AGSA
THE ASSOCIATION OF GENETIC SUPPORT OF 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

Hello there one and all,
As we moved into the new financial year and I am pleased to say AGSA is looking good. In this issue I will include a short profile on our Board members as well as the AGSA team.

Recently I attended the Carers NSW conference at Brighton-le-Sands. It was a good opportunity to network and learn more about support services available for carers. I learnt that your local council may have a carers support group evening running or a community dinner once a month e.g. Mosman Council. Check out your local council's activities.

There are Koori Yarning Camps for Aboriginal and Torres Strait Islander carers through NSW Carers.

Bradfield Park Wellbeing Centre at Milson's Point has a carers program for people who are supporting someone with a mental illness. 02 8920 0675. This group recently ran a sibling program on film making. The presentation on this project showed the siblings having a great time learning how to direct, film, cut and edit.

Cancer Connections is a brand new website with lots of resources for people with cancer, survivors and their partners, family and friends. www.cancerconnections.com.au

Here is some information if you have carers in your workforce who juggle their paid employment with their personal caring role. Contact Carer Support to find out information on how to assist staff who combine caring and work. For more information read NSW Carers Action Plan 2007-2012 or Ph. 02 4320 557.

Carers NSW Older Parent Carer Support Coordination Program. The Older Parent Carer Support coordination Toolkit has been approved and will be available for distribution soon.

If you're 45+ (or Aboriginal 45+) and caring for a son or daughter and would like advice or assistance in planning for the future, please call the Carers NSW Older Parent Carer Support Coordination Program on 02 9280 24744. Other offices are in Broken Hill, Coffs Harbour and Dubbo. Carers in other areas in NSW ring 1800 242 636 (freecall except from mobiles).

Do you want some help with estate planning? Contact Donal Griffin 02 8266 8537 or email; donal.griffin@au.pwc.com. Clarendeene Estate Planning lawyers – a business unit of PricewaterhouseCoopers.

I also attended the HGSA & Genetic Counsellors conference in Fremantle in May. It is always good to catch up with the genetic counsellors and hear first hand what's been happening in their area.

Some websites on grief.
www.ccihealth.wa.gov.au Tools to help reduce anxiety.
www.health.net.au-links
www.blackdoginstitute.org.au
ww.healthtalkonline.co.uk

Until I see you all at Genetic Awareness Week on 2nd September
Keep safe and happy.
Best wishes,
Dianne Petrie OAM

Post Script
For the last year I have been a consumer representative on the Prince of Wales & Sydney/Sydney Eye Hospital Consumer Advisory Committee and I would like to take this opportunity to alert you to this service. Please feel free to contact the CAC or myself regarding any concerns or advocacy issues require for these hospitals.

The Prince of Wales and Sydney/Sydney Eye Hospital Consumer Advisory Committee (CAC)

Prince of Wales Hospital and Sydney Hospital and Sydney Eye Hospital are facilities of the South Eastern Sydney and Illawarra Area Health Service which reports directly to NSW Health

We represent the hospitals and community services and our aims are to tell you how you can assist the hospital and how we can assist you.

Prince of Wales Hospital

- Site established in 1856 and upgraded in 1993
- Around 45, 000 patients attended the Emergency Department
- There are around 3000 staff and 570 beds, including day-only, mental health, hospital in the home (HITH) and overnight beds
- POW admitted 41,984 patients in 2007/08

Sydney Hospital/ Sydney Eye Hospital

- The majority of the Hospital's buildings were opened in 1894 and upgrades completed in 1995.
- The Sydney Hospital site was also home to the first nursing school in Australia, founded by Lucy Osburn, who was sent to the colony by Florence Nightingale
- There are around 500 staff and 113 beds and 10,000 admissions

Why is there a Consumer Advisory Committee?

- "To advocate a consumer perspective to the health service management on behalf of the communities served"

What can you do?

