THE · ASSOCIATION
OF·GENETIC·SUPPORT
OF · AUSTRALASIA

FUNDED BY THE NSW HEALTH DEPARTMENT

DECEMBER 1994 ISSUE 15

merry Christmas

MISSION STATEMENT

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

EDITORIAL

1994 has been one of considerable change for AGSA leading to an exciting and challenging year and one of which we can be justifiably proud. The increase in calls to the office, formation of new groups, attendance at other conferences etc., has required a large time commitment on the part of Dianne and all members of the committee.

We would particularly like to express our appreciation to those professionals who have willingly given of their time, often at considerable personal expense, to attend new group meetings ie Klinefelter, Rare Chromosomal etc and who have subsequently written or reviewed articles for our Newsletter.

No group can exist without a membership base and we would like to thank you all for your support, encouragement and friendship over the last months whilst we have endeavoured to restructure. Our historical belief that the "vision" we had of AGSA evolving as an essential component of Genetic Services, is being realised.

On behalf of the AGSA Committee please accept our best wishes for the Christmas/New Year period and we look forward to furthering AGSA's aims in 1995.

Ros

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DIANNE'S REPORT

I am pleased to announce that AGSA has received funding from the NSW Health Department for another year. This is certainly the best Christmas present.

Our AGM was enjoyable although a very HOT day and I would like to give a special thank you to Ruth Cromer for her excellent talk. A copy of Ruth's speech will be published in our next Newsletter. Eighteen people attended with as nearly as many apologies. Next year the AGM will be held in early November thus avoiding the Christmas madness and enabling more people the opportunity of attending.

A date for your calendar is March 18-19, 1995, AGSA's Living Grief Seminar.

I would like to wish you a happy Christmas and a very enjoyable and safe Christmas break. I look forward to a very busy 1995 with AGSA and its members. Thank you for your support in 1994.

Dianne Petrie

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CAN I HELP ?

Support Groups meet many of your needs. However, if you want to talk things through with a psychologist/ genetic counsellor with wide ranging hospital experience, I am now available for private consultations. Individuals or families welcome. For further information please contact:

Bronwyn Butler
(02) 419 6782

ERRATUM

The Disorder Fact Sheet on Klinefelter syndrome published in the October 1994 newsletter of AGSA has an error regarding a lack of production of testosterone in affected males. There is insufficient testosterone produced by the testes. The Genetics Education Program apologises for the error and any concern it may have caused.

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REQUEST FOR HELP

ANOPHTHALMIA/ MICROPHTHAMLMIA REGISTRY

We are looking for patients with anophthalmia or microphthalmia (unilateral or bilateral) to enter into a new registry.

Our goal is to catalogue as many patients as possible to determine incidence, syndromes and other causes of anophthalmia/ microphthalmia.

All patients entered into the registry will be included on the mailing list of **ICAN**, a new parent support group. (International Children's Anophthalmia Network).

Please direct all inquiries and referrals to:

Adele Schneider, M.D or
Jill Stopfer, M.S.
Developmental Medicine and Genetics
Albert Einstein Medical Center
5501 Old York Road, Levy 2 W
Philadelphia, PA 19141
Phone: (215) 456-8722

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 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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ANDROGEN INSENSITIVITY OR TESTICULAR FEMINISATION

A lady is seeking contact with another person with this condition. Please contact the AGSA office for details.

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CARPAL TARSAL OSTEOLYSIS

A family in New Zealand with a nine year old son with this condition would like contact with another family.
Please contact AGSA for details.

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EHLERS-DANLOS

Female twins in Melbourne would like contact with anyone for support. Contact AGSA for details.

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4p-, 22q11, IGM DEFICIENCY

A family with a 9 year old son would like contact with a family with a similar condition. Contact AGSA for details.

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LEIGH DISEASE

A family in Queensland would like to make contact with other families who have a child or have lost a child with Leigh Disease. For further details please contact AGSA.

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STICKLER SYNDROME

A lady in Tasmania who has an ll year old daughter with this condition would like contact with another family.
Please contact AGSA for details.

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TRIPLE X

A mother of a young baby in Queensland is urgently seeking contact with a family who has an older child with this

condition. Please contact AGSA for details.

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HEREDITARY FRUCTOSE INTOLERANCE

As two people have now been placed in contact with each other, AGSA has decided to print this request again in the hope that we will locate more families. Please contact AGSA for more details.

