



genetic support network of victoria

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GSNV Update

June 2007

Welcome to the June Update. GSNV is very excited about Awareness Week. We have some great events lined up, so be sure to put them in your diary! All the details are included in this newsletter. This edition also includes our regular news and sections...happy reading!

GENETIC SUPPORT AWARENESS WEEK:

Sunday 1st to Saturday 6th July 2007

Genetic Support Awareness Week raises awareness of genetic conditions and what it means to be affected by a genetic condition. It's also an opportunity to meet others "in the same boat", celebrate the joys and work together to overcome the challenges. We hope you can join us at our Awareness Week celebrations:

- **Family Day**

Fun for the whole family, with giant board games, professional story teller & more

- **Seminar: Family Health History – do you know yours?**

Come along and find out why it's important to know your family health history, how to draw your family health history, and how to speak with your health professional about conditions that "run in the family".

- **Coffee Morning (kids welcome)**

Meet others "in the same boat" and local health services over a friendly coffee.

All the details appear on the next page. We hope to see you at one or more of these great events. And if you know someone else who may be interested, please feel free to pass the information along!

Genetic Support Awareness Week is an opportunity to raise awareness about your genetic condition and increase the profile of your group. You may like to get behind Genetic Support Awareness Week by holding your own activity...a seminar, a family day, or perhaps share your story with the media. *Please tell us about your Genetic Support Awareness Week activities so we can include them in our calendar!*

Awareness Week Program

Sunday 1 st July	Family Day
Wednesday 4 th July	Seminar
Friday 6 th July	Coffee Morning
ALL WEEK	Display at RCH

See page 2 for more information.



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PROGRAM

GSNV Family Day

Looking for a great day out during the school holidays? With a midwinter theme, the Family Day includes a baked potato feast, GIANT board games, gingerbread people and animals to decorate (and EAT!), craft activities and a special visit from storyteller Andy Wright. Bring the family and your inner child to this cosy winter gathering!



When: Sunday 1st July, 10.30am – 2.00pm

Where: Wingate Avenue Community Centre
13a Wingate Avenue, Ascot Vale
(Melways ref 28 G10)

RSVP: Phone Leah on 8431 6315 or email leah@gsnv.org.au by 22nd June

The venue has on-site parking, is located 5 minutes' walk from the Ascot Vale train station. Wheelchair friendly, with no steps between the front door and our room.

"Family Health History – do you know yours?" seminar

Family history gives us a good idea about what we might expect for our own health. Do you know your family health history? Learn why family history is important, what to look for, how to record your history and how to talk about your family health history with your doctor. GSNV proudly presents this seminar in partnership with Genetic Health Services Victoria.

When: Wednesday 4th July, 6pm

Where: Yarra Room, Melbourne Town Hall
Swanston Street, Melbourne

RSVP: Phone Leah on 8431 6315 or email leah@gsnv.org.au by 3rd July

Located in the city, the venue is accessible by public transport. Parking is available in nearby parking lots. There is limited on-street parking as signed. Elevator access to the Yarra Room.



Glen Waverley Coffee Morning

Join Leah for a relaxed coffee break and meet others "in the same boat". Children are welcome (colouring in activity provided).



When: Friday 6th July, 10.30-11.30am

Where: Mount Street Neighbourhood House
Mount Street, Glen Waverley

RSVP: Phone Leah on 8431 6315 or email leah@gsnv.org.au

The Neighbourhood House has on-site parking and is located 5 minutes walk from the Glen Waverley Train Station.



OTHER GSNV NEWS

GSNV Subscription Renewals

Renewal notices have just been sent out, and are due by the end of June. Membership is \$22 per year for a group, individual or family...an inexpensive way to keep up to date, receive free or discounted registration to events, eligibility to apply for GSNV's small grants and more! Donations are also greatly appreciated and are tax-deductible.

Shop to Support GSNV

Would you like to help GSNV raise money when you shop? Thanks to Self Fundraising, you can now buy books, gifts, flowers, clothes, and even holidays online - and 5% or more of the price will be automatically donated to GSNV. There's an excellent range of products and shops - visit the website at <http://www.self-fundraising.com.au/cause/gsnv>.

