AGSA
THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA INC.
NEWSLETTER

OCTOBER 2010 ISSUE 92 ISSN1033-8624 FUNDED BY NSW HEALTH

CONTENTS

MISSION STATEMENT

To facilitate support for those affected directly or indirectly by genetic conditions throughout Australasia.

EDITORIAL

Please have a look at AGSA's website and read all about what is happening with the Gene Patents Act 1990. Briefly, Melissa Parke Labour MP for Fremantle WA moved a motion to ban gene patenting on 18th October in the Lower House. AGSA is calling on all our members to write a letter in support of this motion by 20th November. Presently 8 MP's have supported it. This is extremely important. If successful it will mean easier access to genes for research, no expensive costs for gene testing e.g. BRCA1/2 gene in USA costs $4000. It is important for you and your family's future. Our genes are not an innovation or a discovery but are naturally occurring and therefore not patentable.

DATES FOR THE DIARY

Support Group Leaders Workshop luncheon 10th November at 12noon at AGSA and AGSA's AGM Tuesday 23rd November at 11am.- 12noon.

I will be away from 25th November till mid January as I have a lot of leave owing to me. EPPOSI are holding a Rare Disease Conference in Prague on 29-30th November and there will be a Rare Disease Workshop in Brussels on 9th December both of which I will be attending. I am looking forward to visiting many of the support organisations in London while I am there. Until next time

Take care,

DIANNE PETRIE OAM

FILLING THE VOID (FTV)

Hello All,

I hope this finds you well and that the school holidays weren't too taxing. I thought I would update you on the Filling the Void Project, particularly for those of you who haven't heard about it. Filling the Void aims to reduce the isolation which may be felt when caring for someone with a rare genetic condition. As you all know, caring places extra demands on your time, money and emotions. Our aim is to provide various support options which hopefully make it easier for you to access support. We hold seminars which showcase local support available and provide an opportunity to meet other families in the area, sibling workshops which give brothers and sisters of a child with a genetic condition the opportunity to connect with others living a similar experience, telegroup counselling (TGC) for residents of NSW with a landline which connects up to 6 carers with 2 facilitators for a one hour conversation, once per week for seven weeks. In TGC we have had dads groups, mums groups and sibling groups – they are so popular we often have people asking if they can participate a second time. AGSA is also able to facilitate face to face counselling as needed. Recent events include: Orange Seminar and Sibling Workshop – these events were well attended and included presentations from Care West (a local service provider) Agency for Clinical Innovation (ACI) http://www.health.nsw.gov.au/gmct/ definitely worth having a look at the support they can offer families, particularly in terms of accessing support and health care for young adults with disabilities, carer's own personal stories, loss and grief, sibling issues and, of course, pampering time for carers.

The sibling workshop consisted of lots of games, drawing, eating and talking. As always we felt so fortunate to have such an amazing and insightful group of siblings.

We are currently in our third TGC group for this year. Within TGC some topics which tend to come up each time are: sibling issues, loss and grief, communicating with your partner, accessing support, advocacy and respite to name a few.

Next year we are considering holding a seminar and sibling workshop in Broken Hill so would welcome feedback from anyone in and around that area in terms of topics you would like addressed. We will also hold a dads TGC next year, another mums group and a sibling group. Please do contact us if you are in an area we haven't visited and you would like a seminar and sibling workshop to come to you.

This support is for you and your family and I welcome any questions, suggestions or feedback on the program. My contact details are 02 9211-1462 or projects@agsa-geneticsupport.org.au we also have a Facebook presence at Laurie AGSA. I am available from Tuesday – Friday 9am-5pm.

LAURIE TAYLOR, PROJECT OFFICER
AGSA, FILLING THE VOID.

CONTACT CORNER

AGSA will publish requests for contact and letters from people searching for families with similar experiences, from those seeking or contributing specific information as well as other resource information.

Anyone who wishes to reply to a request or a letter should write direct to the individual or group concerned where an address is provided. The AGSA office many be contacted for the information to be passed on in the case of anonymous requests. Privacy and anonymity will be ensured if requested.

While AGSA aims to facilitate contacts between families it is unable to assess the suitability of these in individual cases.

