AGSA
THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA INC.
NEWSLETTER

OCTOBER/DECEMBER 2003 ISSUE 67/68 ISSN1033 – 8624 FUNDED BY THE NSW HEALTH DEPARTMENT

CONTENTS

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

EDITORIAL

NB. We apologise for the non existence of the October 2003 newsletter and for the delay in producing this newsletter through no fault of AGSA. The printers lost the original template and a new template had to be produced taking 2 months!! Thank you for your patience.

I have just returned from the American Human Genetics Society Conference held in Los Angeles. There were some very interesting speakers for over 4000 attendees. I met up with members of the International Genetic Alliance Steering Committee and formulated plans for a global voice on education and awareness of treatments in 2004. I also met up briefly with members of the Genetic Alliance. I have brought back many support group pamphlets and information sheets which I will distribute to families and support groups coordinators.

AGSA's AGM will be held on Saturday 13th December at 10.30 am at the AGSA office in Surry Hills. The guest speaker is Joanne Mulligan from Carers NSW "*Support and information for carers.*" I look forward to seeing you there.

I am delighted to announce AGSA was invited to and has made a written submission on a review of the Carer Allowance (Child) Lists of Recognised Disabilities. As you may be aware on 12 August 2003 some changes were made to The Lists of Recognised Disabilities effective lst July 2003. The changes were:

- The expansion of the criteria for Down syndrome and Fragile X syndrome to include children under 16 years of age;
- Expansion of the criteria for haemophilia to include both Factor Vlll and Factor lX deficiency (less than 10%): and
- The addition of three conditions to the lists:
  - Phenylketonuria
  - Cystic Fibrosis
- Epilepsy (uncontrolled while on medication).
- These changes have been quarantined for a two-year period and will therefore not be considered as part of the review.
- A national advertisement inviting public submissions appeared in the Media on 8 November 2003. Submission must be received by 5 December 2003 at either of the following addresses.

Post: Lists of Recognised Disabilities Review,
Carer Section
Box 7788
Canberra Mail Centre
ACT 2610.

Email: recognised.disabilities.review@facs.gov.au

I look forward to catching up with you at the AGM and I wish you all a very Merry Christmas and a Happy New Year and a safe holiday break.

Best wishes,
Dianne Petrie

"Making the right connections since 1988"

CONTACT CORNER

AGSA will publish requests for contacts 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 may 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 those 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.

HYPERPLEXIA, STARTLE SYNDROME OR KOK DISEASE
A 25 year old lady with this condition would like contact with others. Contact AGSA for details.

FAMILIAL MEDITERREAN FEVER
AGSA knows of two families who have a child with this condition seeking contact with others with the view of starting up a support group.

STEVENS JOHNSON SYNDROME
A mother of a 6 year old boy with this condition is seeking other families for contact.

CONFERENCES – OVERSEAS

World Congress Notice
INAUGURAL WORLD CONGRESS ON CHROMOSOME ABNORMALITIES
June 27 – 30 2004
Henry B Gonzales Convention Centre San Antonio Texas USA

Host organisations will include:
The Chromosome 18 Registry & Research Society
Support Organisation for Trisomy 18 & 13 (SOFT)
Disorders of Chromosome 16
IsoDicentric 15 Education, Advocacy and Support (IDEAS)

Attendance is open to all families affected by a chromosome disorders, interested individuals and medical professionals. Three streams of presentations will include family topics, maintaining genetic support groups, research and scientific presentations. Online registration and abstract submissions will open March 1, 2004.

For more information visit the website at www.chromosome18.org/worldcongress or email: office@chromosome18.org. The website will be updated regularly to include new information.

CONFERENCES – LOCAL

10TH NATIONAL MPS CONFERENCE
Albert Park Melbourne Victoria
Friday 16th April to Sunday 18th April 2004

Celebrate the spirit

Keynote Speakers: Prof. John Hopwood, Prof. David Sillence, Dr Jim McGill, Dr Martin Delatycki

Registration: National Office MPS Australia
PO Box 623
Hornsby NSW 1630

THE PXE (NSW) SUPPORT GROUP
will be holding a meeting on Friday,
13th February 2004 in the Boronia Room
at the Royal Blind Society, Enfield
from 10.30 till 12.30.

All those with pseudo xanthoma elasticum and their carers are welcome to come along. Contact Warren on (02) 4284 9357 or Dot (02) 6568 6684.