Morning Coffee- Monday, 16th April

Our first coffee morning in Ascot Vale was fantastic. While numbers were down, those present enjoyed the benefits that a more intimate group allows. The next coffee morning will be held during Awareness Week (and school holidays) in Glen Waverley...kids are welcome. See the flyer for details.

GSNV Small Grants Project

GSNV's Small Grants have been awarded. We are delighted to have made \$3000 available this year, shared between 13 groups including:

- AIS Support Group Australia
- Aussie Hands Foundation
- Aust. Leukodystrophy Support Group
- Australian Pompe's Association
- Cardiomyopathy Association Australia
- Cystic Fibrosis Victoria
- Fragile X Association Victoria

- Glenroy FMS Self Help Group
- Haemophilia Foundation Victoria
- Klinefelter Syndrome Support Group Vic
- Parent Support Network (Eastern)
- Short Statured People of Australia (Vic)
- Spina Bifida Foundation Victoria

Congratulations to all successful Grant recipients. We look forward to hearing about your projects!

The Small Grants Project is funded from your subscriptions and donations, so a special thank you to all our members and supporters for making this project possible!

Starting a Support Group: Seminar Notes Still Available

Handouts are still available from GSNV's seminar on Starting a Support Group. For your copy, please contact Leah on (03) 8341 6315 or email leah@gsnv.org.au. (NB: notes will be posted to you as they include a bound book)

SG News – Newsletter for Support Groups

SG News is a newsletter specifically for support groups, published by the Genetic Support Network of Victoria. This short-but-sweet newsletter includes information about genetic "hot topics", upcoming grants to apply for, info for your members, Genetic Support Awareness Week information for groups, and advocacy topics.

One of the features of *SG News* is the 'Your Say' section. GSNV has around 140 genetic support organisations on its mailing list – and each group has considerable knowledge and expertise. 'Your Say' is a great way for groups to share knowledge.

Does your genetic support group receive *SG News*? To have your group added to the *SG News* mailing list, phone Leah on (03) 8341 6315 or email leah@gsnv.org.au.



CONNECTING PEOPLE

Facial Hemihyperplasia

Cathy would love to make contact with other people affected by Facial Hemihyperplasia or hemihypertrophy. To contact Cathy email coolvalentinos@optusnet.com.au.

GROUP EVENTS

Camp MDA – 19th – 23th June

The Muscular Dystrophy Association (MDA) will be holding its winter camp from Monday 19th June to Friday 23rd June in Maldon. For more information visit: www.campmda.org.

Intimacy in MS – Seminar 27th June

Intimacy in MS is an opportunity to find out more about the impact MS can have on intimacy and sexuality, with practical advice for managing these issues. The session will be held at Footscray MS Centre on Wednesday 27th June. For more information contact Jen on (03) 9845 2700.

Klinefelter Syndrome Support Group Meeting – 20th June

Next meeting will be on Wednesday 20th June at 8.00pm at the Jika Jika Community House, Northcote. For more information, email Kieran at kieran215@hotmail.com.

Me Time For Mum

The Hawthorn Community House runs a cost-free creative and leisure program for mothers who are caring for a child (or children) with a special need. For more information phone Debbie Zacks on 0401 637 449 or email dzaks@swin.edu.au.

Shwachman-Diamond Syndrome Congress – Boston, 10-12 June

Venue: Conference Center at Harvard Medical School. Keynote speaker: Dr David Nathan. For more information visit the Congress web site at www.sdscongress07.com.

SSPA Grand Gala Dinner – 14th July

The Short Statured People of Australia (SSPA) are holding a Grand Gala Dinner to support fundraising for the 40th National Convention. For more information phone Meredith on (03) 9555 7676.

GROUPS AND SERVICES

Cardiomyopathy Association of Australia

The CMAA holds meetings, provides educational material and a quarterly newsletter. To find out more visit the web site at www.cmaa.org.au or phone Kathy Whelan (National Secretary) on (03) 5688 1400 or email kathleencw@dcsi.net.au.

Football for People with a Special Need

The Montrose Football Club's football for people with a special need meets at the Links Park Stadium, Montrose. There is no age limit. Starts 11am Saturdays. For more information phone David Harbinson on 9736 1555.

