AGSA
THE ASSOCIATION OF GENETIC SUPPORT OR AUSTRALASIA INC.
NEWSLETTER

August 2004 ISSUE 70 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

Recently I attended the NZORD conference in Wellington New Zealand along with Kerri Carboon MDDA from Victoria. It was an excellent conference with some very powerful and moving speakers.

The theme "Partnerships for Progress" was about families and support groups working in partnership with clinicians and researchers

- to make progress in understanding, treating and controlling the incidence of rare disorders
- sharing knowledge to create "expert patients and families"
- meeting the challenges of biotechnology, genetics and ethics.

Sharon Terry CEO of Genetic Alliance USA spoke, via video link up, on the Genetic Alliance BioBank built on a model developed by PXE International. The BioBank provides an infrastructure for genetic groups to bank blood, tissue, cell lines and other biological materials. The genetic support groups retain stewardship of the samples and benefit from sharing resources, training and templates. All access to the samples is regulated by the genetic support group.

A BioBank promotes research, avoids restrictive IP and patent issues, and facilitates the involvement of support groups. New Zealand is looking to produce their own BioBank.

Dr Steven U. Walkley from Albert Einstein College of Medicine New York, spoke on Basic Science and Translation to Therapy and Bronwyn Gray gave an extremely moving talk on research into her daughter's condition, lymphangioleiomyomatosis, for which the only cure is a complete lung transplant.

A big thank you to all who attended the launch of Genetic Disorders Awareness Week at the Powerhouse Museum on 26th July. We were honoured to have Her Excellency, Professor Marie Bashir AC, Governor of NSW, to officially launch the week. AGSA's yearly launch evening provides an opportunity for acknowledgement of people dealing with adversity and all the volunteers and carers who selflessly go about their tasks and generally receive no recognition or thanks. I was humbled by the memorable presentations.

Thank you.

AGSA AGM will be 23rd October 2004. Please put the date in your diary and if you wish to become a committee member we would love to meet you.

Best wishes,

Dianne Petrie

Genetic Awareness Week Program

Laurie Taylor – *"What AGSA means*

Matt Laffan – *"Beyond the muffled crisis"*

Matt – is a Lawyer with the New South Wales Office of the Director of Public Prosecutions and Member of the New South Wales Disability Council since 2003. He is regularly engaged as a speaker and writes a travel column for http://www.accessibility.com.au/ detailing domestic and international sojourns and how they were achieved. Matt ran as an Independent in the Lord Mayoral elections for the City of Sydney in 2004.

Melanie Porter – *"The cognitive neuropsychology of Williams syndrome"*

Melanie - is currently working as a Clinical Neuropsychologist at The Children's Hospital at Westmead and is a researcher at the hospital and within the Macquarie Centre for Cognitive Science (MACCS), Macquarie University, Sydney. She has been a tutor and guest lecturer at Macquarie University. Melanie's PhD investigated cognitive (thinking) and socio- emotional abilities in William syndrome, autism, Asperger's syndrome and Down syndrome; the main focus of her research was William syndrome – a genetic disorder with physical, cognitive and medical characteristics.

Marlene Brightwell – *"Time is what you make of it"*

Marlene is a Music Teacher and is married with two children. Her youngest daughter has 18q deletion syndrome. Marlene is the Australasian Coordinator for The Chromosome 18 Registry & Research Society. The Registry fundraises to support families and to assist research being conducted in the USA.

Seanne Lavender – *"The Singing Household"*

Seanne is married to Tony and has 4 children. Seanne was an Intensive Care Unit Nurse, however, when Gaby was born with Pyruvate Dehydrogenase Deficiency she changed her career focus and now works in general practice with GP's.

Prof Gillian Turner – *"New Hopes for Families with a Learning Disability"*

Gillian – is a Professor of Medical Genetics at the University of Newcastle (part-time) and Director of GOLD Service (Genetics of Learning Disability). There are over 300 extended families with the Fragile X syndrome and over 100 families with X linked pedigrees being studied to find the genes involved as part of a big international collaborative effort. So far 13 genes have been found and there may be over 50 genes to find. Gillian is an international authority on the X chromosome on which most of the genes for how the brain is developed, are actually positioned. She has looked at populations of individuals who are intellectually handicapped and recognised that there are about 50% more males who are intellectually handicapped than females.