PROFILE A–Z OF GENETIC CONDITIONS

It is the intention of AGSA to profile, in each issue, a particular Support Group/Disorder, thus increasing awareness within our membership of the range of genetic conditions. Also it hopes that where overlaps occur in conditions, support Groups may liaise with each other and thus gain a broader understanding of facilities, aids, etc. that may be of value to your individual membership.

Please ensure that all support group information is recent and reliable. It is of paramount importance that you let us know your group is "Alive and Well" and happy to take referrals.

Profile kindly supplied by the Centre for Genetic Education.

HYPOPLASTIC LEFT HEART SYNDROME

Also known as

- Aortic and Mitral Atresia with Hypoplasic Left Heart syndrome
- HLHS

General Information About Hypoplastic Left Heart syndrome

Hypoplastic left heart syndrome is a term used to describe a group of closely related rare heart defects that are present at birth (congenital).

Normal, the heart has four chambers. The two upper chambers, known as atria, are separated from each other by a fibrous partition known as the atrial septum. The two lower chambers are known as ventricles and are separated from each other by the ventricular septum. Valves connect the atria (left and right) to their respective ventricles. The valves allow for blood to be pumped through the chambers. Blood travels from the right ventricle through the pulmonary artery to the lungs where it receives oxygen. The blood returns to the heart through pulmonary veins and enters the left ventricle. The left ventricle sends the now oxygen-filled blood into the main artery of the body (aorta). The aorta sends the blood throughout the body.

Hypoplastic left heart syndrome is characterised by the underdevelopment (hypoplasia) of the chambers on the left side of the heart (i.e., left atrium and ventricle). In addition, the mitral valve, which connects these chambers to each other, is usually abnormally narrow (stenosis) or closed (atresia) and the aortic valve, which connects the heart to the major vessels that lead from the lungs (ascending aorta), may also be narrow or closed. Infants with hypoplastic left heart syndrome also have an abnormally narrow ascending aorta.

More Information About Hypoplastic Left Heart syndrome

The symptoms of hypoplastic left heart syndrome are directly related to the underdevelopment of the left side of the heart and associated structures. In all cases, infants have impaired blood flow from the lungs, through the heart, and on to other parts of the body (systemic circulation).

Symptoms of impaired circulation may include difficulty breathing (dyspnea), a high-pitched noise while inhaling (rales), grayish-blue discolouration of the skin (cyanosis) during the first 48 hours of life and/or fluid build up in the heart, lung and various body tissues (congestive heart failure).

Infants with hypoplastic left heart syndrome may accumulate excessive acids in their blood and other body tissues (metabolic acidosis). Symptoms may include poor feeding habits, frequent vomiting, lethargy, and/or shock. When shock occurs, the symptoms may include abnormally high pulse (tachycardia) and respiration rate, respiratory distress, abnormally enlarged liver (hepatomegaly), cool moist skin, abnormally low blood pressure, and/or paleness. In most cases, if left untreated, life-threatening complications usually occur.

The progression and severity of hypoplastic left heart syndrome can depend upon a structure called the ductus arteriosus, which is present in all newborns. The ductus arteriosus is a passageway that allows blood to travel from the right ventricle to the aorta and then throughout the body, bypassing the left side of the heart and the lungs. However, the ductus arteriosus closes shortly after birth forcing blood to travel through the malformed left ventricle resulting in impaired blood flow throughout the body.

What Causes Hypoplastic Left Heart syndrome

The exact cause of most cases of hypoplastic left heart syndrome is not known. It occurs for no apparent reason (sporadically) in the majority of cases. Research suggests that the interaction of many genes and other environmental factors (multifactorial inheritance) may be responsible for hypoplastic left heart syndrome. Other research has suggested that there could be some families with an autosomal recessive genetic form of hypoplastic left heart syndrome. This is still being explored.

In most cases, the malformations associated with hypoplastic left heart syndrome occur as a result of a developmental failure during early fetal (embryonic) growth. The reason that this occurs is not fully understood.

Who is Affected by Hypoplastic Left Heart syndrome?

Hypoplastic left heart syndrome is a rare condition that affects males slightly more often than females. Hypoplastic left heart syndrome accounts for 7-9 percent of all congenital heart defects. The symptoms of this condition are present at birth (congenital).

