AGSA
THE ASSOCIATION OF GENETIC SUPPORT OR AUSTRALASIA INC.
NEWSLETTER

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CONTENTS

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

EDITORIAL

It is with great pleasure I would like to announce AGSA has been successful in our funding application for a Statewide Carers Grant under the NSW Carers Program. The NSW Carers Program is an important Government initiative that increases the support available for carers of people who are frail, aged or have a disability or chronic condition. AGSA's 'Filling the Void Project' was one of only ten grants funded out of 52 applications. Triennial Funding for AGSA's 'Filling the Void' project will change the face of AGSA and is a significant and timely event in AGSA's evolution. In monetary terms, these funds will enable AGSA to achieve some of its long term goals.

The main activities of AGSA's 'Filling the Void' project for 2005 are:
- Establishment a carer contact register and online confidential database
- Specialised Carer counselling services including face to face and telephone group counselling
- Statewide information seminar and workshop series for carers of people with rare genetic conditions.
- A young carer initiative - telegroup counselling services and annual young carer seminars.

AGSA is hoping that through its 'Filling the Void' project, the potential exists to further enhance this connection through collaborations with outreach clinics, local genetic counsellors, clinicians, community organizations and support groups.

AGSA will continue to be at the forefront of providing peer support and lobbying as well as a vital contact point for families affected by rare genetic conditions.

We envisage launching our project early in the New Year and we will contact you with invitation details nearer the time.

As a member of the International Genetic Alliance Steering Committee I was invited by The Netherlands Minister of Health to attend a conference in The Hague on 'Priority Medicines for Children and the World'. Prior to this meeting, Genetic Alliances from all over the world met with others and attended a two day conference organized by the Dutch Genetic Alliance (VSOP), European Genetic Alliances' Network (EGAN),

European Platform for Patients' Organizations Science and Industry (EPPOSI), and World Alliance of Organizations for prevention and treatment of genetic and congenital conditions. I was invited to present on AGSA and comment on priority medicines in Australia.

The aim was to put paediatric medicine and research on the European and world agenda for years to come. Presently, for many reasons, there is no research into the affects of medicines on children.

I would also like to announce at our AGM last month, Michael Cori agreed to become AGSA's President. In the short time he has been involved with AGSA he has been instrumental in raising funds for the AGSA newsletter and to raising awareness of AGSA's work.

I am looking forward to working with Michael and the new committee.

I look forward to talking with you all in the New Year and I would like to wish you a happy, healthy and safe Christmas and New Year.
Until 2005

Best wishes
Dianne Petrie

And the AGSA team.

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.

WE HAVE MANY FAMILIES WHO WOULD LIKE CONTACT WITH OTHERS WHO ARE AFFECTED BY THE FOLLOWING CONDITIONS :

- Klippel-Trenaunay-Weber Syndrome
- Trisomy 16 partial and Monosomy 8
- Maffucci syndrome
- Kabuki syndrome
- Cerebella Hypoplasia
- Pallister Killian syndrome
- Pheochromocytoma
- Very Long chain Acyl-CoA Dehydrogenase deficiency
- Nail Patella Syndrome

Please contact AGSA for details so we can link people up with each other.

PRESIDENT'S REPORT

My name is Michael Cori. I am a Director of Citigroup Global Markets and have worked in the financial markets for the past 15 years both locally and overseas. I am married to Javiera and have a little girl named Emilia. I was first introduced to AGSA following the birth of our daughter in June last year with Noonan Syndrome, a rare genetic disorder. As first time parents, having a child with special needs is incredibly daunting and AGSA provided the starting point and necessary contacts to learn more about our daughters condition and support networks. In a world where there remain countless unnamed genetic disorders, education and awareness are paramount in understanding the causes and effects, both directly and indirectly, on society and those affected and AGSA serves this purpose on many levels. AGSA has established itself internationally and has links into many other genetic associations around the world - a great achievement and aknowledgement of AGSA's standing in this field. This combined with it's increasing local presence has resulted in greater Government recognition and as a result funding which in turn will lead to greater resources and support for all concerned.

About TACKERS and the camp.

Tackers (Transplant Adventure Camps for Kids). 2 films for use with talks on organ donation - "To Give is to Love" and "A New Journey".

more information on the Internet at http://www.tackers.org/pages/about_en.htm - the rest of our website is being updated very soon!

Our 4th international camp in 2005 will run from the 15th-23rd January.
It is open to any child from 8 - 15 years old who has received a transplant.
This year we are limiting ourselves to 2 children per country to begin with, hoping to have as many different countries as possible represented, so we can maximise the global reach of the camp. We hope to have a total of 50 children at the camp. In previous years, the camp itself has been free, with participants paying for their transportation to the camp. This year we have chosen to ask for a contribution of Euro 200 per camp participant. We came to this decision for two reasons.

We hope that children will be able to raise this amount - with help and support from parents and transplant co-ordinators, by using ingenuity, the local press, business groups like Rotary, friends and family - and that this process will begin the awareness raising process which will continue up to and beyond the time of the camp. By raising a contribution, the children will have helped make the camp happen - they become shareholders! And naturally this helps contribute to the substantial cost of the camp and therefore make it accessible to more children than would otherwise be possible.
The camp experience is great for the children:
"They have all lived through the same experience with the transplant and to see them all in such good health being able to come to events like this is incredible. This helps them to advance and go even further in life" Fabienne Guillerman - Mother of transplanted child and donor. The camp and its participants send out a very positive message about organ donation. To gain the maximum benefit from the camp, in terms of publicity and awareness, we will work closely with representatives from participating countries to generate as much press interest as possible.
This will also help participants find the necessary funds to get to the camp.