- Inform us about any concerns about the healthcare provided (or the need for services to provide healthcare) at Prince of Wales and Sydney/ Sydney Eye Hospital
- Your input assists the hospitals to ensure needs of broader community are represented

Phone: 02 9382 5000
Email:

NNConsumerAdvisoryCommitee@sesiahs.health.nsw.gov.

AGSA TEAM

Dianne and her husband Richard have two children and their daughter Natasha has William syndrome. They started the Williams Syndrome Association of Australia in 1985 and have run an annual WS Picnic Day on the last Sunday in August for 18 years. Dianne is the Director of AGSA and has a BA in Psychology and an Advanced Certificate in Counselling. She has been working in the area of genetics and family support for 24 years and serves on many committees both here and overseas. In 2006, Dianne was awarded an OAM in the Queen's Birthday Honours List in recognition of her work.

Chiu Ling Lau completed a Bachelor of Psychology from the University of South Australia and a Graduate Diploma in Science (Psychology) from the University of Sydney. She is currently undergoing registration with the New South Wales Psychologist Registration Board. Chiu previously worked for Learning Links as an Intern Psychologist on a 6 month contract. She has also worked as an Early Intervention Therapist and has a great rapport with children.

Kathy Fitzgerald has a Bachelor of Applied Science (Computing Science) and a Master of Commerce Degree. She has worked in IT and banking for over twenty years. Following a break from work while having young children she now works at AGSA as the Administration Officer and is responsible for the Rare Chromosome Support Group working in conjunction with Unique, UK.
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Shane Waterton is a Social Worker with over 25 years experience in a variety of non-government services that work with families and young people. She also has qualifications and experience as an adult educator working with staff in community services in areas such as child protection, staff development and staff performance.

AGSA'S Medical and Professional Advisory Board

Associate Professor Kris Barlow-Stewart, BSc (U.Syd), PhD (U.NSW), Genetic Counsellor (FHGSA), has been the Foundation Director of NSW Health's Centre for Genetics Education based at Royal North Shore Hospital since 1988. Her career has centred on addressing the information and support needs of the community, education and

training needs of professionals and the impact of the rapidly developing field of genetic technology. Kris was a co-author of the 2007 national genetics resource for GPs: Genetics in Family Medicine and has developed a number of resources for GP practice as well as for the broader community. She has guided the production of the Australasian Genetics Resource Book since 1993 (8th edition, 2007), bringing together the three essential pillars of support groups, professional services and information. Kris has contributed widely to the development of policies in this area and is a member of a number of peak National and State organisations advising governments and peak bodies. She is currently Chair of the NSW Genetics Services Advisory Committee to NSW Health and a member of the Human Genetics Advisory Committee, a principal committee of the NHMRC. At the international level, Kristine has published widely and is invited to review articles for a number of journals including Community Genetics, Journal of Genetic Counseling, Patient Education and Counselling, Clinical Genetics and the Journal of Medical Genetics.

Professor Bridget Wilcken AM, MD, FRACP, FRCPA (hon), FHGSA
Bridget Wilcken graduated in medicine from Edinburgh University. She is the Clinical Director of the New South Wales Biochemical Genetics and Newborn Screening Services at the Children's Hospital at Westmead, Sydney. She has 35 years' experience in the investigation and treatment of patients with inborn errors of metabolism. Research has been on homocystinuria, disorders of fatty acid oxidation, and in the general area of newborn screening, especially screening for cystic fibrosis and establishing screening by tandem mass spectrometry for many rare disorders. She has published over 170 papers in peer-reviewed journals, written 10 book chapters, and is on the editorial board of several scientific journals. She is former President of the Human Genetics Society of Australasia, the International Society for Neonatal Screening (ISNS), and the Australasian Society for Inborn Errors of Metabolism, and former chair of the Genetics Services Advisory Committee for New South Wales. In 2002 she was awarded the Order of Australia for services to newborn screening, and in 2004, the Guthrie Medal of the ISNS.