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.

FREEMAN SHELDON SYNDROME
A person in Victoria wants to contact other people in Australasia. It is a very rare condition with only 100 cases reported worldwide in 1938. Please contact AGSA for details.

UPCOMING EVENTS

Film's Wanted for Australia's First Disability Film Festival

Source: Arts Access
Posted: 9-3-2004

Arts Access, the peak body for arts and disability in Victoria, takes pleasure in announcing that the inaugural The Other Film Festival will take place from Friday 3 until Sunday 5 December 2004. The festival will coincide with International Day of People with a Disability on 3 December.

The Other Film Festival will present a program of curated sessions, gritty and raw new work by emerging filmmakers, and vigorously debated forums. The festival seeks to engage, enthuse, enlighten and entertain a diverse audience.

The Other Film Festival is particularly proud to announce Academy Award winner, Adam Elliot, as the Patron of Australia's first disability film festival.

Adam Elliot says, "I am honoured to be involved in The Other Film Festival. My films have appeared in other disability film festivals around the world, so it's a great time to introduce an Australian equivalent that will allow audiences the chance to experience films and filmmakers with a focus on difference."

Deadline for film entries is 31 July 2004. Filmmakers can download an entry form from the website, email info@artsaccess.com.au

or call 03 9699 8299 TTY 03 9699 7636.

Website: The Other Film Festival
http://www.artsaccess.com.au/news/index
Contact Name: Nerida Weller

Contact Phone: 03 9699 8299

Contact Email: nweller@artsaccess.com.au

Attached file:
Information on the Other Film Festival – http://www.disabilitynews.infoxchange.net.au/news/items/2004

Disabled slip through cancer screen

July 2, 2004 - 8:05AM

Women with disabilities were slipping through the screening net and missing out on routine breast and cervical cancer checks, a disabilities specialist said.

Women with intellectual, physical or psychiatric disabilities were much less likely to have regular mammograms or Pap smears, Women With Disabilities Australia spokeswoman Jenny Bridge-Wright said.

"In the 70- to 75-year-old age bracket that's been identified as at most risk of dying from breast cancer, 41 per cent of women with (physical) disabilities have never had a mammogram and 30 per cent had never had a Pap smear," Ms Bridge-Wright said.

"Other research has found that women with intellectual or psychiatric disabilities are less likely to have regular Pap smears."

Compounding the problem was evidence that women with disabilities were more likely than the general population to be at risk of cervical cancer, Ms Bridge-Wright told a chronic diseases, disability and disablement conference in Melbourne.

"There are clear indicators to show that we're less likely to be screened and at much higher risk of developing these cancers," she said.

"Research has shown that victims of sexual assault are at a greater risk of developing cervical cancer and statistics show that women with disabilities are twice as likely to be sexually assaulted or raped and 90 per cent of women with intellectual disabilities are likely to be sexually assaulted.

"It's staggering that nobody's identified this previously and public policy hasn't recognised the need for the inclusion of women with disabilities as a target group for screening."

Even when they tried to have tests for cervical and breast cancer, women with disabilities faced particular difficulties, Ms Bridge-Wright said.

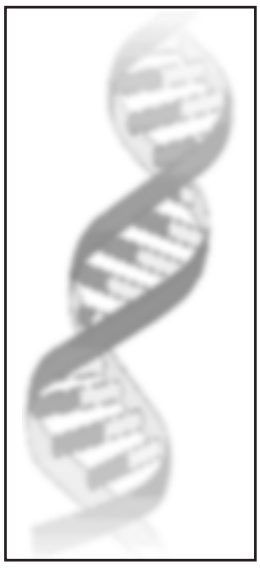
"There are other huge barriers that we face with respect to access in general, to do with physical reasons for access such as there's no transport or there's no accessible examination table or mammography equipment," she explained.

"Or, if information does get to women with disabilities about screening, it may not come in an accessible format - it might not come in Braille or might not have been translated into their language."

Women With Disabilities Australia is calling for more research to be undertaken into the level of screening.

"There's never been any large-scale research undertaken to determine what our rate of screening has been compared with women without disabilities," Ms Bridge-Wright said.