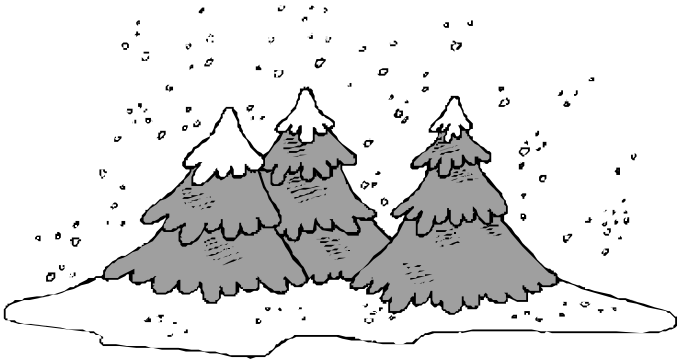
What we are looking for?
- A co-ordinator in that country who can help with organising:
- Selecting suitable children
- Co-ordinating with local press
- Helping children raise the contribution
- Organising transport for children, supplying medical information etc.

You may be able to fulfil the above role yourself, or be able to work with colleagues, or know someone who would be ideal for this role.

You may not have a paediatric department in your hospital. In this case, could you please send us the details of the person responsible for paediatrics in your country so we can write to them?
- 2 transplanted children from each country
You may have an idea of children would most benefit from this experience, and indeed deserve to come: these maybe children who need to 'break away' from 'overprotective' parents who need to develop self-confidence and could do this by meeting children with similar experiences to them; or a child who can confidently speak about transplantation, who could really value this experience and would make a good 'ambassador' for transplant awareness.

Further information and references
If you would like to hear more about our camp from a transplant professional **contact Gillian Wilson**, Paediatric Transplant Coordinator at King's College, London. mailto:Gillian.Wilson@kingsch.nhs.uk. Miss Wilson has attended the camp with several times as has Mr Nigel Heaton, Consultant Liver Surgeon at King's College London. You can also visit our website at http://www.tackers.org.

If you would like any more details, please contact Liz Schick on mailto:info@tackers.org
or call + 41 79 239 90 47.
Tackers is a non- profit organisation to give transplanted children the chance to spread their wings & gain self confidence. We are a project of the Swiss foundation FSOD (Foundation to Support Organ Donation).



PROFILE A - Z 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.

Primary Immunodeficiency Diseases (PID)

PID disorders are much more common than you think. Some people get more infections than they deserve. PID's are congenital diseases that affect immune system function.

Approximately 120 different PID disorders have now been described. Most of these cause recurrent or unusual infections and a range of other medical complications in affected persons. Most are rare but collectively they represent a very important and diverse group of diseases, requiring specialised care and treatment.
PID's are primary diseases in that the defect is present at birth. Nevertheless, symptoms and signs of illness may not develop until adult life, commonly presenting with recurrent bacterial infections in the chest and nasal airways. Diagnosis will then often depend on a high level of suspicion by the patient or their medical carers. The specific mutation is known in only some cases.

Genetic counselling for patients with PID is important. Genetic counsellors can provide patients with information as to risk involved when planning a family. They can also advise of support groups and provide the family with methods to assist the patient to live a normal life. Standard practice would include a recommendation for screening of first degree relatives.

Treatment depends on the specific disease and the severity of symptoms. The most common treatment for PID is immunoglobulin replacement therapy. This treatment involves patients receiving antibodies from donated blood. It restores the patient's immunoglobulin levels, decreasing risk of opportunistic infection. Research has demonstrated the safety and efficacy of replacement therapy with intravenous immunoglobulin (antibodies). In some cases, no treatment is required. On the other hand, early intervention with bone marrow transplantation is required for survival in the most severe of PID. Latest research into PID treatment involves gene therapy. At the forefront of this research is X-linked Severe Combined Immunodeficiency (SCID). A patient with this disease was the first successful recipient of gene therapy. However, gene therapy is only possible when a specific genetic mutation has been identified. Gene localisation is difficult due to the variation in presentation and diagnosis and the rarity of the individual diseases. The PID register has been established to facilitate diagnosis, treatment and research in this field.

The Primary Immunodeficiency Disease Register www.immunodeficiency.org

The Australasian Society of Clinical Immunology and Allergy has established a Register of Primary Immunodeficiency Diseases (PID) with the objective:

'To collect and analyse data on all patients with PID in Australia and New Zealand to facilitate diagnosis, treatment, research, education and quality assurance for patients with PID and their health care providers, and to guide the use of immunoglobulin replacement resources'

Data is held under code subject to patient consent and anonymity is carefully protected. The project has comprehensive Ethics Committee approval. In 1994, an Australian register of patients was first established by means of a questionnaire issued to Clinical Immunologists across the country.

The results were published and have been of great assistance in defining the extent of disease, and in the planning of medical services.

How do I access the Register?

Anyone can access the public page of the Register at www.immunodeficiency.org.au. This website contains a link to an 'Immunodeficiency Resource' which can provide patients and heath care workers with information into PID. Physicians or other health care workers who are responsible for patients with PID may apply for "Approved Access" to the Register for the purpose of data entry and review of summary reports.

Any Physician who is aware of an unregistered patient living with a PID in Australia or New Zealand (or suspects that they might not be registered) is strongly encouraged to apply for access. Ongoing surveillance is vital to the success of this project.