Is There Any Treatment For Hypoplastic Left Heart syndrome?

Diagnosis

The diagnosis of hypoplastic left heart syndrome is made based upon a thorough clinical evaluation, identification of characteristic findings and a variety of specialised tests. Such tests used to confirm hypoplastic left heart syndrome in newborns include x-ray examination and a special ultrasound test to study the structure and function of the heart (echocardiography).

Treatment

Treatment of hypoplastic left heart syndrome is directed toward the maintenance of adequate oxygen levels in the blood. Medication may help to keep the ductus arteriosus open allowing blood flow to bypass the malformed left side of the heart.

Eventually, infants with hypoplastic left heart syndrome require surgical intervention. A neonatal cardiologist is best qualified to give parents an opinion as to the type of treatment which best suits their child.

Other medications may be prescribed to prevent and control congestive heart failure and/or protect against infection in some infants.

Genetic counselling may be of benefit for families with a child who has hypoplastic left heart syndrome. Other treatment is symptomatic and supportive.

HEARTKIDS Nsw Inc

What You Should Know About The High Incidence of Congenital Heart Defects

IN AUSTRALIA ALMOST ONE BABY IN 100 IS BORN WITH A HEART DEFECT.

Some defects are simple, producing few problems throughout life. Others are far more complicated needing surgery, sometimes in stages, to correct them and a few cannot be corrected at all. Sometimes the heart problem is acquired after birth, such as Cardiomyopathy. Some of these children live with a fairly major degree of disability. Exercise intolerance, poor immune systems, side effects of medications and procedures all have consequences for these children. Surgery can lengthen their lifespan and improve their quality of life but we are still a long way from corrective surgery for all. Unfortunately, children still die. Heartkids Nsw Inc is a non-profit voluntary organisation of parents, families and interested people concerned with the care of children born with or acquiring heart defects.

The Aims of Heartkids Nsw Inc

- To give both emotional and where possible practical support, to families dealing with the realities of having a baby or child born with a heart condition.
- To raise awareness in both the community and corporate sectors about heart defects in children, its high incidence and its continuing consequences.
- To give children with cardiac conditions the opportunity to meet, socialise and interact with others 'like them'.
- To encourage and support research programs aimed at the prevention, detection and management of congenital heart problems.
- To ensure the best possible care for children suffering from heart defects.
- To improve the quality of life for children and families living with heart defects.

Heartkids Nsw – supporting and caring for children with heart defects and their families.

Heartkids Nsw Inc is a registered charity and all donations are tax deductible.

If you would like to offer your time or expertise we would love to hear from you.

For more information contact:
Heartkids Nsw Inc
Message Line: 9294 0800
email: mail@heartkidsnsw.org.au
website: www.heartkidsnsw.org.au

FAMILY STORY

Issues of the Heart

Having a child with a genetically related health problem would be confronting and I would think at times filled with moments of sorrow, frustration and fraught with difficulties. Yet undoubtedly there are moments of great joy and much love, moments of triumph over the adversity and little successes.

Having a child with a congenital heart defect are all of those things and at times more. May I tell you why I say this?

Congenital heart defects are the highest occurring birth defect in Australia. They are the highest occurring birth defect in many western societies including the USA, Great Britain and Canada. Approximately 1 child born in every 100 will probably be born with some form of congenital heart defect.

Not all of these children will require medical intervention, heart procedures or even surgery. I believe the figures are close to:

• one third of these children will not require medical intervention on an ongoing basis.

• one third will require ongoing medical intervention, in the form of regular check ups and occasional tests i.e. echocardiographs; and

• one third will require intervention ranging from tests such as cardiac catheterisation to heart surgery and in some cases multiple heart surgery, to living with a pacemaker for the rest of their lives.

While congenital heart defects are the highest occurring birth defect in this country, the awareness level – along with the realities of having a child with a heart defect and its resulting impact on the child – is absurdly disproportionate. Most people know little, if anything, about congenital heart defects.

20% of babies and children with congenital heart defects have a genetic link. 80% of congenital heart defects are stated to be 'a random occurrence in the complex development of the human heart'. Syndromes such as Hypoplastic Left Heart syndrome, Velo Cardio Facial syndrome, Sprinzten syndrome, Down syndrome, Charge Association, Holt Oram syndrome and many more can sometimes have a congenital heart defect issue as part of their diagnosis.