It should be remembered that a shared genetic condition does not mean an equally shared value system between families. Different degrees of acceptance and different mechanisms for coping will be encountered and a non-judgmental approach is recommended in establishing contact.

KLEEFSTRA SYNDROME

Earlier known as 9q34.3 deletion syndrome.

AGSA has a few families with this condition and we are looking to match people up. If you know of others please tell them to contact AGSA. AGSA has some good information on this condition provided through Unique UK with whom we have a working relationship which is greatly appreciated.

Campomelic Dysplasia
Pitt Hopkins syndrome
Xq24 Del
Inverted dup Ch 15 15pter-15q13
Ch22q11.21 duplication
Ch2p,16.3 del
Joubert syndrome

Contact with others requested. Please contact AGSA.

AGSA'S RARE TREASURES

A Chromosomal Disorders Support Group

Represents 250 people who have a child with a rare chromosomal abnormality. AGSA works closely with Unique UK who provide AGSA with fact sheets and regular newsletters. Please contact AGSA if you are trying to find another family with the same or similar chromosomal abnormality or would like information on your child particular condition.

Sue Hawkins

PhD , BSc (Hons), Grad. Dip. Genetic Counselling; Grad. Dip. Psychology; Post Grad. Dip. Psychology; Grad, Dip, Systemic Therapy.

Biography

Sue is a registered psychologist who has a newly established private practice in the heart of Randwick Junction. She has specialised experience in the areas of couples counselling, infertility, adoption, genetic conditions, pregnancy issues and trauma. This unique combination of skills enables her to provide psychological support for individuals and couples who are face with having to cope with the issues that genetic conditions bring to their lives.

Sue's specialties developed through having a strong interest in both science and psychology. Prior to becoming a psychologist, Sue was a research scientist having completed her honours in molecular biology and gaining her doctorate in the area of cell biology and immunology . She then went on to do a post doctoral research project looking at factors involved in prostate cancer progression.

Following her interest in psychology, she then went on to completed a Graduate Diploma in genetic counselling and worked part time as a counsellor at Australian Birth Control Services. In this role she counselled women who were faced with having to make a difficult decision about an unplanned pregnancy. Sue then went to work for Association of Genetic Support Australasia (AGSA) while completing her psychological qualifications. At AGSA she was involved in running workshops to assist members of genetic support groups gain skills associated with their supportive roles and provided support for individuals affected by genetic conditions. Sue was also heavily involved in working with Dianne on the establishment of AGSA's "Filling the Void" project.

Following AGSA, she moved to Anglicare where she worked as a case worker for their special needs adoption service and in their regular adoption program. Sue is currently working part time as a fertility counsellor at one of Australia's leading fertility clinics. In this role she counsels individual and couples at all stages of their fertility treatment. This includes providing mandatory counselling if people are considering donor gametes and giving support during PGD cycles and after a pregnancy loss.

Sue also completed a post graduate course in couples therapy and underwent an internship with Relationships Australia. She has also trained in sensorimotor psychotherapy which works

with the somatic expressions of psychological trauma to help clients integrate their trauma experience so it becomes less overwhelming for them.

Contact details for Sue Hawkins

Phone: 0405637449
Address: Suite 105/2 Albert Street, Randwick, NSW 2031.
Email: shawkpsy@gmail.com
Website: www.suehawkins.org

CONFERENCES

In March 2011, the **Human Genome** Organisation (HUGO) will convene its 15th annual HGM meeting in Dubai, with a main focus on genomics and hereditable disorders. pco@hgm2011.org www.meetingmindsdubai.com

International Congress of Human Genetics / American Society of Human Genetics

October 11-15, 2011
Montreal, Quebec, Canada

AN INTERNATIONAL "PROJECT OF HOPE" SUMMARY

Earlier this month, 127 persons from all states of Australia and New Zealand were involved and gained much benefit from participating at the **5h Family Batten Disease Conference at Seaworld Resort, Gold Coast** of Queensland. On behalf of each of the Batten Disease affected families that were assisted to this unique event, we would like to thank those who helped them to get there.