Contact us

For more information about the Register or the ASCIA PID committee contact Philippa Kirkpatrick, research co-ordinator on ascia.pid@email.cs.nsw.gov.au

Support Groups

Australian Primary Immunodeficiency Association

Secretary Bruce Lamant 02 6882 0377
President Michael Daniel 02 9639 8071

Austalian Primary Immunodeficiency Network

Ruth Taylor 03 9887 4136

New Zealand has a wonderful patient support group. Their website is www.pidsnz.co.nz. On their website is a link to PIDS-Australasia which is a mailing list for those people in Australasia (Australia, New Zealand, Pacific Islands etc) who have a primary immune deficiency or care for someone with a primary immune deficiency. There are also factsheets and links to resources on PID.

Useful Websites

www.immunodeficiency.org
www.pia.org.uk
www.pidnz.co.nz
www.primaryimmune.org
www.uta.fi/imt/bioinfo/idr
www.jmfworld.com

JOHN'S STORY

The following story was written by John Ashcroft in July 2001. John was affected by a rare immune deficiency problem. John passed away in early August 2004 just before his 50th birthday. People who knew John were amazed at his attitude to his medical problems. He was always positive and enjoyed life and an inspiration to all.

JOHN ASHCROFT
LIVING MY LIFE WITH 'XLP'
X-LINKED
LYMPHOPROLIFERATIVE DISEASE

XLP is a genetically determined immuno-deficiency state, which is, characterised by a selective vulnerability to a specific virus, in this case the Epstein Barr virus. EBV is more commonly known as the virus that causes glandular fever. In 1975 the work of Dr David Purtillo et al showed that an inherited gene defect had rendered a group of males more vulnerable to the Epstein Barr Virus. This condition was originally called Duncan's disease after it was found that some 11 males of the Duncan kindred were affected. In patients with an intact immune system, primary infection with EBV is of little consequence. The viral infection is generally brought under control by the natural immune response. In patients with XLP the immune response has been switched off, making XLP highly lethal. The manifestations of this include fatal infectious mononucleosis, malignant lymphoma (cancers), hypogammaglobulinemia (low levels or inability to make antibodies to fight infections) and/or aplastic anaemia'.

In 1978, The XLP register was established by Dr Purtillo to provide a central facility to orchestrate research and collect data on like affected patients.

After many years of uncertainty about my fluctuating health I was officially diagnosed as suffering from XLP in 1989 and entered into the above-mentioned register. Dr. David T. Purtilo, recognised as the discoverer of this condition, visited Australia in 1989 and I was lucky enough to attend one of his lectures and spend an afternoon 'walking and talking' with him.
At that stage there were only about 300 boys in 80 kindred families diagnosed as suffering from XLP. Average life expectancy was not high with about 75% dying by the age of 10 and no one reaching the age of 40. As you can imagine, finally having confirmation of my condition at the age of 35 was a great emotional shock. It was comforting to talk personally to Dr. Purtilo about XLP and hear his thoughts on my possible future and those of other XLP patients.

I am the middle son in a family of three boys and one girl. My older brother Paul passed away from Lymphosarcoma at the age of three. Until I was 10, my younger brother and I, had only suffered from the usual childhood illnesses of colds, measles and chickenpox. In 1965 at the age of 10, I was suspected of having appendicitis and admitted to hospital. Instead of appendicitis I was diagnosed as having Reticular cell sarcoma of the bowel.

I was admitted to the old Camperdown Children's Hospital and placed under the care of some wonderful doctors. I underwent surgery to perform a Hemicolectomy (partial removal of the bowel). To ensure that this cancer did not regrow, I then had extensive radiotherapy and treatment with a drug called cyclophosphamide. This treatment continued until 1973.
Unfortunately, when I was 11, my younger brother, Peter, was admitted to hospital with a diagnosis of reticular cell sarcoma and although he fought well, he passed away, devastating my family and I.

My high school years were spent with sinus infections, regular colds often developing into bronchitis. My parents, both qualified youth workers, helped me live the life of a normal child, although I was constantly being checked by various doctors.

In 1973 at the age of 19, I was admitted to hospital with what was thought to be infectious mononucleosis. I was gravely unwell, and spent 5 weeks in hospital and six more recovering at home. In 1974, at the age of 21, I was back in hospital suffering from meningitis due to haemophilus influenza. My recovery period was very slow which resulted in me being subjected to a vast array of tests. The result of all this testing showed that I had low IgGAM levels (antibodies circulating in the blood).

I avoided the hospital system (as you are want to do at that age) until I was 24 when my GP got tired of my constant visits with sinus and bronchial complaints. Further blood tests at this time showed that my IgGAM levels had dropped even further.

In 1978 I was diagnosed with hypogamma-globulinaemia. As I was at great risk of developing serious infections, I was referred to the Royal Prince Alfred Hospital where I was commenced on a gammaglobulin replacement program. I attended the hospital once a month where I received two huge 'horse needles' as I used to call them. A measured amount of gammaglobulin was injected into each cheek of the buttocks. Intramuscular injections were not a very dignified way to be treated, but it had a positive effect, if you discount the two days it took to be able to walk comfortably again after each visit. The move to intravenous treatment was very welcome.

My hospital immunology support staff, along with my wife and family, were my towers of strength. Although the cloud of XLP was there, they kept me well and free of major problems. 1989 with the confirmation of XLP was and has been the only time I briefly felt sorry for myself. I quickly decided to make the specialists rewrite their notes on XLP by making it to 40. I was saddened to hear of Dr. Purtilo's passing in September 1992 as I had hoped to ring him on my 40th Birthday.

On the 7th of September 1994, I turned 40, the oldest survivor of XLP and the first to reach 40. If nothing else, it gives hope to those families with young boys diagnosed with XLP.

Bone marrow transplant had been talked about as an option for solving my XLP problem, and my sister had been tested and discovered to be a compatible donor.

However, bone marrow transplants have only been successful with boys under the age of 15, with all boys over this age passing away through complications. It was decided not to pursue this avenue, due to my age and my relative good health.