Parent Support Network (PSN, eastern)

The PSN provides support and information to parents/carers of people with disabilities and special needs who reside in the Eastern Region of Melbourne. Events include Art Therapy workshops, pampering days and guest speakers on topics of interest. Phone Rachael on (03) 9259 4312 or email psn-emr@bigpond.net.au.

XXWhy: The Australian Support Group for Klinefelter Syndrome * NEW GROUP*

James has started an online group for people with Klinefelter Syndrome. Visit the website at <http://www.xxwhy.com>.



GENETIC HEALTH SERVICES VICTORIA NEWS

Short Stature Symposium Report

The Inaugural Short Stature Symposium was held in the Ella Latham Theatre at The Royal Children's Hospital Melbourne on Sunday May 20, 2007. This symposium was a joint initiative of parents and families of individuals with short stature and Genetic Health Services Victoria who brought together families, health professionals, allied health professionals and patients' families and friends alike, to discuss the many issues surrounding short stature.

Medical talks discussing the clinical, radiographic and research manifestations of these conditions were mingled with powerful and honest reflections from parents of children with short stature and from adults and teenagers with short stature conditions.

In addition, we had talks from Genetic Counsellors, Social Workers, Physiotherapists and Occupational Therapists including our invited speaker from Queensland, Penny Ireland, who discussed the interim results of the study she is performing in documenting the

normal development of children with achondroplasia.

The symposium attracted approximately 100 attendees and was an overwhelming success, and was educational as well as a day where people with short stature could meet other people with similar conditions and their families. Lunch was kindly sponsored by Pfizer Australia, who has undertaken to sponsor this event annually.

The day finished with an honest and open panel discussion. It is envisaged that this symposium will be the impetus for many new initiatives to improve the care, management and education of individuals with short stature, their families and the community.

Congratulations to all those involved for organising such a successful and inspirational symposium.

*A/Prof Ravi Savarirayan,
Head, Bone Dysplasia Clinic, Royal
Children's Hospital*

The Short Stature People of Australia received funding towards the cost of this Symposium, as part of the GSNV Small Grants Project for 2007. GSNV is delighted that the day was such a huge success and congratulates everyone involved!

Is Awareness Week in your diary?

Which event/s will you attend?

See page 2 for details.

MEET OUR MEMBERS

SAKKS & KABUKI SYNDROME

Supporting Aussie Kids with Kabuki Syndrome

There are many features which can occur in Kabuki syndrome but not all are seen in every child. Features seen in Kabuki syndrome are:

- Unusual facial features.
 - wide eyes with arched, interrupted eyebrows
 - large and low-set ears
 - depressed nasal tip
- Short stature.
- Skeletal abnormalities such as short fingers, loose joints
- Intellectual disability, which varies from mild to severe. Most individuals with Kabuki syndrome have a mild to moderate intellectual disability.
- Many other features are sometimes seen:
 - Cleft lip and palate
 - cardiac abnormalities
 - urogenital and kidney problems
 - anorectal and intestinal problems
 - immune abnormalities
 - ear infections and hearing loss

problem and research is ongoing to try to identify the cause. In most cases of Kabuki syndrome, there is no family history of the syndrome. Kabuki syndrome is found in males and females equally.

There is no cure for Kabuki syndrome but there is a lot that can be done to ensure good health in a person with Kabuki syndrome, and to make sure that each person with Kabuki syndrome achieves their full potential.



Reference: American journal of Medical Genetics 127A:118-127 (2004)

The boy in the picture has Kabuki Syndrome.

His arms are reaching up and holding the world - he has the whole world at his fingertips.

He is supporting his friends here in Australia and the rest of the world too.

Hopefully the world will one day see him down there and know just how special he and his friends are.

The cause of Kabuki syndrome is not known. It is thought to be a genetic

Support for Aussie Kids with Kabuki Syndrome (SAKKS) – www.sakks.org

To help support those affected by KABUKI SYNDROME, we (Peta and Adrian), decided to start this website. We hope to offer support to other families just like ours.

SAKKS offers information, external links to genetics departments and research as well as links to medical information, a forum and a stories page with personal accounts of the challenges of coping with a child that has KABUKI SYNDROME. It also offers photographs, contact with other parents, membership, sibling information, early Intervention and educational links and of course - support.