Sixty people attended the two day conference component. The medicine and science addressed by our Guest Speakers was very encouraging for each family. The Scientists revealed to us their rigorous research and information efforts and was both touching and inspiring to see their dedication and ongoing support towards finding a cure of this dreadful disease. There was some hope in clinical trial treatments, which are in early stages. Field specialists in areas such as neurology, genetics, music therapy, nutrition, manual handling techniques and disability education services who in simple words educated families, carers and other attendees on daily care and support issues. Also knowledge was drawn from the experience of other families; this was invaluable to the complex care of these special children.

Whilst this conference was taking place, affected children, their siblings, carers including volunteer carers participated in the Kids Program which totalled 67 persons. This group enjoyed time at off-site activities such as Seaworld fun park and Movieworld, then on-site activities with entertainers such as craft & games activities and a drumming attraction. Volunteer carers travelled interstate to offer their time and support, ensuring a fun and safe environment for their allocated children.

Saturday night's social dinner brought plenty of fun to the event!! Our event social directors (you know who you are) provided entertainment above and beyond the auction, lucky dip prizes, 120 balloon bursting prize wins and a sensational BBQ dinner. Some kicked up their heals to the DJ and some may not have got alot of sleep over the weekend either.... many memories were made.

Although we missed our group photo this year, many valuable photos were taken throughout the weekend to record the memories. The Remembering Service was priceless as 3 amazing opera singers hit powerful heights and left us in awe.... children blew bubbles and played unknowingly amongst us as we beautifully remembered all our precious children passed.

Many positive comments from family members have been received following this event and these words describe their views:

"a learning experience, well organised, lots of information shared, making new friends, really fun, support felt, a hug helped so much, emotional but worthwhile"

This note is to thank all of you involved.... the venue, the carers, the speakers, our Committee and volunteers, family helpers, prize donors (and those who have kept the momentum going).....thus helping us to have this

opportunity to gather, learn and most of all to share the warmth and compassion that our special children bring out in everyone. With your involvement….. this project become a reality (even in very rainy conditions).

PROFILE

A–Z OF GENETIC CONDITIONS

This fact sheet is kindly provided by the Centre of Genetics Education, Sydney

ALPORT SYNDROME

Includes: Neuropathy and deafness, Collagen IV-related nephropathies

Alport syndrome represents a group of genetic conditions characterised by progressive deterioration of parts of the kidney known as basement membranes. This deterioration may lead to chronic kidney (renal) disease. Eventually, severe renal failure (end-stage renal disease or ESRD) may develop. Some types of Alport syndrome may also affect vision and hearing. Since Alport represents a number of related conditions, the pattern of genetic inheritance can differ from one family to another. Some families with Alport syndrome follow a pattern of X-linked inheritance while others may follow autosomal dominant or recessive inheritance.

The most common early symptoms of Alport syndrome are an abnormal urine colour due to serum proteins or red blood cells in the urine. These signs suggest a decline in the kidney's filtering function. Loss of hearing and/or loss of vision may also occur. Hearing and vision problems tend to affect males more often than females.

As the condition progresses, the affected individual's legs may swell. There may also be swelling around the eyes, chronic heart failure and end-stage renal disease, requiring regular dialysis.

Uraemia occurs when the kidneys fail to remove waste products

from the blood. Upset stomach, which may vary from loss of appetite to severe pain, can occur along with nausea, vomiting of food and blood, weakness, fatigue, excessive need for sleep, and dry, often itchy, skin. A urine-like smell on the breath, pale skin (pallor), shortness of breath, hypertension, and fluid retention may also occur.

Problems of the eye may occur in certain forms of Alport syndrome. The surface of the eye's lens may be cone-shaped (lenticonus) or spherical (spherophakia). The lens of the eye may be opaque or cloudy (cataracts). White dots may appear on the retina (retinal macular flecks). Children with Alport syndrome are often very nearsighted (myopic).

WHAT CAUSES ALPORT SYNDROME?

Most (about 85 percent) cases of Alport syndrome follow an X-linked pattern of inheritance. Almost all of those affected are male. Of the remaining cases, most have an autosomal recessive pattern of inheritance. In a small number of cases, the inheritance pattern is autosomal dominant.

