THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA INC.

FUNDED BY THE NSW HEALTH DEPARTMENT

NEWSLETTER

DECEMBER 1999 ISSUE 45

MISSION STATEMENT

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

Reg Charity CFN15481 Tax Ref AF1595C/SF8566

ANNOUNCEMENT

AGSA'S WEBSITE IS LIVE

website: www.agsa.asn.au
email: agsa@ozemail.com.au

Please note our website address will change as soon as our org. name is registered.

Contents:

MERRY CHRISTMAS & A HAPPY NEW YEAR TO YOU ALL FROM THE AGSA COMMITTEE

PEER SUPPORT & INFORMATION OFFICER'S REPORT

It is very exciting to have our own website up and running. Many thanks go to the students of the NSW University, Dr Sue Fowell and Dr Stephen Eliott. We would like to thank Sue Fowell especially for fine tuning the site and for spending many hours with Marlene Brightwell and myself discussing and correcting the data.

This newsletter will include some highlights of Genetic Disorders Awareness Week.

Meetings to be held in 2000 are Triple X, Ehlers Danlos, Behaviour Seminar and hopefully a rural seminar. Details to be advised.

I would like to wish you all a very happy Christmas and a wonderful New Year. My thoughts go out to those who are dealing with very difficult situations and to those who are grieving. I hope Christmas time finds you surrounded by friends and love ones.

Wishing you a safe and healthy holiday.
Until January 2000

Dianne Petrie

VALE

I was very saddened to hear from Marg Davie that her husband David had lost his fight against Fabry's Disease. Marg and David showed great strength and humour over the past years and together they enjoyed life under great stress. They raised the awareness of Fabry's Disease by establishing the Fabry's Support Group and through raising money for research. It was an honour to know David and our sympathyt goes to Marg and her children. David Davie's Obituary kindly sent to me by Marg.

David John Davie

NATURE LOVER SOWED SEEDS OF SUPPORT

Rotarian
Born: February 2, 1944
Died: November 8, 1999

David Davie was a dedicated man - dedicated to his family, his friends and his community. He was dedicated to improving the lives of the people around him through his friendship and his great love of gardening and nature.

And he was dedicated to providing for his family and fighting a rare genetic disease.

Mr Davie had been sick man but he died a contented man knowing that his wife Marg and children - Megan, Andrew and Matthew - would remember the many happy times they had spent as a family.

Mr Davie was the first of five children born to Ray and Doreen Davie at the Ferntree Gully Bush Hospital.

Soon after his birth, the family moved to Bendigo, where he grew up with his siblings: Ailsa, Robin, Jenny and Merryn.

It was not an easy life with five children and little money, and at 15, Mr Davie left school to enter the work force.

Soon after, the family returned to Melbourne, moving to Boronia, where Mr Davie would spend the next 38 years.

In 1968 he married Margaret. He met her while working at AD Technologies. Their working relationship did not last long but their marriage remained strong.

Mr Davie's love for nature began early and soon became a passion, whether it was time spent pottering in his own garden, with the Australian Plant Society, or designing the gardens at his work-place, Glaxo Wellcome.

He was a committed man, spending most of his working life at Glaxo, working his way through the ranks.

A member of the Boronia Rotary Club, Mr Davie was awarded a Paul Harris fellowship in recognition of his commendable contribution to the club and the Boronia community generally.

Growing up, Mr Davie experienced more than the normal grown pains. But it was not until 1993 when he suffered a stroke that he was diagnosed with Anderson Fabry disease, a rare genetic disorder that affects one in 40,000 people.

Mr Davie was determined to raise the awareness of Fabry's disease. He and Marg formed the Fabry's Support Group and have since raised more than $30,000.

Despite enduring the pain of his illness, which resulted in the amputation of a leg, Mr Davie's humour remained.

In hospital, his friends would arrive solemn but always leave smiling, his last joke ringing in their ears.

Recently, Mr and Mrs Davie had five wonderful weeks away.

It was an important and significant time, for they knew their time together would soon end.

Mr Davie's love for his family, friends and nature will last well beyond his death, and his memory will continue to flourish in the gardens around Boronia and in the hearts of all who knew him.

Mr Davie is survived by his wife and children.

His first grandchild is due in just a few months.

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 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.