Professor Ron Trent is a medical graduate from the University of Sydney. His interest in genetics started in the early 1980s when he was at Oxford from where he obtained a DPhil degree. He is a Fellow of the Royal Australasian College of Physicians and the Royal College of Pathologists of Australasia. He is presently Professor of Medical Molecular Genetics at the University of Sydney, and Head of the Department of Molecular & Clinical Genetics at the Royal Prince Alfred Hospital. He is

involved in a number of national committees relating to research and genetics including the NHMRC Research Committee and the NHMRC Human Genetics Advisory Committee of which he is the Chair. Ron is also a member of the Council of the NHMRC. His current research interest in genetics focuses on gene – environmental interactions. In his hospital work, he supervises a DNA testing laboratory. His major clinical/laboratory expertise in medical genetics is in the thalassaemia syndromes.

Professor David Sillence MD Melb MB BS FRACP FRCPA FAFPHM FAFRM (Hon) MACMG is a Professor of Medical Genetics and Head of the Discipline of Genetic Medicine at the University of Sydney. He undertook specialist training in medical genetics at the Murdoch Institute for Birth Defects Research, Victoria, from 1975 to 1977 with Professor David Danks and gained his MD for studies into the genetics of skeletal disorders. He then proceeded to postdoctoral studies at the Division of Medical Genetics, Harbor– UCLA Medical Centre, Torrance, California with Professor David Rimoin. Professor Sillence is a certified clinical geneticist. He is a Fellow of the Australian Faculty of Public Health Medicine (RACP), reflecting his involvement in genetic health services organisation and management, and also a corresponding member of the American College of Medical Genetics. He was a member of the working party that developed the New South Wales Genetic Service and established the Department of Clinical Genetics in the Western Sydney Genetics Program based at The Children's Hospital at Westmead. For the past 18 years Professor Sillence has taught postgraduate courses in medical genetics and public health. At the same time he pioneered the New South Wales Genetics training program for clinical geneticists. He is a member of the Genetics Services Advisory Committee of the Health Department of NSW. He is chair of the Professional Advisory Committee of OI Australia, SSPA and a member of the Professional Advisory committees of OI Federation of Europe and AGSA.

IMPORTANT INFORMATION FOR YOU

The Companion Card
The Companion Card is for people with a significant permanent disability, who always need a companion to provide attendant care type support in order to participate at most available community venues and activities.

Attendant care type support includes significant assistance with mobility, communication, self-care, or learning, planning and thinking, where the use of aids, equipment or alternative strategies do not enable the person to carry out these tasks. It does not include providing only reassurance, social company or encouragement.

The requirement for attendant care to access most events does not include requiring support to deal with infrequent, unexpected or unpredictable events. The Companion Card was not developed to overcome or compensate for any particular venue's lack of accessibility; including the absence of ramps, lifts, accessible toilets, appropriate signage or captioning, etc. Responsibility for these access issues remains with venue and activity operators.

The Companion Card is not issued to every person who has a disability. The card is issued to people who can demonstrate that they would not be able to participate at most venues and activities without a companion, and that this need is life-long. Companion Cards cannot be issued if the applicant may become independent in the future as a result of treatment/management, training, recovery or developmental improvements. Companion Cards can only be issued when an ongoing need for a companion can be demonstrated.

There are no income or assets tests applied to applications for a Companion Card, and people may apply irrespective of their employment status or nationality.

Application Criteria
Companion Card applicants must meet criteria developed by the Victorian Department of Human Services, based on the Disability Services Act 1991 (Vic).

In summary, you can apply for a card if:

1. You live in New South Wales; Victoria; Queensland; South Australia, Western Australia and Tasmania, and
2. You have a significant, permanent disability, which may include issues related to ageing and psychiatric illness; and
3. Due to the impact of your disability you would be unable to participate at most community venues or activities without attendant care support; and
4. Your need for this level of support will be life-long.