REMEMBER you are not alone. Others have been there before you and will help catch you if you fall. Thankyou for visiting www.sakks.org

Thanks to SAKKS for providing the information on this page.

10th Floor, Royal Children's Hospital, Flemington Road (PO Box 1100), Parkville VIC 3052
Ph: (03) 8341-6315 Fax: (03) 8341-6390 E-mail: info@gsnv.org.au

OUR STORY: Zachary – Worth Every Tear

By Peta

Our little man Zachary was born in November 1997. He has Kabuki Syndrome.

A routine ultrasound of our twins showed that our little boy was very sick. He had a condition called Hydrops Fetalis. At 31 weeks an emergency C section was performed. Through the ether I remember the doctor telling me "it looks grave". After delivery I remember being wheeled on my bed to NICU to see my babies, twin 1, our little girl Hannah was tiny but doing fine, twin 2 our little boy was seriously ill. My world had changed that day forever. I can't explain the pain I was feeling - a combination of fear, loss, and grief.

The day you enter NICU nothing can prepare you for the roller coaster journey that follows as a series of steps that lead you to here, this day.

I spent the first 10 days as a patient at the hospital, which allowed me to spend every minute with the twins. Hannah graduated from NICU, to SCUBU 1, but decided on another short stay back in NICU a little later.

The first priority for Zachary was to drain the fluid that filled his body and chest cavity, so many drains, so many tubes, so many probes, and machines that went beep. Expressing milk gave me something else to think about every few hours.

Zachary was on a ventilator and a zillion drugs to keep him going, and after a few days it was necessary to do a complete blood transfusion. This was successful and his next achievement was going to be to poo. He also had a cranial haematoma.

The time had now come for me to go home and leave my babies behind. It was the hardest day of my life. My husband sat at the wheel and my two beautiful daughters sat in the back and I howled all the way home. I cried and cried. I remember

pushing my girl's beds together and sleeping in the middle that night, but my husband Adrian needed me too.

Next was a routine of getting up, putting breast milk on ice, dressing and feeding the girls, and going to the hospital. Our girls were part of the furniture in the hospital crèche, and their world had changed significantly too.

One particular day, I remember skipping into the hospital with Adrian after being told Zachary had finally pooped. After walking through the doors with big smiles we were asked into the doctor's room for a chat. Our happiness turned to devastation as we were told our little man had a coarctation of the aorta. For now they would keep him alive with hourly doses of Prostin and when he was at least 2 kilos he could have surgery to repair his heart. He didn't grow and he developed a necrotising bowel disease which hindered his growth even more.

After 5 weeks we were allowed to bring Hannah home. This was short visit home because she had Pyloric Stenosis, so back to hospital for her for some surgery along with our 5 year old that had her adenoids out at a different hospital. I was taxiing breast milk and my love and mothering between 2 hospitals; 3 separate wards at the same time. On Hannah's last night in hospital I stayed in the parent's room. After little sleep I woke up with Zachary's cardiologist standing at my bed. He told me that we were booked on a flight to Melbourne's Children Hospital for Zachary's heart surgery for the following morning. Even though Zachary wasn't 2 kilos yet but he never would be if he didn't have the surgery. Our girls stayed with my parents.

The surgery went well, but his blood pressure was a worry and after 10 days we flew back to Adelaide.

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Zachary spent a couple of days back in NICU then graduated to SCUBU 1, where his health improved little by little, he would then have surgery for his hernias and undescended testicle.

One of the other complications for Zachary was his cleft lip and palate. He did not tolerate any oral stimulation and could not suck. He was fed through a naso-gastric tube. It was decided that we could take Zachary home on N.G. feeds and we fed Zachary 20 mls every 2 hours; we had a suctioning unit to clear his throat. As you can imagine with the two of us feeding him so regularly day and night there was little time for anything else especially dishes which were piled 5 feet high.

I guess I was lucky I had older children so I wasn't a new mum. The usual scary things weren't an issue, but I must say that the challenges of Zachary were sometimes unbearable. To mention another of his problems were kidney gravel or stones and his nappy was often full of blood. This can be very daunting, and our usually placid happy boy was in agony when they happened.