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Contact with another family is requested for the following conditions:

Chromosome 20q del
46XY del(20) (q11.23q13.3)

47XX,+mar.ish idic (15) (q11.2)(SNRPN++)
'de novo' i.e a female karyotype with an extra bisatellited marker chromosome.

46XX, del 4 (pter-2q21.1 - 23-q ter)

CORRECTION

OCTOBER 1999, NEWSLETTER , ISSUE 44

ARTICLE

'THE RETT GENE HAS BEEN FOUND'

A DEFECTIVE GENE FOR RETT SYNDROME should read MeCP2 not McCP2.

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.

The Human Genome Project

Grant R Sutherland AC, FAA,FRS

Director,
Department of Cytogenetics and Molecular Genetics, Women's and Children's Hospital, Adelaide South Australia 5006

Introduction

The Human Genome Project (HGP) is the most exciting exploration of human biology ever undertaken. It is a large multinational endeavour aiming to identify and determine the functions of all human genes. It will determine at the molecular level what constitutes a human: each of us is the product of our genome and it s interaction with our environment. We all begin our existence as the result of the fusion of a sperm and an egg at the moment of conception. Each contributes a haploid genome to the single cell embryo and the resultant diploid genome contains all the information required to specify our development from that moment until adulthood. Our genome then, in computer language, becomes our operating system. At present we only understand a small fraction of the information encoded in our genomes.

The HGP arose from a series of meetings in the U.S. in the mid 1980s. The initial intention was to determine the sequence of the approximately 3 billion bases in the DNA molecules which comprise the human genome. It was soon realised that this project would also require investment in informatics training, the study of the genomes of other organisms and ethical matters.

The HGP has gone very well to this time with the goals set from time to time being reached mostly ahead of schedule and under budget. The main aims when the project formally began in 1991 were as follows:

1) To have the human genome fully sequenced by 2006

2) To study (if not completely sequence) the genomes of a range of model organisms of increasing complexity:

(a) the bacterium *Escherischia coli*

(b) the yeast *Sacchromyces cerivisiae*

(c) the worm *Caenorhabddditis elegans*

(d) the fruit fly *Drosophila melanogaster*

(e) the mouse

3) To develop informatics (computers) to handle all the data generated and make it accessible to the scientific community.

4) To explore the ethical, legal and social implications of the HGP. From the very beginning 3.5% of genome funding was devoted to this area.

A number of outcomes of this project were envisaged and these include:

1) Understanding the genetic basis of human disease. About 4000 mostly rare human diseases are caused by mutation in single genes and considerable progress in isolating these genes has been made. There are however more than 100 relatively common diseases each affecting 0.5% or more of the population (e.g. are diabetes, hypertension, some cancers, osteoporosis, asthma) that involve the interaction of susceptibility genes with the environment. The identification of these genes is much more difficult but they will eventually be found. Once these are understood it should be possible to

delay the onset of this group of common diseases and to develop new drugs to combat them when they do develop.

2) The use of gene products as drugs e.g. insulin, clotting factor IIX.

Almost all gene products that are used as drugs have not come about from the HGP. However many that were originally natural animal or human products are now produced from cloned genes and are thus pure and safer.

3) Genes as drugs, that is gene therapy.

Gene therapy, especially for malignant disease (cancer) is predicted to become a major industry early in the 21st century. Cancer is a genetic disease, although mostly not an inherited one. Genetic changes in bodily (somatic) cells result in an escape from the normal controls on unrestricted cell growth,. Gene therapy to restore growth control or to kill cancerous cells is now at an advanced stage of development and holds much promise for the future.

4) **Predictive medicine**

Predictive medicine is the determination of risk of future disease based upon identification or susceptibility genes. Technologies are being developed to compare the DNA sequences of large numbers of individuals against a 'standard' sequence of many genes. Such genetic testing, would reveal many differences, most of these would be normal genetic variation, that which makes each of us different from each other, but a small number would indicate the presence of disease susceptibility genes. Once a full understanding of the mechanisms by which these genetic changes can result in disease, strategies to delay the onset of disease and provide better treatments should be devised. These might include lifestyle changes, drug treatments or gene therapy. Worldwide, the pharmaceutical industry is investing hundreds of millions of dollars in the genomics of disease since it is believed that the drugs of the next century will be developed from an understanding of the genetic susceptibility to common disease.