Alport syndrome is caused by variations (mutations) of genes involved in the production of proteins known as collagens. The gene associated with the X linked form of the syndrome has been located on the X chromosome (Xq22). Other forms of Alport syndrome have been found to be caused mutations on the long arm of chromosome 2 (2q36-q37) and chromosome 11 (11q24).

For more information about genes, chromosomes and different forms of genetic inheritance please refer to Genetics Fact Sheets 1, 2, 4, 8, 9 and 10.

WHO IS AFFECTED BY ALPORT SYNDROME?

The prevalence rate for Alport syndrome has been reported to affect 1 in 50,000 newborns. There is no information regarding the incidence in Australia. The more common X-linked form of Alport syndrome affects mainly males.

HOW IS ALPORT SYNDROME DIAGNOSED AND TREATED?

Diagnosis

In suspected cases of Alport syndrome, electron microscopy of a sample of kidney tissue may be performed to evaluate the condition of the basement membrane. Progressive loss of kidney function accompanied by loss of hearing is a clue to diagnosis.

Treatment

The treatment of individuals with Alport syndrome will be directed towards the needs of each individual. It may be necessary for a team of specialists to work together and plan for the best strategy to enable each individual to reach their full potential. Specialists may include paediatricians; surgeons; physicians who diagnose and treat conditions of the kidneys; geneticists; specialists who assess and treat hearing problems (audiologists); eye specialists (ophthalmologists); and/or other health care professionals. Just like each individual will be different, the treatment plan will be unique and best discussed with the health professionals involved in the care plan.

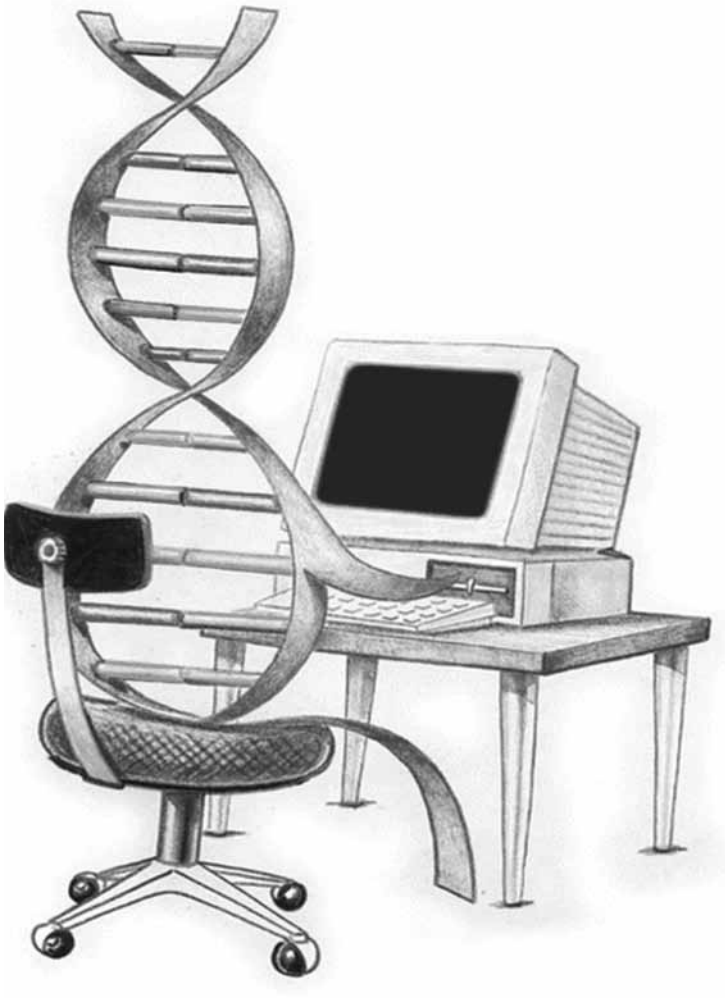
Hearing aids may be required for deafness as well as corrective surgery for vision problems. Renal function and certain components in the blood should be regularly monitored. Dialysis and/or transplantation may be initiated when end stage renal disease (ESRD) develops.

Genetic counselling will be of benefit for patients and their families. Other treatment is symptomatic and supportive.