The advances in treatment for hypogammaglobulinemia have been very kind to me. I still attend the hospital once a month to receive Intravenous immunoglobulin therapy (IVIG). Apart from this being time consuming, it rarely interferes with my current lifestyle and even though I realise that I require this for the rest of my life, I hope with further research the treatment for XLP may be simpler. I am very thankful to all those wonderful citizens that take the time to donate blood of which IVIG is derived.

Taking part in the CPIVIG (the currently used product called Intragam P) research project gave me the opportunity to give back in some way to those who had helped keep me well.

With the exception of ongoing sinus problems and one episode of pneumonia in 1999, I have remained and will continue to remain well. I receive 30grams of immunoglobulin (Intragam P) every 4 weeks in hospital where the immunology staff have been wonderful in making this as stress free interruption to my life as it could possibly be.

The discovery of the gene and the mutation, which leaves boys susceptible to XLP, paves the way for identifying babies at risk so they can be protected from EBV (Epstein-Barr virus), the virus that triggers XLP. It is also possible that by cloning the gene, a cure may eventually be discovered.

I consider myself very lucky. The doctors call me unique. I feel sad that I never got to grow with my brothers and that they were taken at such an early age.

My current goal is to reach 50 years of age in 2004 and then to hold my grandchildren. But to my daughters Jessica and Melanie, who are 9 and 11, please don't hurry, grandchildren can wait.

IDEAS EXPO 2004

'On Common Ground'

The Expo was held at Dubbo from the 18th - 20th September. There were 80 exhibitors providing information on disability related products and services.

AGSA had a stall and fielded many inquiries from service providers and the general public. Sue Hawkins and Astrid King also conducted a workshop on 'The emotional impact of diagnosis and beyond'. People attending the Expo would have come away with a changed view of what people with disabilities can do. Wheelies with Wings is a Cooma based organization that provides accessible aircraft to teach people with disabilities to fly.

Andrew Meddings uses a wheel chair to get around except when he is driving heavy vehicles! His motto is “Life is too short to harp on what might have been, get on with what still can be”. Andrew teaches people with disabilities to drive heavy vehicles. 'Once behind the wheel, any disability disappears and productivity is equal to any driver'.

Ame Barnbrook and her father, Barny gave a wonderful performance during the Expo dinner. Ame plays the trumpet at grade 7 level which is remarkable given she only has one limb with three toes on it. Ame is also a world champion sailor.

Ame Barnbrook playing the trumpet at Ideas Expo Dinner
Ame has a condition called phocoamelia.

Ame and her family run the Clark Bay Cottages near Narooma on the south coast of NSW. The facility allows access for people with disabilities to all areas. The kitchens have height adjustable bench tops bringing all the appliances to within easy reach of anyone.

The IDEAS EXPO clearly demonstrated that with some modifications, people with disabilities can do things previously thought impossible.

MELBOURNE researchers are developing a world-first microchip that will be used to screen embryos for all genetic disorders.

The chip will allow embryos to be tested simultaneously for all known genetic defects responsible for conditions such as cystic fibrosis, breast cancer, beta thalassemia and Huntington's disease.
The technology could also be used to screen for diseases in fetal cells collected from pregnant women through established pre-natal practices such as amniocentesis.

The chip will store genetic data which will be compared with gene sequences in the embryo cell sample to identify any defects.

AGSA's

CORNELIA DE LANGE WORKSHOP FOR REGIONAL LEADERS

BR: Rose Humphrey (Qld), Steve Sandilands (WA), Mandy Brookland (NZ), Jenny Rollo (NSW), Peter Crawford(ACT)
FR: Jaci Wiley (Vic), Liz Molloy (NZ), Phyl Crawford (ACT), Sharyn Burston (Tas).

AGSA held a very successful one day workshop for regional leaders of the Cornelia de Lange support group. Support group leaders travelled from all over Australia and New Zealand to learn about the stages of grief, burn out, counselling skills, how to say set boundaries etc.

If you would like your group to hold a one day leadership skills workshop please contact AGSA on 02 9211 1462.

Dianne Petrie, Sue Hawkins, Phyl Crawford

The Australasian Genetic Alliance

AGA is a newly formed network of peak organisations that represent genetic support groups, individuals and their families in the Australasian region who are affected by a genetic condition or a genetic predisposition.
http://www.australasiangeneticalliance.org.au/html/about_us.html

Members Secretariat
Genetic Support Council WA (GSCWA)
The GSCWA is a not for profit organisation that acts as a peak body for genetic support groups in Western Australia
Level 1, Oasis Lotteries House, 37 Hampden Road, Nedlands WA 6009
Tel: +61 8 9389 6722Fax: +61 8 9389 9377
Email: info@geneticsupoprtcouncil.org.au or info@australasiangeneticalliance.org.au
Http://geneticsupportcouncil.org.au

The Association of Genetic Support of Australasia (AGSA) Inc.
In l988 AGSA pioneered the non-clinical approach to help ease the burden for people affected by a genetic condition. Its client database is the largest in Australia and has over 550 genetic conditions represented.
66 Albion Street, Surry Hills NSW 2010
Tel +61 2 0211 1462
Fax +61 29211 8077
Email: agsa@ozemail.com.au
www.agsa-geneticsupport.org.au

Genetic Support Network of Victoria (GSNV)
The GSNV is an information, education, support and advocacy network that empowers people to overcome the challenges presented to them by genetic conditions.
10th Floor, Royal Children's Hospital
Flemington Road, Parkville Vic 3052
Tel: +61 3 8341 6315
Fax: +61 3 8341 6390
Email: info@gsnv.org.au
www.gsnv.org.au