5) **Data on other genomes**

There is great similarity between the genomes of all animals. Humans have many of their genes for basic cellular functions that can be found to have similar recognisable ancestors in yeast. Mammals mostly have genomes the same size as humans with the same genes in the same order over many regions of their genomes. Thus, data from model organisms throw light onto the human genome and vice versa. There are currently projects looking at the genomes of many commercially important species of plants and animals.

Progress

Progress and goals for 1998 -2003 for the DNA sequencing and gene identification components of the HGP are given in table 1. The human genome will be completely sequenced by the end of 2003. At about the same time all human genes will be identified but their functions will often not be known. Some idea of function may be suspected from the DNA sequence but experimental work will be required for each gene.

Finding genes

1. Single gene diseases. The biochemical defects in the overwhelming majority of the ~4000 single gene diseases are not known. The way to isolating these genes is by first finding their position in the genome, that is where and on which chromosome they are located. From knowledge of this location the gene can be isolated. Before much mapping or sequencing of the genome had taken place this was a very laborious task. For example, the fragile X chromosome was first described in 1969 but was not isolated until 1991. Huntington disease was mapped to the short arm of chromosome 4 in 1983 but the gene was not found until 1993. These were regarded as major prizes in genetics and many person years were spent in these projects. Progress in the HGP has greatly shortened these tasks. For example a new epilepsy syndrome was described by Prof Sam Berkovic at the Austin Hospital in Melbourne in 1994 and colleagues in my Department in 1995.

The difference in time scale was due to the mapping of many human genes, the availability of DNA sequence already for parts of the genome and detailed maps of many regions.

At present the main limiting factor to the isolation of all the genes which cause single gene diseases is the availability of families in which these genes are present so that they can be mapped. Many of the single gene diseases are very rare and may affect only 2-3 per million people.

2. Susceptibility genes. These are much more difficult to find. Each disease that follows what is known as multifactorial or polygenic inheritance may have 20-30 susceptibility genes that potentially have a role in its causation. Environmental factors are also likely to be very important. A good example here is that there are almost certainly genes for susceptibility to alcohol dependence, but a susceptible person who never drinks alcohol obviously will not become an alcoholic.

The susceptibility genes that are important in one population of ethnic group or environment may not be relevant in others. Those genes which confer a high level of susceptibility are relatively easy to find. A good example here are the breast cancer susceptibility genes BRCA1 and BRCA2. These confer a risk of 40-50% of developing breast cancer over a lifetime, compared with an approximately 9% population risk, yet these genes are responsible for less than 10% of breast cancer. Genes which only double a population risk, or perhaps increase it by 20% will be much harder to find.

There are several approaches to finding susceptibility genes. These include disease association studies where a particular allele of a DNA polymorphism may be found in association with the disease more often than expected. it is thought by some that this approach, using very large numbers of polymorphisms typed on large numbers of unrelated patients will identify associations that can then be related to genes.

The approach which has been most used to date has been the 'affected sib-pair' method. This is to study siblings who both have a polygenic disease and look for the regions of genome that they share. Any pair of siblings will have 25% of their genome in common, thus it is necessary to study large numbers of sib pars. This approach while not always successful, is beginning to yield genes involved in, for example, diabetes and asthma.

Other approaches include the use of animal models of human diseases where breeding experiments can help to determine on which chromosome susceptibility genes might lie.

The identification of disease susceptibility genes remains a major challenge to genome science.

Gene Function

One of the areas of major difficulty is in determining the functions of genes. There is currently no set of standard procedures that can be followed that will ensure that the function of genes can be determined. There are a number of emerging technologies and one is the use of high density gene arrays. These are sometimes called gene or DNA chips by analogy with computer chips. They are very high density spots of DNA from, at least in yeast, all the genes that yeast has. By then hybridising cDNA from yeast cultured under different conditions it is possible to see which genes are up-or-down regulated. This is a genomic approach to gene function which allows the response of all genes to specific environmental change to be studied. It has great promise in the comparison of diseased and normal tissue from humans and should reveal all the genes involved in the disease process.

Conclusions

The HGP will not be completed until the function of all genes are understood and the contribution to human health and disease of all genetic variation has been determined. This may well take most of next century but when it has been completed an understanding of life at its most basic molecular level will be close to being achieved.

AGSA would like to thank Grant Sutherland for kindly providing this article.