Genetic Testing Options

Genetic testing may be available for this condition. It may be carried out on individuals, on an unborn baby (prenatal testing) or on an embryo (pre-implantation genetic diagnosis). For the most appropriate and accurate information, contact a genetic counselling service to find out if genetic testing is available for this condition and discuss your specific options and questions.

For further information on genetic counselling, prenatal testing and pre-implantation genetic diagnosis please refer to Genetics Fact Sheets 3, 17 and 18 on the Centre for Genetics Education website.



A PERSONAL STORY

PREVENTION OF ALPORT SYNDROME IN THE NEXT GENERATION

Pre-implantation Genetic Diagnosis IVF

By Dr Alison Blatt

I was 34 years old in 2007 when I discovered my brother had Alport Syndrome and I was a carrier. We were devastated to say the least. I had one daughter, Matilda, and was unaware of her status. But I knew I wanted more children so my husband and I consulted a geneticist at Sydney IVF and requested Pre-implantation Genetic Diagnosis (PGD). Sydney IVF PGD website

This technology had only been available in the last 10 years and only one other person with Alport Syndrome had gone through this process in NSW. I knew Sydney IVF was one of the few places in Australia with the expertise and experience in this technology. PGD would enable us to exclude Alport-affected embryos during the in-vitro fertilisation (IVF) process and potentially have an Alport-free baby.

Finding the Genetic Defect

First the genetic defect needed to be confirmed. My brother and I had our blood sent to the UK and it took many months to get a result. It eventually confirmed that the defect was on our X chromosome. This was supported by our family tree which strongly suggested X-linked inheritance in our family.

Designing the Probe for screening my embryos

Rather than design a test to find the tiny defect on the chromosome, the test was designed simply to identify my faulty X as it was passed on to embryos. Blood was collected from my husband, my brother and me. My X chromosomes were identified and matched with my brother so that it was clear which the normal X was and which had the faulty gene. (see figure 1) Then my husband's X chromosome was identified. A probe was designed to mark these three Xs. This took the scientists about 6 months to design and create.

Figure 1

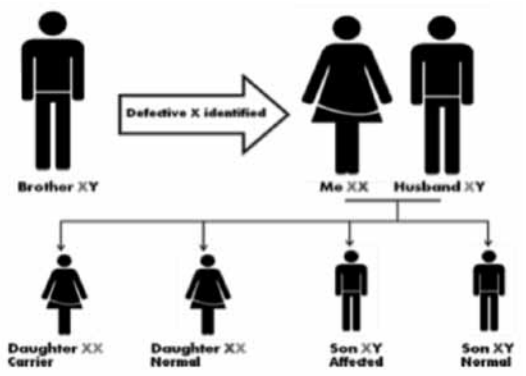


Figure 1: Designing a probe involved identifying the X chromosome containing the defective gene (in red) by matching my chromosomes with my brother's chromosomes. The embryos were each biopsied and their X chromosomes were labelled to identify Alport-affected embryos. My normal X chromosome is purple, my husband's normal X chromosome is green. There are four possible outcomes of combining our chromosomes which include (from left to right) one female carrier, one normal female, one affected male and one normal male.

The IVF-PGD Process

Once the probe had been designed my husband and I started the IVF process. I started a series of medications which manipulated my hormones and resulted in the ovaries going into overdrive. Where the ovaries would usually produce one egg per month, multiple eggs matured. I was bloated and uncomfortable and it made me feel tired and crabby (like PMS only worse!). Every second day or so I had to have my bloods taken to monitor my hormones, then as the eggs were "ripening" I was having 2nd to 3rd daily ultrasounds. When the eggs were ready I went into hospital for the "egg retrieval". This was a minor procedure done under local anaesthetic with the doctor using a long needle to collect eggs through the vaginal wall. The same day my husband had to provide a sperm sample which was used immediately to fertilise the eggs. After the procedure I had to have bedrest. We went home and waited.

Over a 5-6 day period the fertilised embryos were closely observed and I got a call every morning to give me an update on how many embryos were thriving. I had an excellent result with nine embryos eventually reaching the biopsy stage. The biopsy itself is a miracle of modern technology and involved microsurgery on the embryo. Have a look at the SIVF website to see footage of a biopsy. A single cell was taken from the outer shell of the embryo (at this stage called a "blastocyst") which is a non-essential part of the blastocyst. This cell was then tested for the genetic abnormality. I had five embryos which were Alport free. This was more than I'd dreamed of! The best embryo was chosen and the rest were frozen.