However, the family where there is not an additional issue of a syndrome, have to be satisfied with 'it just happens'. While there is much more to be discovered about congenital heart defects and the specialists involved have not yet finished their discoveries of the complexities of the human heart, it at times can be extraordinarily frustrating to know that your child's heart defect 'just happened'.

While many are exploring issues of the heart and there has been heightened awareness due to campaigns such as those run by The Heart Foundation, children's heart issues are little known and little understood.

While this research and exploration is great and necessary into lifestyle issues affecting the heart, this is not going to assist children born with congenital heart defects greatly. Knowing how to reduce the risk of damage to the heart and arteries is great for me, as I approach my 40th birthday. For a child born with half a functioning heart, as in Hypoplastic Left or Right Heart, or with a hole in their heart i.e. VSD or ASD, or with a missing or blocked pulmonary valve as in Pulmonary Atresia, which is what my son has, lifestyle issues have little if nothing to do with all these defects and therefore research into these issues will have little effect in assisting these babies or children.

I have been told that if I choose to have another child that my risk of having a second child with congenital heart defects is increased by 3%. Not much you say and I agree. My risk is only 3% higher than that of the general population; however my risk of having a child with a heart defect in the first place was approximately 1 in 100.

It's very scary having a child with a congenital heart defect as I am sure that it is frightening having a child with any health concern. But the heart … if your heart stops life stops. It gets the blood and nutrients to all the body and funny enough it's the part we all visually associate with feelings and love. A broken heart is seen as a tragedy in the greatest romantic dramas of life and yet our children have broken hearts. Many parents too unfortunately face the realities of empty arms and broken hearts because children with congenital heart defects can die. During this past year we have said goodbye to some very dear, unique and much loved babies and children.

When we think of heart surgery, open or closed, we think of grandparents and, as we age, of our own parents. We do not think about the cute little 6 month old; or the playful mischievous toddler; or our 'oh my gosh off to school' little 5 year old. However the reality is that these children do have both closed and open heart surgery and in some cases, multiple surgeries by the time they are fully grown adults. A child with the

best known of all the heart defects, 'a hole in the heart', known as either a VSD or ASD, if requiring surgery for the closure of this hole WILL have open heart surgery to close it.

My son, (who is now aged 7) by age 2, had had one closed and two open heart surgeries. I have found much comfort, solace, and kinship with other 'Heart Families'. While burgeoning awareness along with the attempts of understanding in others has been encouraging. Finally the understanding and support through Heartkids Nsw has been immeasurable.

We hope this story touches your heart and moves your world

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AGSA
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Funded by the NSW Health Department
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You are invited to AGSA's

Annual General Meeting

on

Saturday December 13, 2003

at 66 Albion St, Cnr Commonwealth and Albion Streets
Surry Hills (Old Children's Court Building)
Time: 11.15 am for 11.30 am

AGENDA

1. Welcome and Introduction Scott Brightwell
2. Apologies
   12. 45 a.m. Guest Speaker: Joanne Mulligan, Carers NSW – *"Support and information for carers"*
3. Acting President's Report
4. Information Officer's Report
5. Treasurer's Report and audited accounts
6. Election of Office Bearers for 2003/4
   a) All positions declared vacant and appointment of returning officer
   b) Election.
   The committee, including executive, comprises a maximum of 10 members.
7. Appointment of Public Officer
8. Appointment of Auditor
9. General business
10. Close of meeting

A light lunch will be provided following the conclusion of the meeting.

RSVP 1st December 2003.
Please telephone AGSA if you will be attending.

THE PATENTING OF YOUR GENES – an exercise in money making

Laurie Taylor

Cystic Fibrosis, asthma, familial cancers, heart disease, Crohn's disease... these are some of the genetically influenced conditions which depend on non – coding (or junk) D.N.A. both for testing for the condition and to ultimately find a cure. The active, or coding, part of our DNA makes up only a very small part, the rest (about 95%) is non coding DNA.

In the past, testing for these conditions and research behind the search for a cure was done as a free service to the patient in our public hospitals. However, an Australian company, Genetic Technologies (G.T.G.) now owns patents which cover 95% of DNA. testing. This gives them the legal right to charge hospitals licensing fees for providing these services.