Facilities, organisations or potential companions are not eligible to apply for a Companion Card. Cards will only be issued to, and will remain the property

of, the person who has a disability. This enables the cardholder to choose whom they prefer to take as a companion to each venue/activity.

Can children apply?
Children may apply for the Companion Card however they must demonstrate a life-long need for attendant care support. In the case of children, it is often difficult to determine their potential. As Companion Cards are given for life, no card can be approved before their life-long potential can be verified. As with all applications, children are assessed case by case and cards are not provided for supervision, social support or reassurance alone.

Am I required to complete the application form for the applicant?
The application form is to be completed by the applicant/legal guardian or agent.

What section do I complete?
On a Companion Card application form you are required to complete the Health Professional Declaration. Before completing this declaration you are required to verify the information contained in the application form, sign the reverse of the applicant's photographs and provide details regarding the applicant's disability and their requirement for attendant care support. Please see below for the full list of what your signature confirms.
When describing the functional impact of the applicant's disability, their attendant care support requirements or their treatment and recovery; please provide a definitive assessment. Companion Cards will only be issued to applicants who will require life-long support.

How can I get more information about the Companion Card?
Companion cards are available in the following states:
NSW, Qld, WA, Tas, Vic.,S.A., Please call Free Call 1800 893 044 during business hours to speak to a Companion Card Information Officer.

Who accepts companion cards?
Please go to this website for specific information for NSW:
http://www.nds.org.au/nsw/companioncard/affiliates.htm

Eligibility for Rent Assistance

You may be eligible for Rent Assistance if you:

- receive a pension (special rules apply if you are under 21 years and receive Disability Support Pension), or
- have dependent children and get more than the base rate of Family Tax Benefit, or
- have care of a child between 14% and 35% of the time and are not eligible for Family Tax Benefit but meet other Family Tax Benefit requirements, or
- receive an allowance or benefit (but don't have dependent children) and:
  - are over 25 years, or
  - have a partner, or
  - are under 25 and living permanently or indefinitely apart from your parents or guardians.

To receive Rent Assistance you must also meet the residence requirements of your pension, allowance, or benefit.

Paying rent

If you pay your rent directly to State or Territory Housing Authorities, you are not eligible for Rent Assistance.
To be eligible for Rent Assistance you must be paying more than the amount of rent shown in the table below for:

- rent (other than for public housing), or
- service and maintenance fees in a retirement village, or
- lodging (if you pay for board and lodging but are unable to tell us exactly what you pay for each, two thirds of the amount you pay will be accepted), or
- fees paid to use a caravan site or other accommodation that you occupy as your principal home, or
- fees paid to moor a vessel you occupy as your principal home.

Rent cut offs for Rent Assistance

If you are	You must be paying more than this amount of rent per fortnight
single with no dependent children	$95.40
single, sharer, no dependent children	$95.40
single with children	$125.44
a couple with no dependent children	$155.20
one of a couple who are separated due to illness, no dependent children (including respite care and partner in prison)	$95.40
a couple who are temporarily separated, no dependent children	$95.40
a couple with children	$185.64

For more information about Centrelink Rent Assistance phone: 13 2717.

Share your story to help medical research.

Dear AGSA Members,
The Children's Medical Research Institute (CMRI) is an independent organisation committed to unlocking the mysteries of disease. Our scientists investigate conditions such as birth defects, cancer, and epilepsy. Our philosophy is that major advances in prevention and treatment of disease and disability come from research into the fundamental processes of life.

Our work is funded in large part by the community, which includes our national Jeans for Genes® campaign. It is this enormous community support that makes it so important for us to share our progress with the public. And this is where we thought you may be able to help us.

