from 9.00am to 5.00pm in South One Lecture Theatre, Building 64, Monash University, Clayton. Cost is \$100 for ABIA members and \$140 for non-members. For further details or to register please call (03) 9885 7463 or email abia@netlink.com.au

Thyroid Australia Annual General Meeting

The Thyroid Australia AGM will be held on November 29 from 2.00pm to 5.00pm, venue to be confirmed. For more information call (03) 9561 2483 or visit the website www.thyroid.org.au

CMT Australia – National Seminar

The CMT National Seminar will be held on November 2 in Lecture Room 1, Concord Hospital, Concord. Speakers will include Prof Garth Nicholson, Prof Robert Ouvrier, Miss Daniella Radovanovic, Mrs Mary Jenkins to name a few. For more information contact the GSNV on (03) 8341 6315.

Heartkids Victoria – Heart Racing Events

Heartkids will be holding a sailing day for Heartkids members 10 years and over on November 9. The day will go from 10.00am to 2.00pm at the Elwood Sailing Club. Heartkids are also holding their annual Christmas Party!! Entertainment will be provided by the Step it Up Dance School followed by a great lunch. Santa is also sure to make an appearance. The day has limited numbers so if you are a Heartkids member, please RSVP through the Heartkids Office, or get more information by email heartkids@heartkids.org.au

We'll Meet Again...

REMINDER

Next Committee Meeting

Monday 17 November at 6pm

Conference Room B

10th Floor RCH, Flemington Rd Parkville

All members and interested parties are very welcome to attend our meetings!

END-OF-YEAR MEETING

Celebrate the GSNV's achievements in 2003.

Monday 15 December at 6pm (brief meeting followed by celebrations)

Redback Brewery Hotel

75 Flemington Rd, North Melbourne

Everyone is welcome to join us for complimentary drinks and snacks. RSVP to Eilis in the office.

**For more information on anything you've read here, please contact Eilís or Jo
in the GSNV office on (03) 8341-6315 or email info@gsnv.org.au**