New Zealand Organisation for Are Disordrs (NZORD)
NZORD works to improve information, support, diagnosis, treatment and cure of rare and genetic diseases.
PO Box 38-538 Petone 6008 New Zealand
Tel: +64 4 566 7707
Fax: +64 4 566 7717
Email: exec.director@nzord.org.nz
www.nzord.org.nz

Self-Help Organisations United Together (SHOUT)
SHOUT is an umbrella organization established in 1982 to provide resources and assistance to self help member organizations within the ACT.
P O Box 717 Mawson ACT 2607
Tel: +61 2 6290 1984
Fax: +61 2 6286 4475
Email: shout@cybermac.com.au
www.shout.org.au

Self Help Queensland Inc
SHQ is a network of self help and support groups across a broad range of health issues. It is a not for profit community organization which was started in l983 and received funding from Queensland Health in 1996.
PO Box 353 Sunny Bank Qld 4109
Tel/Fax: +61 7 3344 6919
Email: qnosho@gil.com.au

AGA News The Australasian Genetic Alliance launched a National Genetic Support Awareness Day within the Genetics and Population Health Conference. AGA kindly acknowledges the support of Prof. Alan Bittles for the opportunity to raise the importance of genetic support groups with key speakers: Terry Keating, Eilis Hughes and Prof Jai Rup Singh (sponsored by a kind donation given to AGSA) who spoke on the role of genetic support groups. (see abstracts below)

The Genetics and Population Health Conference 8th-10th August 2004 Fremantle, Western Australia organized by Prof Alan Bittles and Dr Wendy Erber. The conference attracted papers from over 23 countries. The key aim of the conference was to bring together like minded people and encourage collaboration on a regional and global level to improve genetic services and health outcomes of people across the world

To look at the abstracts:
http://www.geneticsandpopulationhealth.com/abstracts/index.html

Below are some abstracts for your information.

Genomics and the role of Genetic Support Groups: an international perspective *Singh JR. Centre for Genetic Disorders, Guru Nanak Dev University, Amritsar, India
The rights and dignity of individuals with disabilities attributable to genetics are recognised and honoured mostly in the developed world. Genetic Support Groups (GSGs) in these countries sensitised their public and Governments about the special needs of such individuals, which led to the enactment of specific regulations.

They also played a proactive role in promoting genomics research in specific diseases, either by prompting their Governments or by raising resources themselves. However, in the majority of developing countries the struggle is still going on to ensure basic dignity for affected individuals.

Prevailing prejudices in these countries ensure that a severely afflicted individual is confined within the house, or is simply allowed to die at birth, or is abandoned in a desolate place for nature to take its course. When female infanticide and feticide have been so difficult to eradicate, because of their social acceptance in developing countries, protection of the rights of genetically-ill individuals is an uphill task for GSGs. International Alliances of GSGs which played a prominent role in deciphering the riddle of genetic diseases have a crucial responsibility here. Genetics and genetically-ill individuals both can gain significantly if such Alliances from the developed world join hands with scientists from developing countries where the genetic load is maximal.

The importance of Genetic Support Groups and the challenge of providing care in adulthood for those with genetic conditions - Keating T.Genetic Support Council WA, Perth, Australia

The role of Genetic Support Groups (GSGs) is largely unknown or little understood outside those individuals with genetic conditions or predispositions, their families, friends, and others who work within the sector. Nevertheless, GSGs make an enormous contribution to these individuals and their families.

Increasing community awareness of this work is a significant challenge and efforts to raise awareness as to the role of GSGs are ongoing. Identifying and providing commentary on issues is a part of increasing this awareness. Peak bodies representing GSGs in Australia and New Zealand have formed the Australasian Genetic Alliance (AGA) which is supporting efforts to better respond to the needs of GSGs and their members. An emerging concern relates to primary care. Improved medical intervention and better health care has had a positive outcome in increasing life expectancy into middle or late adulthood for many people with previously life-limiting genetic conditions.
Primary care needs for this group are likely to become a serious concern. There has been some thought that advances in genetic technology may result in fewer children being born with genetic conditions, to date this is not generally seen to be the case.

The role of Genetic Support Groups in the development of Genetics Services in Victoria - Hughes E. Genetic Support Network Victoria, Melbourne, Australia

Genetic Support Groups possess very powerful information, both biological and social. Clinical genetics services and researchers in genetics have traditionally drawn upon this information in a researcher-subject relationship, where the support group members are lesser partners in that relationship.

In recent years there has been a move towards more collaborative relationships where the knowledge and power of the support group is recognised, respected and utilised. This has occurred in the context of reduced isolation of people due to electronic communication, and a strong movement of consumer participation in other health sectors. This talk will illustrate some examples where Genetic Support Groups have positively influenced the development of genetics services and research and demonstrate the power of both information and knowledge that is found in consumer organisations.

The London IDEAS Translation Project - Mehta P, Newall E, Kessling A. Genetic Interest Group, London, UK

The London IDEAS Translation Project aims to develop meaningful and accessible patient information about genetics for London's linguistically diverse communities, and ultimately to improve patient access to genetic services. London is the most linguistically diverse capital of the world, inhabited by over 45% of Britain's minority ethnic populations. Therefore, although this project is a local initiative, material generated will have global applications. Resources are available to translate up to 27 patient information leaflets in 12 languages, and there is limited provision for providing this information in audio formats.

This five-year collaborative project is between The North-West Thames Regional Genetic Service and the Genetic Interest Group. To date, leaflets have been written in accessible English with uniform style, and a panel of clinicians has verified their content and accuracy. A "best practice" model for translating patient information has been developed, which includes steps of validation and community consultation. With this model, the first four languages have been translated. Language needs have been assessed by surveys and a conference of interested parties from around the UK. Translated leaflets will be made freely available (alongside the English version) to clinics over the Internet.