Basic medical research is a meticulous process and progress can sometimes seem slow, but we regularly have important results to share with the scientific community and the public.
In sharing this progress, it can help if we have a personal story to tell alongside the laboratory breakthroughs. Would you be interested in telling your family's story? This way we can work together to raise awareness for conditions that need more public understanding and help raise funds and awareness for medical research at the same time.

CMRI scientists are currently working on: developing a panel of drugs for the treatment of epilepsy; developing gene therapy techniques for treating inherited liver and immune disorders; revealing the basic mechanisms allowing cancers to keep growing, and studying the genes involved in abnormalities and malformations that are present from birth.

The fundamental nature of research at CMRI means that it has the potential to uncover treatments for huge variety of conditions affecting both children and adults.
By telling the story of how you have been affected by a genetic disease you can increase public understanding and make a valuable contribution towards improving progress in medical research.

For more information please call us on (toll free) 1800 436 437 or email info@cmri.org.au. You can learn more about our research at www.cmri.org.au

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.

KWTS
"We live in Toowoomba, Queensland and have a 6 year old Boy with KTWS and would love to make contact with anyone else who also has this condition" Please contact AGSA for details if you wish contact.

HERNS SYDNROME (Hereditary Endotheliopathy, Retinopathy, Nephropathy and Stroke)
This family have suffered greatly due to this disease and are desperate to find some help or to even understand more about HERNS syndrome. If you know of another family or can provide information please contact AGSA.

BIONEWS

'Reprinted with permission from BioNews (www.bionews.org.uk)"a free web-and-email-based news service on human genetics and assisted reproduction, published by the UK charity Progress Educational Trust.

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Week 08/06/09 - 14/06/09

TEN YEARS ON - PERSONAL GENOME SEQUENCING FOR UNDER £50K:
By Adam Fletcher:

The age of affordable genome sequencing is inching ever closer, spurred on last week by the announcement that San Diego biotech firm Illumina is launching its personal sequencing service for under $50,000. Speaking at the Consumer Genetics Show in Boston, Massachusetts, US, Jay Flatley - the president and CEO of Illumina - unveiled a service that represents the first time that an individual's genome can be sequenced so thoroughly, for such a(relatively) low price.

Illumina has offered basic genotyping services since 2001 - reading a customer's single nucleotide polymophisms (SNPs) and relating these to specific disease traits - but is better known as supplier of the popular sequencer instrument - Genome Analyzer II - to both academic and industry sectors. In February, Flatley predicted that babies' genomes would be sequenced at birth by 2019, given the current rate of sequence development, fueling rumours that Illumina would soon enter the whole-genome sequencing market itself.

Conceding that demand for such an 'information goldmine' may not yet be huge, an optimistic Flatley nonetheless proposes that the current market potential could be on the order of hundreds of customers. 'We think there is quite a number of people who want to be among the first ten named genomes in the world, or the first 100, or the first 1,000, so I think there is some market here', he said.

In a move deemed as pragmatic yet naive, the service will only be available via referral from a physician. Direct-to-customer (DTC) sequencing remains controversial, as customer anonymity might more easily be comprised should no doctor be stationed as mediator and, furthermore, patients may not be in a position to make informed decisions in response to unanticipated results. Germany has recently passed a law against any DTC sequencing operations. However, prescriptions are available to customers via Illumina's website, where customers can choose from a list of physicians allied to the firm.

Increasingly rapid sequencing will ostensibly drain the market, as individuals will need their genome sequencing just once. The arguably more interesting service - the interpretation - is being left by Illumina to third-party firms, like part Google-financed 23andMe, deCODEme and Navigenics, who will calculate disease risks, ancestries and other traits of interest, based on the literature. Whilst sequencing will one day reach a peak, interpretation will be an ever-evolving market, as our understanding of the human genome expands. Illumina has yet to invest in this field.