Adrian and I kept a record chart of fluid in and out, bowel action and respirations, Zachary's respirations were too fast, and he was constantly turning blue. On Good Friday whilst visiting my parents we rang the doctor to tell him our son was very blue, he told us to come in and we did. A chest x ray showed that he had inhalation pneumonia caused by his very severe reflux, he was very sick. After he was over the pneumonia it was decided that Zachary needed to have a feeding button surgically inserted into his abdomen and also a Nissen Fundoplication was performed. This is a wrap of the top of the stomach to stop stomach acid from going back up.

On Sunday, we were having a lazy morning in our pyjamas when the phone rang, it was the surgeon who performed the operation, we were informed that Zachary was acute, and he had peritonitis. When they put the

feeding catheter into his stomach it had travelled down into his duodenum and out into the pelvic cavity, consequently he was fed into his pelvis for 2 days.

On our arrival Adrian and the girls talked to the doctor while I ran into PICU. He lay limp on the bed while doctors and nurses were busy doing what they do. His tiny veins had shut down, and the doctor's hands were shaking as he probed and probed for a vein to put the lines into. At one point he asked me to help and make him cry... he was hoping to stimulate a vein by doing this. Zachary didn't, he just lay there speaking to god I imagine. I couldn't and wouldn't move, I needed to be there. There wasn't any time left, so without any lines in they rushed him to theatre. He returned to PICU after the surgery and was very sick. I can't believe we nearly lost him again.

A week or so passed and we brought Zachary home. He had severe diarrhoea that never stopped, it was so bad that his backside was raw, and we kept him on blue sheets instead of nappies. We couldn't go anywhere. We tried but it just didn't work.

It wasn't too long before he was back to hospital for the first of his craniofacial surgery – they repaired his lip and inserted grommets into his ears and when saw Zachary's new mouth I was a little torn. This little man looked so different now. Very cute, but I had become so used to the way he used to look that at first I wasn't sure if I like the new him.

Eventually after months of enquiries I had the services of physiotherapy, occupational therapy and speech pathology. They came to our house weekly and fortnightly with advice and help.

The diagnosis of kabuki syndrome happened around this time. While we were seeing the gastroenterologist he happened to mention that the pit in Zachary's bottom lip looked like one he had seen before on a child with Kabuki. That night we were talking and I asked Adrian what was the name of the

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condition the doctor mentioned today and he said he thought it was something like kabuki, so we turned to our smart friend; the internet and typed in the word we heard that day, the same word that has impacted on our lives for 9 years.

It was quiet as we read the synopsis, this was our son and up until now our son just had some medical problems; he was going to be alright eventually. We quietly agreed that this condition was a possibility.

We had an appointment for Zachary's pulmonary specialist. When we spoke to him and told him all that we had learnt, we asked at what age can you tell if a child has an intellectual disability? He looked at us and quietly said "now". Even though I loved this little man with my whole heart, I had to let go of the son I thought I was going to have. An appointment was made to see the geneticist. It was really just a formality and I think they knew the answer before we arrived. The diagnosis was confirmed and Zachary was stamped with the title of Kabuki Syndrome.

One of the biggest mile stones was eating. He just hated anything in his mouth; he arched and screamed when we tried. But I pictured him at lunch time at school being fed through a tube while others ate, so for 6 hours a day every day we worked on swallowing and eating. It was the hardest thing I have ever done and I remember thinking at the time that it would never end, but it did. He screamed and screamed when I tried to feed him, and it was exhausting but every day more and more was being swallowed. His improvement was being helped by his hunger. I would sit him on plastic with all sorts of food to play with and one day I put a big bowl of spaghetti bolognese on his lap and he picked it up with his hands and yes it was going to his mouth; and yes he was putting it in; silence and anticipation as I watched the handful of wiggling strands of spaghetti; and yes they were going in; he repeated this until it was all gone. He had independently eaten all by himself. It finally happened he was enjoying

food. We look at Zachary today as he's asking for seconds and it's hard to imagine any of this.

Babies usually learn all the basic stuff on their own, but I had to teach Zachary everything. To help Zachary with his speech we spent a lot of time sitting in front of the mirror sounding out letters, I would get him to talk and watch his mouth in the mirror. Actually speech was just as much hard work as eating. Until he was five he was completely incomprehensible. So lots of hours were spent teaching him sounds.