Short on the outside but tall within
- Karamesinis M.
Genetic Support Network of Victoria, Melbourne, Australia

The presentation will tour the website, launching the book on Turner's syndrome (TS) to the wider world of parents, families, teachers and health professionals. Genetic counsellors at a delicate interface between families and the medical profession need to know of this work. Produced by a General Medical Practitioner, and consumer of health services, the focus is on information and empowerment of individuals affected by Turner's syndrome. The combined personal and professional understanding of the challenges adds depth to the themes explored. The resultant tapestry of personal narrative, shows the similarity yet diversity of people's attitudes and experiences and is a rich resource for health professionals. For health professionals, listening to people's experience and perceptions, allows better understanding of the difficulties they face. It also allows services to be developed to best meet the needs of consumers.

For teachers, recognition of a child's potential, with appropriate expectations and educational scaffolding may transform a student's ability to achieve. For parents, key issues are support, advocacy, and cultivation of self-esteem and resilience. A treasury of people's life experiences, this unique work explores the social and emotional impact on individuals and families affected by Turner's syndrome. Pertinent issues of self-esteem, relationships and fertility, are relevant to all people with a genetic condition, not only those with TS.

FOOD FOR THOUGHT

Australia's National Family History Day as a part of ANZAC Day or Australia Day?

A Report from Genetic Alliance USA

National Family History Day
"My Family Health Project"

Soon, all health care providers, regardless of specialty area, role, or practice setting, will face questions about implications of genetics for their patients. Common diseases such as coronary heart disease, stroke, diabetes, and cancer are due to the interaction of genetic and non-genetic risk factors. Recognizing genetic factors that contribute to common diseases can help identify individuals with increased risk.

Family health history collection and interpretation is the most practical personalized genomic tool available. It represents complex interactions of genetic, environmental, cultural, and behavioral factors shared by family members.

Health care professionals can use family health history information to design individualized care that integrates disease prevention and health promotion.

It is important that individuals are knowledgeable about their own family health history, and that they have a convenient way to share this information with their health care professionals. Recent polls indicate that the vast majority of people believe that family history information is important to their health, but that most people have never attempted to gather such information. To help with this, the Surgeon General Richard H. Carmona, M.D., M.P.H., FACS is launching **The U.S. Surgeon General's Family History Initiative.**

Several offices and agencies within the U.S. Department of Health and Human Services, including the Office of the Surgeon General, the National Institutes of Health, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and the Agency for Healthcare Research and Quality - as well as other organizations are coordinating efforts to increase America's awareness of the importance of family health history.

Our goal is to provide accessible methods for easily obtaining an accurate family health history and to increase use of the family health history in disease prevention and health promotion. Together, we are teaming up to make Thanksgiving Day the annual National Family History Day. Thanksgiving Day 2004 will serve as the inaugural National Family History Day.

The Surgeon General's Family History Initiative encourages discussion of health history at family gatherings to increase awareness and documentation of family history. The initiative includes an easy-to-use, downloadable, web-based family history tool, "My Family Health Portrait," which will be available November 8 at http://www.hhs.gov/familyhistory. This tool will also be available in print and in English and Spanish.

We encourage you to join this initiative, to be informed about the importance of considering family history in caring for your patients, and to consider personal and professional efforts that you can contribute, now or in future years, to assure the success of National Family History Day.

The future health of all can be improved through partnering to make a difference in knowledge gathering and utilization of family health history in disease prevention and health promotion. Learn more about available resources by visiting http://www.hhs.gov/familyhistory.