Flatley also unveiled a prototype iPhone app that would allow doctor and customer to share and analyze sequencing results, fitted with a biometric

* **WRONG EMBRYO IMPLANTED IN WOMAN AT CARDIFF FERTILITY CLINIC:**
By Ailsa Taylor:

An embryo belonging to a couple being treated at a Cardiff fertility clinic was accidentally implanted into the wrong woman and subsequently destroyed. The prospects of Deborah, who is 40, having another child with her partner Paul, 38, are slim and both are said to be devastated that their last hope of conceiving a sibling for their six-year-old son has been lost.

'In less than 10 seconds our wonderful world was shattered when the senior embryologist stood in front of us and said, 'I'm very sorry to tell you, but there's been an accident in the lab. Your embryo has been destroyed', the woman told the Mail on Sunday newspaper. It was only after the incident that the hospital came clean with the couple and told them that their embryo had in fact been implanted in the wrong woman and then any potential pregnancy terminated using the morning after pill.

The couple have recently succeeded in claiming damages against the University Hospital of Wales, where the incident took place in December 2007. If the other

woman's pregnancy had been allowed to go ahead, it would have meant a further court case to decide who would have custody of the child, according to the couple's lawyer, Guy Forster of Irwin Mitchell.

Ian Lane, Medical Director of the Cardiff Vale NHS Trust which governs the University Hospital of Wales, has apologised 'unreservedly' for the mistake. 'This was a rare but extremely upsetting incident for everyone involved and we take full responsibility for the distress caused to both couples and their families,' he said.

The IVF mix-up happened when a trainee embryologist took the embryo from the wrong shelf of the incubator. Forster called the incident 'an accident waiting to happen' and said that the hospital had been involved in two 'near misses' during the year prior to the incident and that the Human Fertilisation and Embryology Authority (HFEA) had previously warned the hospital to ensure basic operating procedures were carried out, particularly following some similar cases in recent years and an official enquiry into how such mistakes could have happened.

Speaking to the Times newspaper today, Gedis Grudzinskas, a consultant in infertility and gynaecology, said that samples in all hospitals should be electronically tagged to avoid further mix-ups. 'The technology for tagging will minimise the risk and increase confidence in fertility treatment, because this case in Wales shows that things are still going wrong,' he said, adding that the standard measures set in place by the HFEA to prevent further IVF mix-ups, such as 'double witnessing' had clearly proved insufficient.

- The Mail on Sunday 14/6/2009 'Ten seconds that ruined our lives: Couple whose last embryo was put in another woman tell of their agony'

CONFERENCES

4th Global Patients Congress – Istanbul, Turkey – 23-25 February 2010

IAPO is delighted to announce that the 4th Global Patients Congress will be held in Istanbul, Turkey. IAPO's Congress provides a unique opportunity for patient advocates, across diseases and across borders, to come together and participate in an exciting agenda which will help to foster global networks, develop practical skills, and enable engagement and understanding of key policy issues affecting patients in the international arena.

As IAPO increases its membership in Africa, Asia, Latin America and the Middle East, it is appropriate and exciting to be able to invite you to this event in Istanbul, a city founded on three great civilizations, where the East meets the West. Whether this is your first time, or your fourth time at IAPO's Global Patients Congress, we hope that you will enjoy the multi-disciplinary, participative and supportive environment at this unique international event.

Please look out for more news and updates about IAPO's Global Patients Congress, which will be published here in the IAPO monthly newsletter and on our website. If you would like more information about previous Congress', please see our website at www.patientsorganizations.org/congress. If you have any queries, please do not hesitate to contact us by emailing Esther at membership@patientsorganizations.org.