Zachary and his twin Hannah started kindergarten. We were lucky enough to find an excellent place not too far away. The principal was the most fantastic lady. There were a couple of other special needs kids there; one with cerebral palsy and another with a rare condition. I found it amazing the natural and almost instant bond that formed between the kids. The little girl with cerebral palsy was Zachary's first girlfriend.

It was probably around this time Zachary had his next lot craniofacial surgery. We decided that whilst he was having his palate stitched he would have his ears pinned and nose redone and the pit in his bottom lip removed. We felt mean do this to him, but his ears stuck out and it was just another barrier to him being socially accepted.

We have been lucky enough to get Zachary into the same school as his sisters – it's a great school and he has great support. In just 1 year he has gone up 19 levels in readers, can catch a ball, run, and is making good friends.

During the Christmas carols at the end of last year he stood proudly and sang two songs, I don't remember the songs but I will never forget the emotion. Sometimes I could cry forever at how much we have been through. But looking at him right at this moment he is worth every tear.

Thanks to Peta for sharing her story.

RESOURCES

New Book Answers "Silly Questions"

There's No Such Thing As A Silly Question is a practical guide for families living with a child with chronic illness, disability, mental illness or a life-threatening condition. Written by a group of parents and committed health professionals, it provides valuable insights into what other families have learnt, felt or found helpful in their experience of caring for a child with additional needs. To obtain a copy, phone Camille on (03) 9804 6222 or email secretary.interact@gmail.com . (A copy will be available from the GSNV library soon.)

Department for Victorian Communities – Office for Disability

The Department for Victorian Communities has opened its Office for Disability. To contact the Office, phone 1300 880 043, or TTY 9208 3631 or email clare.thorn@dvc.vic.gov.au .

Infoxchange Service Seeker

Infoxchange Australia has developed the Infoxchange Service Seeker (ISS) (<http://www.serviceseeker.com.au/>) to allow people to access up-to-date, accurate information on health and welfare support services. This service allows you to search for service by area, target group (family, youth, male, female, aged...) and accessibility (after-hours service, wheelchair accessible). The Infoxchange Service Seeker currently contains details on 115,336 government and non-government services and agencies in Victoria. It's updated regularly, so that the information is up to date... well worth a look! (and yes, the GSNV is on there - not only does it list our website, phone numbers and wheelchair accessibility, it even lists the tram numbers if you come in to visit us in person...)

GRANTS AND FUNDING

DHS Capital Grant Scheme

This grant assists by repairing or replacing major essential gas, electrical or water appliances which are faulty and/or have failed within the last 12 months. It is available to households which hold a current Concession Card and own the property for fixed appliances. You do not need to own the property if you are applying to have a fridge or washing machine repaired. For more information phone 1800 658 521 or visit <http://hnp.dhs.vic.gov.au/wps/portal> .

DHS Utility Relief Grant Scheme

This grant scheme provides assistance to low-income individuals and families who are unable to pay electricity, gas or water bills due to a short-term financial crisis. The grant provides for full or partial payment of an outstanding utility bill where the applicant is at risk of disconnection for non-payment. Application forms are available from electricity and gas retailers, and water authorities. For more information call the Concessions Unit on 1800 658 521 or visit http://www.dhs.vic.gov.au/concessions/guide/g_finance.htm .

If you don't have access to the internet, the GSNV staff are happy to print information on any of these grants or awards and post it to you. Please phone GSNV on (03) 8341 6315.

ADVOCACY

Review of Disability Standards for Accessible Public Transport

Submissions are being invited for the five-year review of the Australian Government's Disability Standards for Accessible Public Transport, being conducted by the Allen Consulting Group. Stakeholders are encouraged to make submissions by Friday 24th August, via email (dstransport@allenconsult.com.au). Public hearings will also be held in every state and territory during July and early August, to allow people to speak directly to the review team.

Hobsons Bay City Council Disability Action Plan Survey

Hobsons Bay City Council is developing a Disability Action Plan, and is calling on residents to complete a survey to help guide the future of services and facilities for people with disabilities by providing feedback. For more information contact Megan Salisbury on (03) 9932 1000 or visit the Hobsons Bay City Council web site at <http://www.hobsons.vic.gov.au/>.