Francis Crick, DNA pioneer, dies



Co-discovered the double helix

By Mark Feeney, Globe Staff
July 30, 2004

Francis Crick, who with James D. Watson discovered the double helix structure of the DNA molecule in 1953 - one of the 20th century's most celebrated scientific breakthroughs -- died Wednesday in a San Diego hospital.

He was 88 and had colon cancer.

The importance of their discovery can hardly be overstated. It all but created the field now known as molecular biology, and led to an understanding of the genetic basis of diseases, which has revolutionized the search for drugs and other treatments.

It also was the making of Dr. Crick, who at the time was still pursuing his doctorate at Cambridge University. He acknowledged that personal importance by later naming his house in England The Golden Helix.

''I will always remember Francis for his extraordinarily focused intelligence and for the many ways he showed me kindness and developed my self-confidence," Watson said yesterday in a statement from his office in Cold Spring Harbor Laboratory in New York. ''For two years I was almost a family member, the much-younger brother prone to intellectually stray... I always looked forward to being with him and speaking to him, up until the moment of his death."

Watson and Dr. Crick received the 1962 Nobel Prize in Physiology or Medicine for discovering that the structure of DNA was a double helix. In making their discovery, Dr. Crick and Watson drew upon the research of Maurice Wilkins, who shared the Nobel, and his colleague, Rosalind Franklin, who died in 1958.

Dr. Crick always downplayed the significance of his achievement, saying in his 1988 memoir that ''it is the molecule that has the glamour, not the scientists."

But the scientists who followed him never believed that.

''Francis Crick was a connection to that founding generation of molecular biologists who changed the world, and in terms of pure intellect he was the most extraordinary of them," said Eric S. Lander, director of the Cambridge-based Broad Institute, who was instrumental in mapping the human genome.

Publicly, Dr. Crick was less well known than Watson, who had a gaudier personality. Not that Dr. Crick was a wallflower.

When at Cambridge, he and his wife, Odile (Speed) Crick, were famous for the liveliness of their parties. He was also renowned in

scientific circles for his blunt honesty, puckish wit, and considerable self-assurance. As Watson wrote in the famous first sentence of his memoir, "The Double Helix" (1968): "I have never seen Francis Crick in a modest mood."

Watson's greater fame was even more attributable to "The Double Helix," which was an immediate best seller and soon attained classic status. Dr. Crick liked to joke how often he was complimented on his authorship of the book. Indeed, his and Watson's names were joined in the public mind. Even some colleagues lumped them together. In 1955, Watson was visiting his old haunts at Cambridge. Dr. Crick introduced him to the new head of the university's Cavendish Laboratory. "Watson?" he said to Dr. Crick. "I thought your name was Watson-Crick."

Francis Harry Compton Crick was born on June 8, 1916, in Northampton, England, the son of Harry Crick, a footwear manufacturer, and Anne Elizabeth (Wilkins) Crick. The family moved to London when Dr. Crick was a boy.

Having demonstrated an early interest in science, Dr. Crick studied physics at University College London. He earned his bachelor's degree in 1937 and began doing graduate work on the viscosity of water. He later described this as "the dullest problem imaginable," but it led to his working for the British Admiralty during World War II, developing naval mines.

With the war over, Dr. Crick found himself at a crossroads, bored with physics and intrigued by what he called "the chemical physics of biology." Pondering the advisability of switching to biological research, he consulted various friends. "I've known a lot of people more stupid than you who've made a success of it," one told him.

Thus encouraged, Dr. Crick went to Cambridge to work on his doctorate. He met Watson there in 1951. "A certain youthful arrogance, a ruthlessness, and an impatience with sloppy thinking came naturally to both of us," Dr. Crick later wrote. They almost immediately began their pursuit of what Watson once called "the most golden of molecules."Drawing on X-ray diffraction studies by Wilkins and Franklin, as well as work by the US chemist Linus Pauling, Dr. Crick and Watson spent the better part of two years working on models of the DNA molecule. At one point, Dr. Crick was forbidden to continue work on DNA (he was supposed to be researching proteins). When they finally hit upon the double helix as DNA's structure, Odile Crick was initially unimpressed.

"You were always coming home and saying things like that," she later explained, "so naturally I thought nothing of it. "Dr. Crick, who received his doctorate in 1954, later became a central figure in the study of protein synthesis and genetic coding. Along with Sydney Brenner, he showed how DNA provides instructions to make amino acids and then proteins, the basic building blocks of life.