8th Malaysia Genetics Congress
4 to 6 August 2009
Awana Genting, Pahang, Malaysia
Website:
http://www.persatuangenetikmalaysia.com/congress.htm
Contact name: Prof. Dr. Mohamad bin Osman

American Society of Human Genetics
October 20-24, 2009 Honolulu, Hawaii

HUGO Symposium on Genomics and Ethics, Law and Society - Sequencing of individual Genomes: Impact on Society and Ethics
Geneva, Switzerland, November 1-3, 2009

European Human Genetics Conference
Gothenburg, Sweden, June 12-15, 2010European

Human Genetics Conference
Amsterdam, The Netherlands, May 28-31, 2011

SURVEY

Examples of names of Birth Defect Registers around the world

Country/State	Register Name
Australia	National Congenital Anomalies Monitoring System
- NSW	NSW Birth Defects Register
- Victoria	Victorian Birth Defects Register
- South Australia	South Australian Birth Defects Register
- Western Australia	Western Australian Birth Defects Register
International clearinghouse	International Centre on Birth Defects
Canada	Maternal and Infant Health Section Public Health Agency of Canada
China	National Centre Birth Defects Monitoring
Costa Rica	Costa Rican Birth Defects Register Centre
Cuba	Centro Nacional de Genética Medica ISCM-Habana
Czech Republic	National Register of Congenital Anomalies in the Czech Republic
Finland	The Finnish Register of Congenital Malformations
France - Rhone	Registre Des Malformations en Rhone Alpes
Germany - Saxony	Malformation Monitoring Saxony-Anhalt
Hungary	Hungarian Congenital Abnormality Registry
Italy -	Registro Campano Difetti Congeniti
Italy - Sicily	Sicilian Registry of Congenital Malformations
Italy – Northern Lombardy	Congenital Malformation Registry of Northern Lombardy
Malta	Malta Congenital Anomalies Registry
New Zealand	New Zealand Birth Defects Monitoring Programme
Norway	Department of Medical Birth Registry of Norway
Slovak Republic	Slovak Teratologic Information Centre
Spain	Spanish Collaborative Study of Congenital Malformations Centro de Investigación sobre Anomalías Congénitas
South America	Estudio Colaborativo Latino Americano de Malformaciones Congénitas
Ukraine	Omni-Net Ukraine Birth Defects Prevention Program
USA - Atlanta	National Center on Birth Defects and Developmental Disabilities
USA - California	California Birth Defects Monitoring Program
USA - Texas	Texas Birth Defects Epidemiology and Surveillance
USA - Utah	Utah Birth Defect Network
Wales	Congenital Anomaly Register and Information Service

See following page for survey

Possible names suggested for NSW Birth Defects Register suggested by community members:

Congenital Abnormalities Register
NSW Birth Anomaly Register
NSW Births – Congenital conditions
Register of People with Different Capabilities
NSW Birth Variation Register
NSW Birth Analysis Register
NSW Register of Congenital Conditions

As members of AGSA we would like your opinion on the proposal to change the name of the Birth Defects Register. We have provided examples of names of registries around the world for your information.

To assist us in this, please complete this short survey and return to AGSA by 25th July 2009.

SURVEY

PROPOSAL TO CHANGE THE NAME OF THE NSW BIRTH DEFECTS REGISTER (BDR) TO;

NSW REGISTER OF CONGENITAL CONDITIONS

Please tick √ and circle comments you agree with.

1. I do not have a problem with the current name.

2. I do not like the current name.

3 .I would like/would not like the name changed

_____
_____

4. Do you have any preferences for the new name of the BDR?

_____
_____
_____
_____

5. I like the name YES NO

NSW Register of Congenital Conditions

6. How did you receive your parent copy of the BDR registration form? In person or in the mail?

_____
_____
_____

Don't remember_____

7. I was upset/was not upset, when I received my notification form stating my child was registered on the Birth Defects Register.

_____
_____
_____

If you answered yes, please briefly explain how you received this information and how you felt.

_____
_____
_____
_____

Other comments

_____
_____
_____

Thank you for your participation.
Please tear out and return to
AGSA
66 Albion Street,
Surry Hills NSW 2010
Or
Email us your comments to:-
dianne@agsa-geneticsupport.org.au
or telephone the AGSA team on
02 9211 1462