GSNV is AGA Secretariat from July

There are more than 1000 genetic support groups in Australasia. The Australasian Genetic Alliance (AGA) facilitates networking between these groups, health professionals and patients and families to improve community and professional knowledge of genetic conditions, their impact and available services.

The Alliance has taken a lead advocacy role in representing members' interests in

national genetics issues. The AGA provides written and verbal submissions to Government and others in the field of genetics and participates with like bodies nationally to further represent Genetic Support Groups and their members.

The Australasian Genetic Alliance (AGA) is an alliance between genetic support and advocacy networks from around Australia and New Zealand. GSNV is one of the founding members of the Alliance and continues to be very active within the Alliance to represent people in Victoria affected by genetic conditions and their families.

Because the AGA has no funds of its own, duties are shared between all participating groups. The Secretariat rotates between member groups every two years.

From July 2007, the GSNV will take up the mantle of Secretariat to the AGA. This means GSNV will be the official contact point for the AGA. The AGA Co-Chairs from July will be GSNV's Vice President and immediate-past President, Mr Tony Briffa, and our multi-talented Coordinator, Leah Lonsdale.

If you have something you would like raised at a National/Australasian level, you can contact Tony on (03) (03) 9315 8809 or email aissg@iprimus.com.au, or phone Leah at GSNV on (03) 8341 6315 or email leah@gsnv.org.au.

Want to know more about the AGA? Visit www.australasiangeneticalliance.org.au

WHEELCHAIR ACCESSIBLE TAXIS

13 CABS (Formerly Yellow Cabs) - Wheelchair Accessible Taxis

AQA is meeting with 13CABS (formerly Yellow Cabs). 13CABS want to revamp their wheelchair accessible taxis service, and would like feedback from people who use this service. This is a great

opportunity to put forward concerns regarding all taxi services, not just 13CABS (formerly Yellow Cabs). To have your say, contact Peter at AQA on (03) 9489 077 or email petervanbenthem@aqavic.org.au.

If you're calling from outside Melbourne, you can call on 1800 999 128.

DISABILITY AND TELECOMMUNICATIONS

Linking people with communication or speech difficulties into telecommunications - CAUS

CAUS is a provider of services to people with disabilities. Its new national project links people with communication or speech difficulties into telecommunications. The project will involve meeting with people who experience communication or speech difficulties throughout Australia and identifying their telecommunication needs e.g. mobiles, national relay service, internet, telephones and any barriers preventing them from accessing these services. CAUS will promote and raise

awareness about telecommunication to people who experience speech and communication difficulties and ensure that appropriate training and support exists to build confidence in using the technology provided. Focus groups will be held in each major city Australia-wide in early 2007 and questionnaires will be available to fill out. For more information, or to participate, visit www.caus.com.au or phone 03 9557 5551, rural: 1800 995 383 or email mwilliams@caus.com.au.

New guideline for making payphones more accessible

A new industry guideline to ensure that payphones are accessible for people with disabilities has been developed by Communications Alliance and the Human Rights and Equal Opportunity Commission (HREOC).

The guideline states that payphones should be installed so they can be more easily accessed by people with wheelchairs or other mobility aids; they should have features including volume control so that people with hearing impairments can use the phone; and they should have other features such as keys that are recessed or concave, with clear lettering and/or numbering that allows easy use for people with vision impairments or other physical disabilities.

Communications Alliance CEO Anne Hurley encouraged payphone manufacturers, installers and operators to use the guideline in their disability action plans as a new benchmark for payphone accessibility in Australia.

"Publication of this guideline represents a commitment to the development of industry-wide best practices for increasing the level of accessibility of payphones and thus to a narrowing of the digital divide," Ms Hurley said.

Human Rights Commissioner and Commissioner responsible for Disability Discrimination, Graeme Innes, said there was a growing number of Australians with particular needs for whom communications equipment, including payphones, must be accessible.

"Although adoption of this guideline by the payphone industry is voluntary, we are encouraged by the cooperative spirit that has gone into its development and see this as an important achievement," Mr Innes said.

The guideline can be viewed and downloaded from the Communications Alliance website www.commsalliance.com.au

Got any news for this page? Know of an advocacy group or organisation that should be featured? Contact the office on 8341 6315 or email info@gsnv.org.au to tell us about it...