Table 1. Status and goals of the DNA sequencing and gene identification components of the HGP

Area	Status as of Oct 1998	Goals 1998-2003
Genetic map	1 cM map published Sept 1994	Completed in 1994
Physical map	52,000 STSs mapped	Completed 1997
DNA sequence	180 Mb human plus 111 Mb nonhuman	Finish 1/3 human sequence by end of 2001 Working draft of remainder by end of 2001 Complete human sequence by end of 2003
Sequencing technology	90 Mb/year capacity at ~50.50 base Capillary array electrophoresis validated	Integrate and automate to achieve 5000 Mb/year at <$0.25 per base Support innovation
Human sequence variation	Begun	100,000 mapped SNPs Developed technology
		Full-length cDNAs
Gene identification	30,000 ESTs mapped	Full-length cDNAs
Model organisms		
E-coli	Published Sept 1997	
Yeast	Released April 1996	
Celegans	80% complete	Complete Dec 1998
Human	9% done	Sequence by 2002
Mouse	12,000 STSs mapped	Lay basis for finishing sequence by 2005 Produce working draft before 2005

(Modified from Collins et al. 1998)

For those who wish to explore the human genome project a number of internet sites are listed in the references.

References

1. Collins FFS, Patrinos A, et al: New goals for the US Human Genome Project: 1998-2003. Science, 282:6882-689; 1992.

2. Phillips HA, Scheffer IE, et al: Localization of a gene for autosomal dominant nocturnal frontal lobe epilepsy to 20q13.2. Nature Genetics, 10:117-118, 1995.

3. Pruitt KD: WebWise: Web sites of the Human Genome Project. Genome Research, 8:11109-1111,1998.

4. Human genome most used links httpp://128,165,108.11/HGhotlist,hgtml.

5. Learning tools for Understanding Genetics and Genetic Research. httpp://wwww.nhgri,nih.gov/DIR/VIP/Learning Tools.

FAMILY STORY
Tips - Special Diet

Education of the primary carer:

Talk to a dietitian, get as much advice as possible, what food is suitable and what is not.

Take time out and learn to read food labels, what they mean, chemical and other names for the forbidden nutrient.

Look if there are books available on the diet required.

Try to find another family with a child that has the same condition, exchange recipes.

Telephone big food companies, usually there is a nutritionist available who can provide information on the suitability of products.

Ask the nutrition department of universities for help and information.

Inform your pharmacist, sometimes medication can contain forbidden nutrients e.g. lactose as a filler in pills and capsules, not all ingredients are listed on the label, but the pharmacist can look them up.

Talk to your local butcher/baker and ask about the ingredients.

Health food stores are normally quite helpful and can give dietary advice.

Prepare suitable food in advance and freeze it, so that you are prepared for unplanned events (visitors, going to friends' places)

Set some time aside to visit food shops you have not been to before and explore the labels on unknown food products, if in doubt, write to the company.

Education of other carers, family, friends:

Give clear information and written lists about allowed food to all family members and friends

Make specific lists for day-care personnel, kindergarten teachers, and primary school teachers

Prepare suitable food yourself and give it to teachers to keep at the day care centre or school.

Use all your imagination and creativity to make these replacement foods look nice and special.

Birthday parties: give your child suitable food to take to the party, inform the host/hostess about the special dietary needs a couple of days in advance.

Sweet treats can be replaced with little toys, stickers or a gold star, when the child has a certain amount of stars give them a little present.

Have always a collection of these treats ready.

In severe cases of allergies ask if the day-care centre/school can store emergency medication for you, the specialist can prescribe it, is there somebody who can administer it?

Education of the child:

Explain over and over again (do not loose patience) the consequences of not sticking to the diet (hospital, itchy skin,)

Teach them from an early age what food has to be avoided.

Teach the child very early to prepare food for him/herself.

Children who cannot yet read: spell the word of the food that they should not eat e.g. "lactose" for them, involve them in label reading, perhaps they can detect the word on the label among other words, this should be a game.

Children who can read: involve them actively in the shopping process, help them read labels and detect suitable products themselves, plan this activity as a game, it needs plenty of time.

Very important: make sure that the child has plenty of self-esteem and dares to say to adults: "Sorry, I am not allowed to eat this"

Some work with a professional counsellor might be necessary to overcome feelings like jealousy of siblings, who are healthy.

Give plenty of reassurance and acceptance so that the child does not feel he/she is the only "odd one".