List of Conditions on AGSA's Contact Register

Aarskog syndrome
Achondrogenesis
Achondroplasia
Acoustic Neuroma
Acrocallosal syndrome
Acromegaly
Adams Oliver syndrome
Addisonís
Adrenoleukodystrophy
Agenesis of the Corpus Callosum
Alagille syndrome
Albinism
Alcardi syndrome
Alexander Disease
Alpha Manniosidosis
Alpha I Antitrypsin Deficiency
Alpha Thalassaemia X-Linked Mental Retardation
Alport syndrome
Alstroms syndrome
Amyloidosis
Amyotrophic Lateral Sclerosis
Angelman syndrome
Aniridia
Ankylosing Spondylitis
Anodentia ñ Congenital
Anticardiolipin AB Type
Anti-Phospholipid Syndrome
Apert syndrome
Aplasia Cutis Congenita
Argininosuccinic
Aciduria & Citrullinaemia
Arnold-Chiari
Arthrogryposis
Aspergers syndrome
Ataxia ñhereditary
ATR16 syndrome
Autism
Baller-Gerold syndrome
Bannayan-Riley-Ruvalcaba syndrome
Bardet-Biedl syndrome
Bartter syndrome
Basal Nevus syndrome
Batten Disease
Beckwith-Wiedemann syndrome
Behcetís syndrome
Behr syndrome
Benign Essential Tremor
Berardinelli syndrome
Bilateral Iris Coloboma
Binder syndrome
Bloom syndrome
Blountís Disease
Borjeson-Forssman-Lehmann syndrome
Brown syndrome
Caffeys familial neurovisceral lipidosis
Caffeys generalized gangliosidosis
Caffeys Pseudo -Hurler syndrome
CAH & Hypoplasia Ducheene Muscular Dystrophy
Camptomelic Dysplasia
Canavans Disease
Cardio facial cutaneous syndrome
Cardiomyopathy
Caroli syndrome
Carpal-tarsal osteolysis
Carpal Tunnel syndrome
Carpenter syndrome
Central Core Disease
Cerebellar Hyperplasia
Cerebo-Costo-mandibular
Charcot-Marie-Tooth Disease
Choanal Atresia
Chronic Granulomatous Disease
Choroid Plexucyst
Chronic Granulomatous disease
Cleidocranial dysplasia
Cobalamin E, C/G deficiency
Cockayne syndrome
Coffin-Lowry syndrome
Coffin-Siris syndrome
Cohen syndrome
Congenital Adrenal Hyperplasia
Congenital Alopecia Totalis
Congenital Anodontia
Congenital Cone dystrophy
Congenital Fibre Type Disproportion
Congenital Myotonia Dystrophy
Congenital Protein C deficiency
Conradi-Hunnermannís
Cornelia-de Lange syndrome
Corticobasal degeneration
Costello syndrome
Craniosynostosis syndrome
Cri-du-chat syndrome
Crouzon syndrome
Cushing syndrome
Cutis Marmorata Telangiectatica
Cyclical Vomiting Syndrome
Cystic Fibrosis
Cystinuria
Cytochrome C. Oxidase Deficiency
Dancing Eye syndrome
Dandy-Walker Malformation
De Barsy syndrome
Dejerine-Sottas disease
Dercum Disease
Desbuquois syndrome
Developmental Verbal Dyspraxia
Diastematomyelia
Di-George
D 2 hydroxyglutaric aciduria
Drash syndrome
Double Y syndrome
Duane syndrome
Dubowitz syndrome
Dysautonomia
Dyschondrosteosis
Ebsteins Anomaly of the Tricuspid Valve
Ectodermal dysplasia
Ectrodactyly
Ehlers Danlos syndrome
Ellis-Van Creveld Syndrome
Emery Dreifuss Muscular Dystrophy
Encephalocraniocutaneous Lipomatosis
Epidermolysis Bullosa
Epidermal nevus syndrome
Erythropoietic protoporphyria
Fabrys Disease
Facial Haemangioma
Factor V Leiden
Familial adenomatous polyposis coli
Familial Hiberian Fever
Familial Hyperinsulinaemia
Familial Mediterranean Fever
Familial Spastic Paraparesis
Fanconi Anaemia
Farber Lipogranulomatosis
Fazio-Londes syndrome
FG Syndrome
Fibrodysplasia Ossificans
Fish Odor syndrome
48, XXXY
48, XXYY
49, XXXXY
Fragile X syndrome
Fraser syndrome
Friedreichís Ataxia
Froelich syndrome
Frontanasal Dysplasia
Fryns syndrome
Fukuyama syndrome
Galactosaemia
Gardner syndrome
Gastroschisis
Gaucher Disease
Gitelman syndrome
Glucose 6 Phosphaate Dehydrogenase (G6PD) deficiency
Glucosidosis Enzyme deficiency
Glycogen Storage Disease
GM1 Ganliosidosis
Goldenhar syndrome
Gorlin syndrome
Graves Disease
Guillain Barr syndrome
Haemochromatosis
Hailey-Hailey Disease
Hajdu-Cheney syndrome
Hallermann-Streiff syndrome
Hallervorden-Spatz Disease
Hartnup Disease
Hemihypertrophy
Hemimegalencephaly
Hereditary Angioneurotic Edema
Hereditary Fructose Intolerance
Hereditary Haemorrhagic Telangiectasia (Rendu Osler Weber syndrome)
Hereditary Multiple Exostoses
Hereditary non polyposis colorectal cancer
Hereditary Spastic Paraplegia
Hereditary Spherocytosis
Hirschsprungís Disease
Holoproscenphaly
Holt Oram syndrome
Holoprosencephaly
Homocystinuria
Homolateral Brain syndrome
Hunter syndrome
Huntington Disease
Hydrocephalus
Hydronephrosis
Hyperargininaemia
Hyper IGE syndrome
Hyperexplexia (Startle Disease)
Hypertrophic Cardiomyopathy
Hpoochondroplasia
Hypoplasia of the Cerebellum
Hypomelanosis of Ito
Hypophosphatemic Bone Disease (HBD)
Hypophosphatasia
Hypopituitarism
Hypoplastic left heart syndrome
Hypoplastic Primary Vitreous
Hypotension Orthostatic
Hypothyroidism
Idiopathic pulmonary fibrosis
Idiopathic Thrombocytopenic Purpura
Immotile Cilia syndrome
Incontinentia Pigmenti
Ivermark syndrome
Jacobsonís syndrome
Jeune syndrome
Job syndrome
Johanson-Blizzard syndrome
Joubert syndrome
Kabuki Make-up syndrome
Kallmann syndrome
Kawasaki syndrome
Kearns Sayre syndrome
Kennedyís disease
Keratosis follicularis spinulosa decalvans