The embryo transfer required no analgesia (like having a pap smear) and used ultrasound guidance to deliver the embryo to the centre of the uterus. Then it was back to waiting… After two weeks a blood test was performed. I got a phone call with the results after lunch. I was not pregnant and even though I knew my chances were poor (I'd been given a 30% chance of success with each transfer) I had still lived in hope. After many tears we picked ourselves up and tried again. Every month, with the help of medication and blood tests, I underwent an embryo transfer until all five of my precious embryos were gone. Then we started again.

By this stage you can imagine I was doing everything I could to improve my chances. I hadn't drunk any alcohol for 6 months and was barely drinking any caffeine. I was avoiding any food additives and a long list of potential ingredients that were vaguely rumoured to decrease one's fertility. Despite

my medical background the hard scientific evidence was not necessary to scare me off even the mildest potential offenders. We had been living on a rollercoaster of emotions and it was hard to focus on outside commitments and goals. I was fortunate to have a busting two year old to keep a smile on my face and remind me of how lucky I was every day.

So, the next round of drugs and blood tests and ultrasounds started. Everything went smoothly but only two embryos made it to the end of the line. I went into the IVF hospital for my embryo transfer. For the next two weeks I did everything I could to forget about IVF and get on with things. So I ignored the tender breasts and slight constipation and told myself the bloated feeling was premenstrual tension. When my specialist called me with the good news I almost cried, "I know".

Dr Alison Blatt and her baby daughter.

Success

My second daughter was born in April 2010. She's an absolute delight and her big sister is the proudest three year old in town. It's a great relief to me to know that although the IVF process was difficult I'm extremely fortunate to have had PGD available to me. In choosing to have a family I didn't just "roll the dice" as many people do with genetic diseases when PGD is unavailable. I highly recommend the Sydney IVF website for more information.

You are invited to attend

AGSA'S ANNUAL GENERAL MEETING

Tuesday 23rd November 2010 at 66 Albion St, Surry Hills (Old Children's Court Building)

Time: 11am

AGENDA

1. Welcome and Introduction
2. Apologies
3. President's Report
4. Directors Report
5. Treasurer's Report and audited accounts
6. Election of Office Bearers for 2010/11
   a) All positions declared vacant and appointment of returning officer
   b) Election.
   The committee, including executive, comprises a maximum of 6 members.
7. Appointment of Public Officer
8. Appointment of Auditor
9. General business
10. Close of business

Light Refreshments will be served

If you wish to attend you must RSVP by 19th November for catering purposes

Dianne Petrie:

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Surry Hills NSW 2010 Australia

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email: dianne@agsa-geneticsupport.org.au