This itself was a profound insight, but he also showed the essence of how these instructions work: DNA can be thought of as a long string of letters, and every three letters is like a word that specifies a particular amino acid, he and Brenner showed.

Dr. Crick also theorized that molecules called "transfer" RNA play a crucial role in this process -- a theory that was later proven correct.

"Not only did he discover with Jim Watson the double-helical structure of DNA, but Francis Crick

intuited the mechanism by which the genetic code is written and read out," Lander said. "Those three things -- the double helix, [RNA] molecules, and the triplet nature of the genetic code -- I think of as the greatest intellectual hat trick in the history of biology, and they emerged from pure insight with very little data for guidance."

Dr. Crick held several visiting professorships at universities in the United States, including Harvard and the Rockefeller Institute, while maintaining his affiliation with Cambridge. In 1976, he moved to the Salk Institute for Biological Studies in La Jolla, Calif., where the focus of his work became brain research. He continued doing theoretical work until shortly before his death.

Lander recalled the experience of working with Dr. Crick at Salk in the early 1980s.

"What I most remember was his pure joy in ideas. He just took such pleasure in thinking about hard problems," Lander said. "He was the most playful 70-year-old you might imagine, and there was the sense he was like that at every age."

Dr. Crick also made headlines in 1981 with his "panspermia" hypothesis, which he propounded in his book (with Leslie Orgel) "Life Itself: Its Origin and Nature." Dr. Crick suggested that life on Earth began when an unmanned spacecraft from another world crashed here billions of years ago, depositing microorganisms.

Dr. Crick was also author of "Of Molecules and Men" (1966) and "The Astonishing Hypothesis: Scientific Search for the Soul" (1994). The latter book offers Dr. Crick's thoughts on the brain and the nature of consciousness.

In it, he announces, " 'You,' your joys and your sorrows, your memories and your ambitions, your sense of personal identity and free will, are in fact no more than the behavior of a vast assembly of nerve cells and their associated molecules."

In addition to his wife, Dr. Crick leaves a son, Michael, of Seattle, from his first marriage, to Ruth (Dodd) Crick, which ended in divorce; two daughters, Gabrielle and Jacqueline M.T. Nichols, , both of England; and four grandchildren.

The funeral will be private.

Material from the Associated Press was used in this obituary.

CONFERENCES

The Chromosome 18 Registry & Research Society (Aust) Inc.

Annual Family Meeting

Saturday 28th August 2004

At Meerilinga Community Hall, 30 Chischester Drive, Woodvale Perth WA

Time 10.00 .am

The Meerilinga Community Hall is situated 15 kilometres north from the centre of Perth and 7 minutes from the beach area. The Hall is equipped with indoor/outdoor play activities for the children. Respite carers for children can be organized through your local area coordinator. Discuss your requirements with them. For enquiries and further information contact:

Veronika: (08) 9409 9854 or 0416 240 066 or Marlene: (02) 9580 5707 or 0400 809 366

Cost AUD20.00 per adult. Includes morning tea, lunch and afternoon tea.

School age children and disabled individual free.

Conferences - Retina Australia Biennial Congress

Great opportunity to hear of current research into causes and treatments of degenerative retinal dystrophies from scientists funded by Retina Australia. Sufferers of retinal dystrophies such as RP AMD and others are welcome to share, to learn, and to network. Two days of reports, workshops and social activities. From Saturday, October 16 to Sunday October 17. Limited accommodation available on site. Sighted guides will be available to help visually impaired delegates.

Further information from www.retinaaustralia.com.au or from Retina Australia (SA) on 08 8362 1111.

Website: www.retinaaustralia.com.au
Retina Australia

Contact Name: Philippa Cooper

Contact Phone: 08 8362 0030

A National Conference on Sibling Issues

Wednesday 17 – Friday 19 November 2004

The University of Adelaide

North Terrace, Adelaide, South Australia

More information is available from http://www.siblingsaustralia.org.au

NZORD Conference Wellington 2004

Dr Michael Sullivan, Director of Research Childrens Cancer and Developmental Genetics Research Group, University of Otago

Dr Matthias Klugmann, Dept of Molecular Medicine and Pathology, University of Auckland.