Klinefelter syndrome (47,XXY)
Klippel-Feil syndrome
Klippel-Trenaunay Weber syndrome
Krabbe Disease
Kyphomelic Dysplasia
Landau-Kleffner syndrome
Langer-Giedion syndrome
Larsen syndrome
Laurence-Moon-Biedl
Lebers Optic Atrophy
Leigh Disease
Leopard syndrome
Leri-Weill syndrome
Lesch Nyhan syndrome
Leukodystrophy
Li-Fraumeni
Limb Girdle Muscular Dystrophy
Lipodystophy & Brownís syndrome
Lissencephaly
Long-chain-3-hydroxyacyl coenzyme A, dehydrogenase deficiency
Long QT syndrome
Loweís syndrome
Lujan-Fryns syndrome
Lymphas Genphasia
LAM (lymphangioleiomyomatosis)
Lysosomal Storage Disorders
Machado Joseph syndrome
Maple Syrup Urine Disease
Marfan syndrome
McCune Albright (Polkystotic Fibrous Dyplasia)
McKusik Kaufman
Megalocornea Mental Retardation
MELAS syndrome
Menke syndrome
Metachondromatosis
Metatropic Skeletal Dysplasia
Methylmalonic academia
Microcephaly
Miller-Dieker syndrome
Minicore disease
Mitochondrial Myopathies
Moebius syndrome
Monosomy 9p
Motor Neurone Disease
Mucopolysaccharidoses
Mullerian Duct Agenesis
Multiple Endocrine Neoplasia 2B
Multiple Epiphyseal Dysplasia
Multiple Exostores
Muscular Dystrophy
Myasthenia Gravis
Myotonia Congenita
Myotonic dystrophy
Nager & Miller syndrome
Nail Patella syndrome
Narcolepsy
Netherton syndrome
Neuroaxonal Dystrophia
Neurofibromatosis
NF + Noonan syndrome
Neuronal Intestinal Dysplasia
NF1 Noonan syndrome
Niemann-Pick Disease
Nonketotic Hyperglycinaemia
Noonan syndrome
Norrie syndrome
Nystagmus
Oculo-dento-digital syndrome
Ohdo syndrome
Olivo-Ponto-Cerebellar-Atrophy
Olliers Disease
Ophthalmia: Anophthalmia & Microphthalmia
Opitz Fg syndrome
Opitz trigonocephaly
Oral-Facial-Digital syndrome
Organic acidemia
Ornithone transcarbamylase deficiency
Osteogenesis Imperfecta
Osteopetrosis
Pachyonychia congenita
Paget disease
Pallister-Hall syndrome
Pallister-Kellian syndrome
Paroxysmal Nocturnal Haemoglobinuna
Paroxysmal kinesigenic choreoathetosis
Partington syndrome
Peho syndrome
Pelizaeus-Merzbacher Disease
Pena-Shokeir syndrome type1
Pendred syndrome
Peripheral Neuropathy (CMT TypeII)
Persistent hyperinsulinenuic hypoglycemia (PHHI)
Perthes syndrome
Peutz-Jeghers syndrome
Pfeiffer syndrome
Phenylketonuria (PKU)
Picks Disease
Pierre Robin syndrome
Poland syndrome
Polyostic Fibrous Dysplasia
Polycystic Kidney Disease
Polycystic Ovarian syndrome
Pompe disease
Popliteal Pterygium syndrome
Porphyria
Post Polio syndrome
Potter syndrome
Potterís syndrome
Prader-Willi syndrome
Primary agammaglobulinaemias
Primary Immune Deficiency
Progeria syndrome
Progressive Myoclonic Epilepsy
Progressive Supranuclear Palsy
Proteus syndrome
Pseudo hypoparathyroidism
Pseudoxanthoma Elasticum (PXE)
Pycnodysostosis
Pyridoxine dependency
Pyruvate dehydrogenase deficiency
Pyruvatekinase deficiency
Rare Chromosomes Disorders ñ includes deletions, inversions, trisomies, duplications, ring, uniparental disomy, mosaicism, tetrasomies, translocations
Raynaudís disease
Reinfenstein syndrome
Retinitis Pigmentosis
Rett syndrome
Richardson-Steele-Oblizewski syndrome
Robinow syndrome
Rubenstein-Tabi
Russel-Silver syndrome
Refsum disease
Saethre-Chotzen syndrome
Sandhoffs disease
Sanfilippo disease
Sarcoidosis
Schinzel Giedion syndrome
Schmid Type Metaphyseal Chondrodysplasia
Schwachman syndrome
Septo-optic Dysplasia
Severe Combined Immune Deficiency
Severe Immune Deficiency
Short stature and Skeletal Dysplasia
Shprintzen syndrome
Shy Drager syndrome
Simpson Golabi syndrome
Sjogren syndrome
Smith-Magenis syndrome
Sotos syndrome
Spina Bifida
Spinal Muscular Atrophy
Spinocerebellar Ataxia TypeII
Spondylocostal Dysplasia
Spondylometaepiphyseal dysplasia
Sponylo Epiphyseal Dysplasia
Shprintzen syndrome (Velo Facial Cardio syndrome)
Steve Johnson syndrome
Stickler syndrome
Sturge Weber syndrome
Systemic Lupus Erythematosis
TAR syndrome
Tay Sachs disease
Thalassaemia
Tibial Hemimelia
Tourette syndrome
Townes Brock syndrome
Treacher-Collins syndrome
Trichothiodystrophy
Trimethylaminuria
Triple X syndrome (47,XXX)
Trisomy4,5,8,9,10,12,13,18
Tuberous Sclerosis
Turner syndrome (45,X)
Tyrosine Anaemia
Undiagnosed conditions group
Usher syndrome
Vater;s syndome
Velo-Cardio-Facial Syndrome
Vitiligo
Von Hippel-Lindau syndrome
Von Witterbrand disease
Weaver syndrome
Weill-Marchesani syndrome
Werding-Hoffman syndrome
West syndrome
Whistling face syndrome
Wiedemann-Rautenstrauch syndrome
Williams syndrome
Wishott-Aldrich syndrome
Wolf-Hirschhorn syndrome
Wolfrau syndrome
Wolfmans disease
Xeroderma Pigmentosa
X-linked Agammaglobulinanaemia
X-linked Hypophosphatemia (XLH)
XLP syndrome
Zellweger syndrome

PLUS 134 ORGANISATIONS AND SUPPORT GROUP MEMBERS.

AGSA'S SUPPORT GROUP & ORGANISATIONAL MEMBERS as at January 2004

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
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.

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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*