How did this happen?
In the late 1980's, a New Zealand immunologist, Dr Malcolm Simons, studied stretches of DNA in non coding DNA within one particular human gene. He found that patterns in junk DNA were ordered and concluded from this that they could be used to predict mutations in active coding genes. He then suggested this could apply to all genes. At the time, his conclusions were given no credence by other scientists.Simons then secured financial backing to the tune of $20million from Dr Mervyn Jacobson, Director and CEO of G.T.G. to assist with his application to the U.S. Patent Office to patent his discoveries. The patent with the widest scope was granted after eight years and allows providence over 98% of the genome, not just the human genome.

In order for a patent to be granted, it must satisfy three requirements.
- it must be novel at the time of application.
- It must not be obvious to other researchers.
- It must have clear utility.

Many Scientists, such as Graham Suthers (Clinical Geneticist, S.A.), have queried the validity of all three requirements having been met. Suthers asserts that non coding DNA has been around for analysing technology for around fifty years so was therefore not novel in the 1980's. As for clear utility, are these patents for the good of the community? In other words are they

for the benefit of all or the financial gain of some? There's certainly big money in gene patents. G.T.G. have tripled their share prices in four months and are currently looking to New York for more investors.

The issue of our patent laws not being in line with the vast leaps and bounds being made in the science of genetics has been raised. Particularly as the scope of these patents are so widespread and have a life of twenty to twenty five years.

Despite widespread concern however, according to patent lawyer, Gavin Recchia, there are no grounds to contest the patents given the vigorous examination they were initially subjected to by the U.S. Patent Office.

The question then becomes, where will this patenting leave us? In the mid 1990's, a private American laboratory, Myriad, won the race to identify and patent BRCA1 and BRCA2, the genes which can predispose people to ovarian, breast, prostate and a host of other familial cancers. Myriad now hold a monopoly over these tests in the U.S. and charge $U.S. 5000.00 per test. In order to conduct the test however, junk D.N.A. is needed. Myriad and G.T.G. struck a mutually beneficial deal – Myriad announcing G.T.G. as their sole agent in Australia and New Zealand and G.T.G. receiving $2million upfront from Myriad for the privilege of using junk D.N.A.

Prior to October 2002, women with a high risk of breast or ovarian cancer could visit a familial cancer service at our public hospitals and receive free genetic counselling, free testing and advice on options should they test positive to a BRCA1 or 2 gene fault.

As of October 2002, G.T.G. announced that hospitals providing this free service were in breach of G.T.G's license. The only place in Australia that women can now be tested is at a private laboratory in Melbourne at a cost.

G.T.G. appeared to offer a concession to public hospitals when they allowed free access to the BRCA test. However, at the same time, they demanded huge licensing fees for procedures using non coding DNA. Non coding DNA is essential to the BRCA test. Given that South Australia's Familial Cancer Service has a budget of $1million per annum and G.T.G. are requesting the same amount in license fees it is no great leap to see that a fee of that magnitude would render the service inoperable.

In defense of G.T.G., Mervyn Jacobson, points out that G.T.G. is bringing new technology into Australia from overseas, they are investing considerable funds into Australian research and offering research facilities cheap licensing fees for the life of their patents.

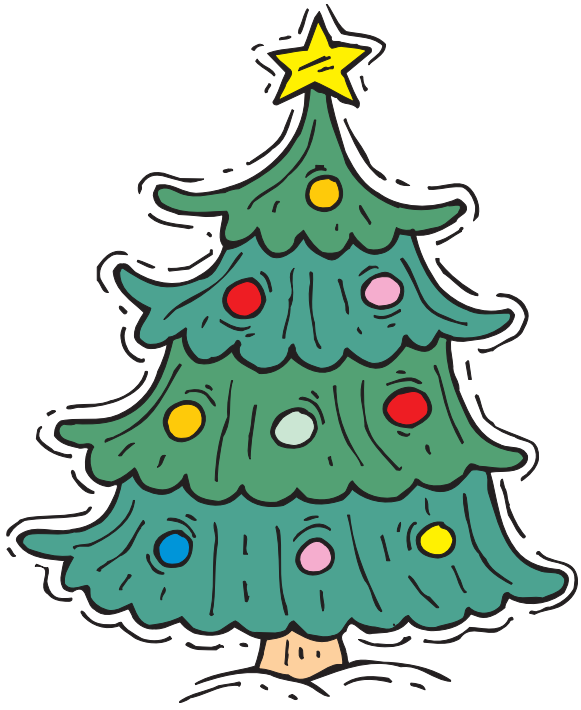
Indeed G.T.G. have offered research facilities a license fee of $ 1000.00 for the life of the patents. An offer which both Sydney and Utah Universities have paid. It's worth noting, however that in the past, publicly funded research was altruistic. Research, for the good of the community, was exempt for paying patent fees.