AGSA's SUPPORT GROUP & ORGANISATIONAL MEMBERS as at March 2010

Actelion Pharmaceuticals
ACT Muscular Dystrophy Association Inc
Ageing and Disability Department
Androgen Insensitivity Assoc. Support Group of Australia
Alagille Syndrome Support Group
Albino Support Group
Alport Foundation of Australia
Angelman Syndrome Assoc.
Alzheimer's Aust ACT
Immune Deficiencies of Australia)
Assoc. for Children with a Disability, Vic.
Assoc. for the Wellbeing of Children in Healthcare (AWCH)
AUSSIE FOLKS
Australian Addison's disease Assoc Inc.
Aust. Arthrogryposis Group (TAAG) Inc.
Aust Assoc for Families of Children with Disability
Australian Chapter of the BDSRA
Aust. CHARGE Association
Aust. Crohn's & Colitis Assoc.
Aust. Huntington's Disease Assoc. (NSW) Inc. Aust. Huntington's Disease Assoc (Qld) Inc.
Australian Kabuki Syndrome Assoc Inc
Australian Leukodystrophy Support Group Inc.
Aust. Speak Easy Assoc.
Australasian Tuberous Sclerosis Society Inc.
Aust. Leukodystrophy Support Group
Australian Thyroid Foundation Ltd
Autistic Spectrum Australia (ASPECT)
Foundation, Aust
Beckwith-Weidemann Syndrome Support Group
Bundaberg SEDU Norville Special School
CAH Support Group
Cardiomyopathy Assoc of Aust. Limited
Catholic Education Office
CdLS Association Inc.
Centacare Early Intervention.
Central Coast Genetic Counselling Service
Cancer Institute NSW – Hereditary Cancer Registry
Charcot Marie-Tooth Assoc. of Aust Inc.
Charcot Marie-Tooth Disease, USA
CHARGE Syndrome Assoc of Australasia
Chatswood Assessment Centre
Child Health & Safety Vic
Children Hospital at Westmead
Children's Medical Research Institute (CMRI)
CJD Support Group Network
CLIMB Children Living with Inherited Metabolic Diseases UK
Community Support Team
Connected, Connective Tissue Dysplasia Clinic
CONTACT A FAMILY U.K.
Coorinda Family Support Group
Cleft Pals, The Cleft Palate & Lip Society
Coeliac Society of NSW Inc.
Congenital Adrenal Hyperplasia Support Group
Cornelia de Lange Syndrome Support Group
Cri du Chat Syndrome Support Group of Australia
CVS Support Group (WA)
Cystic Fibrosis NSW
Cystic Fibrosis Assoc of Qld Ltd.
Cystic Fibrosis Assoc. Vic
Cystic Fibrosis Assoc of ACT
Cystic Fibrosis Foundation, North Ryde.
Darling Point Special School
DEBRA A NSW Inc.
Dept of Ageing Disability & Homecare, Albury, ACT
Dept of Clinical Genetics, Westmead, Liverpool Health Service
DIAL (Qld)
Disability Information Resource Centre (SA)
Donor Conception Support Group
Depressive & Manic Depressive Assoc.
Dystrophic Epidermolysis Bullosa Research Association (DEBRA) NSW Inc.
Early Education Clinic, North Sydney
Early Childhood Intervention Program, Coffs Harbour
Early Learning, Devonport,Tasmania
Eastern Suburbs Services for the Developmentally Delayed
Ehlers-Danlos Syndrome Support Group
Exceptional Parent (USA)
Fabry's Support Group Australia Inc.
Family Planning Assoc.
FAP Register (NSW Cancer Council)
Fragile X Assoc of Australia
FRANS
Friedreich Ataxia Assoc of NSW
Gaucher Assoc. of Australia
Genetic Support Network of Victoria Genetic Alliance USA.
Genzyme Australasia Limited
Genetic Interest Group (GIG)
Greater Southern Area Health Service
Haemochromatosis Information Service & Support Group QLD
Healthlink
Haemophilia Foundation NSW
Haemophilia Foundation, Qld
Hastings Early Intervention - Coffs Harbour
Health Consumer Council (WA) Inc
Hereditary Haemorrhagic Telangiectasia
Hereditary Fructose Intolerance
HSP Research Foundation
Hunter Orthopedic School
Huntington's Disease Assoc. (NSW)
Huntington's Disease Assoc. (QLD)
Huntington's Disease Assoc, Wellington
IDEAS Inc
Information Centre, RCH, Vic
Kidney Kids of NZ Support Group Inc.
Klinefelter Syndrome Support Group
Ku Children's Services
Kurrajong Early Intervention
Maternity Alliance
Leukodystrophy Foundation (USA)
Leighs Disease Support Group
Library/Disability Information and Resource Centre (DIRC)
Liverpool/Fairfield Disabled Persons
Lowe's Syndrome Assoc. Inc.(USA)
Lower North Shore Community Support Team
Lucas Gardens School
Lysosomal Storage Disorders
M.P.S. Society
Marfan Syndrome Support Assoc. NSW
Medical Library, RHW
Meniere's (NSW) Support Group
Metabolic Dietary Disorders Association (MDDA
Mid North Coast Area Health Service)
Motor Neurone Disease Assoc. of NSW Inc.
Multiple Epiphyseal Dysplasia Assoc.
Australian MPS Society
Muscular Dystrophy Assoc of NSW
Muscular Dystrophy Assoc (NZ) Inc.
National Council of Intellectual Disability
Neurofibromatosis Assoc of Aust Inc.
Noonan Syndrome Support Group
Northcott Society
North Coast Area Health Service
NZORD, Wellington
Osteopetrosis Support Group
Osteogenesis Imperfecta Society of Aust
OzED-Australian Ectodermal Dysplasia Support Group
Paroxysmal nocturnal haemoglobinuria (PNH) Support Assoc of Australia Inc.
Parents Bereavement Support Group
Parent to Parent (NZ)
Pen-Parents of Aust. (ACT)
Physical Disability council of NSW
PKU Assoc of NSW
Post Adoption Resource Centre
Pseudohypoparathyroidism Support Group
Port Macquarie Community Health Centre
Pseudoxanthoma Elasticum Support Group
Prader-Willi Syndrome Assoc
Pyruvate dehydrogenase deficiency.
Rare Chromosomes Disorders Support Group (Unique UK)
Society of NSW Inc.
Rett Syndrome Assoc. of Aust.
Retina Australia (NSW) Inc.
Royal Blind Society of NSW
SANDS (Qld)
Schizophrenia Fellowship NZ
Self Help Qld.
Short Statured People of Aust (NSW)
Short Statured People of Aust (Vic)
Short Statured People of Aust. (SA)
Spinal Muscular Atrophy
Smith Magenis Syndrome Support Group Inc.
Spastic Society of Victoria
Spina Bifida Assoc. of NSW
Spina Bifida Assoc. of WA Inc.
Society of Ectodermal Dysplasia
SOFT Australia
Southern Child Care Support Program
Sotos Syndrome Support Group
Stillbirth & Neonatal Death Support Qld Inc.
Tasmanian Clinical Genetics Service
Thalassaemia Society of NSW
The Centre for Genetics Education
The Coeliac Society of NSW Inc
The Chromosome 18 Registry & Research Society (Aust) Inc.
The Lupus Association of NSW
The Northcott Society – Coffs Harbour, Dubbo, Tamworth, Wagga
Thalassaemia Society of NSW
The Centre for Genetics Education
TS+
Turner Syndrome Assoc. of Aust. Ltd. (NSW)
Uncontrolled Epilepsy Support Assoc (Vic)
United Leukodystrophy Foundation (USA)
VCFS & 22q11 Foundation.
Wellington Huntington's disease Assoc. (Inc.) (NZ)
West Syndrome Support Group
Williams Syndrome Association of Aust. Inc.
WISH
Wolf-Hirschhorn 4p- Syndrome Support Group
Women with Disabilities Australia
Yeerongpilly SEDU