Dianne Petrie, Director, AGSA

Kay Gregan-Parish, Parent to Parent

Kerri Carboon, Executive Director Metabolic Dietary Disorders Association

John and Judith Forman NZORD

COMING OF AGE

Parent to Parent Conference celebrating 21 years

Exploring futures for young disabled people and their families

When & Where

22 - 24 September 2004

Michael Fowler Centre, Wellington, New Zealand.

Purpose

Coming of Age aims to promote understanding of possibilities in the development of dynamic futures for young disabled people and their families in New Zealand.

The conference will be essential for all people committed to advancing the social value and personal aspirations of disabled people and their families.

For more details including the programme and presentation abstracts, please read the conference overview online.

Registration

Conference registration is now available www.imaginebetter.co.nz

Presenters

The following presenters are confirmed:

Keynote Presentations

Jeff & Cindy Strully, California, USA

Philip Patston, Auckland, New Zealand

Principal Speakers

Ray Murray, Auckland, New Zealand

Ann Greer & Jane Lister, Queensland, Australia

Minnie Baragwanath, Auckland, New Zealand

Anna Jamieson, Dunedin, New Zealand

Please click on our Events and Conference page or click on www.imaginebetter.co.nz for more information.

Do you know of a child with a brother or sister with Autism or Asperger's Disorder?

Is that child current attending school (Years 4 - 7)?

Would the child like to have a weekend away with other kids who have similar interests?

If you have answered yes to the above then you need to know about the Sibling Weekend - 10 to 12 September 2004 (see below for details)

The flier and registration for the sibling weekend away is now available!! Call the Autism Information Line for more details.

Autism Information Line

Autism Association of NSW

(02) 8977 8377

www.autismnsw.com.au

SIBLINGS WEEKEND

The Autism Association of NSW is holding a Siblings weekend.

This is an opportunity for siblings of children with an Autism Spectrum Disorder to:

- Meet other children in the same circumstance and make a friend or two
- Feel special
- Talk about their issues and get constructive advice on how to cope with them (under professional guidance)

HAVE LOADS OF FUN!!

WHAT DOES THE WEEKEND INVOLVE:
The weekend will include a variety of fun games and recreational activities such as horse-riding and canoeing. There will also be an opportunity to meet Lisa Llorens and her sister. Lisa (who has autism) is a gold medallist from the 2000 Paralympic Games, competing in sprint and track events. Lisa and her sister have offered to share their experiences.

WHERE: Vision Valley, 7 Vision Valley Road Arcadia, Sydney www.visionvalley.org

WHEN: Friday 10th September - Sunday 12th September 2004

TIME: 7pm Friday Evening (after dinner) until 2pm Sunday afternoon COST: $140 per participant (this includes accommodation, food and all activities)

AGE: School age in Year 4 - Year 7

CONTACT: Autism Association of NSW for more details 8977 8377

AGSA
THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA, Inc
Funded by the NSW Health Department
ABN 83 594 113 193

66 Albion St, Surry Hills NSW 2010
Ph: (02) 9211 1462 **Fax: (02) 9211 8077**

You are invited to AGSA's Annual General Meeting

on

Saturday October 23, 2004
at 66 Albion St, Cnr Commonwealth and Albion Streets
Surry Hills (Old Children's Court Building)
Time: 11.00 am

AGENDA

1. Welcome and Introduction
2. Apologies
3. Acting President's Report
4. Information Officer's Report
5. Treasurer's Report and audited accounts
6. Election of Office Bearers for 2004/05
   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

Guest speaker *(to be confirmed)*

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

RSVP 15th October, 2004. Please telephone AGSA if you will be attending.

Form of Apppointment of Proxy
Rule 33 (2)

I, ……
(full name)

of ……..
(address)

being a member of the Association of Genetic Support of Australasia Inc, (AGSA) hereby appoint

……

of……
(full name of proxy)

being member of that incorporated association, as my proxy to vote for me on my behalf at the Annual General Meeting of the Association to be held on Saturday the twenty third of October 2004.

……..
Signature of member appointing proxy

……..
Date

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.

66 Albion Street
SURRY HILLS
New South Wales 2010
AUSTRALIA

Email: agsa@ozemail.com.au
Web: www.agsa-geneticsupport.org.au

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

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*