Once G.T.G. invoked their licensing rights and began pushing for payment it left many publicly funded research centres in peril.

Dr Jim Watson, macrobiologist and CEO of biotechnology company GENESIS in New Zealand, heads a department working on disease resistance in plants and treatments for asthma, psorrhasis and cancer.

He received a letter from G.T.G.stating that all their work falls within the scope of G.T.G.'s non coding D.N.A. patents. He was also informed that G.T.G. have extensive patenting insurance to cover litigation costs if challenged by geneticists. He is now left wondering whether to pay the lower price of the license or take his chances and pay the higher price to challenge G.T.G.'s claims. Indeed, G.T.G. are already taking court action against three major U.S. biotechnology companies to enforce patent licenses. G.T.G. maintain that biotechnology companies look at their patents and decide it would be prudent for them to take licenses.

Finally, Jacobson asserts that G.T.G. own technology. They have an invention using human intelligence to do something not done before and therefore have the right to profit from that invention. But was profit really the point of tracking our genome?



AGSA'S SUPPORT GROUP & ORGANISATIONAL MEMBERS as at January 2003

Act Muscular Dystrophy Association Inc.
Androgen Insensitivity Assoc. Support Group of Australia
Alagille syndrome Support Group
Albino Support Group
Angelman syndrome Assoc. Inc.
Alzheimer's Assoc of Aust Inc.
A.P.I.A. (Aust.Primary Immune Deficiencies Assoc.)
Assoc. for Children With a Disability, Vic.
Assoc. for the Welfare of Child Health (AWCH)
AUSSIE FOLKS
Australian Addison's Disease Assoc. Inc.
Aust. Arthrogryposis Group (TAAG) Inc.
Australian Assoc. for the Welfare of Child Health (AWCH)
Aust. CHARGE Association
Aust. Crohn's & Colitis Assoc.
Aust. Huntington's Disease Association (Qld) Inc.
Aust. Huntington's Disease Assoc. (NSW) Inc.
Aust. Speak East Assoc.
Australasian Tuberous Sclerosis Society Inc.
Aust. Leukodystrophy Support Group
Aust. Society for Ectodermal Dysplasia
Autistic Assoc. of NSW
Batten's Disease Support & Research Assoc. Inc. (Australian Chapter)
Beckwith-Weidemann syndrome Support Group
Bunyip Special Needs Group Inc.
Cardiomyopathy Assoc of Aust. Ltd.
Centacare Early Intervention.
Centre for Developmental Disability Studies
Charcot Marie-Tooth Assoc. of Australia Inc.
Charcot Marie-Tooth Disease, USA
Child & Family Health Centre
Child Health Information Centre
Community Resource Team (Albury)
CONTACT A FAMILY U.K.
Cleft Pals, The Cleft Palate & Lip Society
CLIMB Children Living with Inherited Metabolic Diseases
Coeliac Society of NSW Inc.
Congenital Adrenal Hyperplasia Support Group
Cornelia de Lange syndrome Support Group
Cri du Chat syndrome Support group of Australia Inc.
CVS Support Group (WA)
Cystic Fibrosis Assoc of Qld Ltd.
Cystic Fibrosis Assoc. of Vic
Cystic Fibrosis New South Wales
Early Education Clinic, North Sydney
Early childhood Intervention Program
DIAL (Qld)
Donor Conception Support Group
Depressive & Manic Depressive Assoc.
Dystrophic Epidermolysis Bullosa Research Association (DEBRA) NSW. Inc.
Early Learning Tasmania
Ehlers-Danlos syndrome Support Group
Exceptional Parent (USA)
Fabry's Support Group Inc.
Family Advocacy
Family Planning Assoc.
Fragile X Assoc of Australia
Friedreich Ataxia Assoc of NSW
Gaucher Assoc. of Australia
Genetic Alliance (USA)
Genzyme Australia Pty. Ltd.
Genetic Interest Group (GIG) (UK)
I.D.E.A.S. Inc
Kidney Kids Support Group NZ
Klinefelter syndrome Support Group
Kurrajong Early Intervention