Kindly written by Lydia Laustenschlager, Founder of the Hereditary Fructose Intolerance Support Group.

CONFERENCES

UNIQUE 8TH ANNUAL CONFERENCE

SATURDAY 29TH APRIL 2000

THE HILTON NATIONAL HOTEL

WADDON WAY, PURLEY WAY, CROYDON, SURREY

TEL: 0181 680 3000

Fax: 0181 681 6171

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International Early Psychosis Association

FUTURE POSSIBLE

2nd INTERNATIONAL CONFERENCE ON EARLY PSYCHOSIS

NEW YORK CITY,

Friday 31st March - Sunday 2nd April 2000

Call for papers

CONTACT: Secretariat,

International Early Psychosis Association,
Locked Bag 10, Parkville Vic 3052

email: leps@vicnet.net.au

tel: 61 3 9342 2837 Fax: 61 3 9342 2941

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NATIONAL RESPITE CONFERENCE

PERTH WESTERN, AUSTRALIA

11 - 13 OCTOBER 2000

SHERATON PERTH HOTEL

Contact Promaco Conventions Pty Ltd

Tel: 08 9332 2900 Fax: 08 9332 2911

AGSA SUPPORT GROUP MEMBERS as at February 1999

Androgen Insensitivity Assoc.Support Group of Australia
Alagille Syndrome Support Group
Albino Support Group
Alliance of Genetic Support Group, U.S.A.
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
Aust. Arthrogryposis Group (TAAG) Inc.
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 Foundation
Beckwith-Weidemann Syndrome Support Group
Cardiomyopathy Assoc of Aust. Inc
Centacare Early Intervention.
Charcot Marie-Tooth Assoc. of Aust Inc.
Charcot Marie-Tooth Disease, USA
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 Assoc of Qld Ltd.
Cystic Fibrosis Assoc. of Vic
Cystic Fibrosis Assoc of ACT
Cystic Fibrosis Foundation, North Ryde.
Early Education Clinic, North Sydney
DIAL (Qld)
Donor Conception Support Group
D.E.B.R.A.
Depressive & Manic Depressive Assoc.
Ehlers-Danlos Syndrome Support Group
Exceptional Parent (USA)
Fabry's Support Group Inc.(Vic)
Family Advocacy
Family Planning Assoc.
FAP Register (NSW Cancer Council)
Fragile X Assoc of Australia
Friedreich Ataxia Assoc of NSW
Gaucher Assoc. of Australia
Genetic Interest Group (GIG)
Genzyme Australia Pty. Ltd.
Haemochromatosis Information Service & Support Group NSW
Haemophilia Foundation NSW
Hereditary Fructose Intolerance
Hereditary Haemorrhagic Telangiectasia
Hunter Orthopaedia School
Huntingtons Disease Assoc. (NSW)
Huntingtons Disease Assoc. (QLD)
I.D.E.A.S. Inc
Klinefelter Syndrome Support Group
Kurrajong Early Intervention
Maternity Alliance
Leukodystrophy Foundation (USA)
Leighs Disease Support Group
Lowe's Syndrome Assoc. Inc.(USA)
Lysosomal Storage Disorders
M.P.S. Society
Marfan Syndrome Support Assoc. NSW
Meniere's (NSW) Support Group
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
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
Psoriasis Society
Pseudoxanthoma Elasticum Support Group
Prader-Willi Syndrome Assoc
Pyruvate dehydrogenase deficiency.
Rare Chromosomes Disorders Support Group
Retinitis Pigmentosa Society of NSW Inc.
Rett Syndrome Assoc. of Aust.
Royal Blind Society of NSW
R.T.M.D.C. (U.K.)
SAFDA
SANDS
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
The Chromosome 18 Registry & Research Society Society (Aust Region).
The Northcott Society
Thalassaemia Society of NSW
Turner Syndrome Assoc of Aust. Ltd. (QLD)
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)
Wolf-Hirschhorn 4p- Syndrome Support Group
Williams Syndrome Association of Aust. Inc.

*(**NB**: This list represents support groups and associations only. In addition to this list of members AGSA has established a Contact Register over 450 genetic condtiions representing families and individuals seeking contact.)*

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ANNUAL SUBSCRIPTION

Individual	$20.00
Group/Organisation	$40.00

Subscription Year lst July - 30th June

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****