Members of the Australasian Genetic Alliance (AGA) *formed 2003 –*
Assoc of Genetic Support of Australasia
Genetic Support Council of WA
Genetic Support Network of Victoria
NZORD
SHOUT ACT

AGSA is on the Board of the
International Genetic Alliance (IGA)
World Alliance of Organisations (WAO)
NB: This list represents support groups and associations only. In addition to this list of members AGSA has established a Contact Register of over 850 genetic conditions representing families and individuals seeking contact.

AGSA has established a Chromosomal Disorders Support Group, Rare Treasures representing over 250 chromosomal abnormalities. A Rare Treasures Newsletter is produced twice a year. AGSA works in partnership with Unique on this project and we thank them for their support.

The Association of Genetic Support of Australasia (AGSA) Inc.

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New South Wales 2010
AUSTRALIA

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Fax: + 61 2 9211 8077

Office Hours:

Monday – Wednesday 9am – 5pm
Thursday – Friday 10am – 4pm

Medical and Professional Advisory Board

Subscription Year Ist July - 30th June

ANNUAL SUBSCRIPTION

Individual	$30.00 incl.GST
Group/Organisation	$48.00 incl.GST

AGSA aims to:-

- provide a contact point for families who are affected by genetic conditions so rare that they do not have their own support group.
- facilitate access to individual support groups for those families with a particular genetic disorder.
- provide a forum for the exchange of information between support groups regarding available community services.
- educate the medical and allied health professionals and the community about genetic disorders.
- consult with government bodies, both Federal and State, for appropriate funding for genetic services.
- **The views expressed in this Newsletter are not necessarily those of AGSA***