Haemochromatosis Society Inc.
Haemophilia Foundation NSW
Hereditary Cancer Registers (NSW Cancer Council)
Hereditary Haemorrhagic Telangiectasia
Hereditary Fructose Intolerance
Hunter Orthopaedia School
IDEAS Inc.
Kidney Kids of NZ Support Group
Maternity Alliance
NALAG
Leukodystrophy Foundation (USA)
Leigh's Disease Support Group
Lowe's syndrome Assoc. Inc. (USA)
Lower Nth Shore Community Support Team
Lupus Association of NSW Inc.
Lysosomal Diseases Australia
M.P.S. Society
Marfan syndrome Support Assoc. NSW
Marfan syndrome Assoc. Australia (S.A.Branch))
Meniere's (NSW) Support Group
Mental Illness Nervous Disorders Association
Metabolic Dietary Disorders Association (MDDA)
Mid North Coast Area Health Taree Genetics Service
Motor Neurone Disease Assoc. of NSW Inc.
Multiple Epiphyseal Dysplasia Assoc.
Muscular Dystrophy Assoc of NSW
Muscular Dystrophy Assoc (NZ) Inc.
National Council of Intellectual Disability
NCOSS (NSW Council of Social Services)
Neurofibromatosis Assoc.
Noonan syndrome Support Group
NSW Genetics Education Program
NSW Cancer Council
Osteopetrosis Support Group
Osteogenesis Imperfecta of Aust.
Parents Bereavement Support Group
Parent to Parent (NZ)
Pen-Parents of Aust. (ACT)
PKU Assoc of NSW
Polycystic Kidney Disease Association
Psoriasis Society
Pseudohypoparathyroidism Support Group
Pseudoxanthoma Elasticum Support Group
Prader-Willi syndrome Assoc. of NSW (Aust) Inc.
Pyruvate dehydrogenase deficiency.
Rare Chromosomes Disorders Support Group
Retina Australia (NSW) Inc.
Rett syndrome Assoc. of Aust.
Royal Blind Society of NSW
SAFDA (Support After Foetal Diagnosis of Abnormality)
SANDS
Short Statured People of Northern Qld
Short Statured People of Aust (NSW)
Short Statured People of Aust (Vic)
Short Statured People of Aust. (SA)
Spinal Muscular Atrophy
Schizophrenia Fellowship NZ
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
Steele Street Early Special Education Centre Devonport
St Paul's Special School
The Chromosome 18 Registry & Research Society
The Northcott Society
The Toybox Centre Inc.
Thalassaemia Society of NSW
Turner syndrome Assoc of Aust. Ltd. (QLD)
Turner syndrome Assoc of Aust. Ltd. (SA)
Turner syndrome Assoc. of Aust. Ltd. (NSW)
Uncontrolled Epilepsy Support Assoc (Vic)
United Leukodystrophy Foundation (USA)
Velo-Cardio-Facial syndrome Foundation of Australia.
Wellington Huntington's Disease Assoc. (Inc.) (NZ)
Western Institute for Self Help (W.I.S.H)
West syndrome Support Group
Wolf-Hirschhorn 4p- syndrome Support Group
Williams syndrome Association of Aust. Inc.

(NB: This list represents support groups and associations members only. In addition to this list of members AGSA has established a Contact Register over 550 genetic conditions representing families and individuals seeking contact.)

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

66 Albion Street
SURRY HILLS
New South Wales 2010
AUSTRALIA

Email: agsa@ozemail.com.au
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Tel: **+ 61 2 9211 1462**
Fax: **+ 61 2 9211 8077**

Peer Support/Information Officer:
Dianne Petrie

Office Hours: 10.00 am – 4.00 pm
Monday – Friday

Medical and Professional Advisory Board
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Prof. D. Sillence
MB BS; MD (Melb; FRACP; FRCPA, FAFPHM
Prof. G Morgan
MB BS; FRACP
Dr B Wilcken
MB;ChB;FRACP
Prof. R.Trent
PhD; BSC (Med); MB BS (Syd; BPhil (Oxon), FRACP; FRCPA.

Subscription Year lst July – 30th June

ANNUAL SUBSCRIPTION

Individual:	$22.00
Group/Organisation:	$44.00

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*

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