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TRISOMY 5

A Victorian mother of a six weeks old baby boy would like contact with another family. Please contact AGSA for details.

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DELETION 9

A mother of a four month old baby girl would like contact with another family. Please contact AGSA for details.

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SUPPORT GROUPS

POLAND SYNDROME

Lindsey Sabberton would like to start up a support group. Lindsey has a four month old son with this condition and she can be contacted on (042) 61 6655 or contact the AGSA office.

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CHANGE OF NAME:

The Osteogenesis Imperfecta Society of Australia
P.O. Box 401,
Epping NSW 2121
Contact Lynne Foxall
Phone: 869 1486
Support groups are now in most states, please phone for names and numbers.

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NEW SUPPORT GROUPS OVERSEAS (Thanks to Alliance Alert, October 1994)

Klippel-Trenaunay Syndrome Support Group, 4610 Wooddale Ave, Edina, MN 55424; TEL: 612/925-2596

Familial Erythrophagocytic Histiocytosis Support Group, 609 New York Road, Glassboro, NJ 08028; TEL: 1/800/548-2758

Spotlight 6 (Chromosome 6 disorders): Valerie Wiggins, 2617 Ted Toad Rd., Rising Sun, MD 21911; TEL: 410/658-6264

Family Support Group for Pallister-Hall Syndrome: Debbie Messer, Bradford, VT; TEL: 802/222-9683

Dr Leslie Biesecker of the National Center for Human Genome Research (301/402-2041) and Dr John Graham, Jr. of Cedars-Sinai Medical Center, Los Angeles, CA 9310/855-2211) have initiated a study of Pallister-Hall syndrome. Thought to be sporadic and uniformally lethal, this poorly understood rare disorder can be inherited and is compatible with long-term survival. Researchers want to determine the range of the symptoms, the natural history of the symptoms, and the gene that causes the disorder.

LETTERS TO THE EDITOR

From Queensland Clinical Genetics Service, Brisbane North Regional Health Authority, P.O. Box 251, CHERMSIDE QLD 4032

Re: CLINICAL GENETICS IN QUEENSLAND

A submission into Queensland Health's New Initiatives program was successful, and has seen the provision of $850,000 to commence a state-wide clinical genetics service for the state of Queensland within 1994/95. Built into this submission was an initial staffing level of sixteen, with a proposal for expansion to 33 staff planned for by the year 1999.

The Queensland Clinical Genetics Service will be facilitated through the Brisbane North Health Region, and will be based within the Herston Hospitals Complex in close proximity to the Royal Children's Hospital, the Royal Brisbane Hospital and the Royal Women's Hospital. A Steering Committee has been appointed to oversee its implementation and accommodation.

Although the central core of the Queensland Clinical Genetics Service will be based in Brisbane, it is envisaged that Genetic Counsellors will be based in provincial areas according to clinical need, with Geneticists providing a regular outreach service.

It is anticipated that training may have to be provided for some Genetic Counsellors, as there are currently only eight fully trained and accredited genetic counsellors in Australasia, and Queensland Health is collaborating with Universities with regard to the provision of this training.

Advertising for the positions of Director, Clinical Geneticists, Genetic Counsellors, Molecular Geneticist and Cytogenetic Technicians has taken place. The process of appointing people to these positions will be undertaken as soon as possible.

A Senior Registrar has been appointed to undertake six months of training in laboratory and clinical duties, and this will be followed by a twelve-month clinical genetic training program at Newcastle-Upon-Tyne in the United Kingdom.

Mrs Barbara Hogan, Clinical Genetics Project Officer, Children's Hospital, Herston Road, HERSTON QLD 4029

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From Victorian Clinical Genetics Service

Royal Children's Hospital Genetics Clinic

Margaret Sahhar, Social Worker, has written to say a successful meeting was held on 12th November for the Angleman Support Group. For further information please contact Margaret on (03) 345 5157 or Heather Church on (03) 735 4877.

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INFORMATION

Meryl Bolin, Grief and Loss Counsellor, for the Retinitis Pigmentosa Society wrote to inform AGSA that there is now a clinic for RP providing a medical team including a Genetic Counsellor. For appointments ring (02) 736-7115

Address: Retinitis Pigmentosa Clinic
Concord Hospital
Gate 3
Concord Road
CONCORD NSW

Phone: (02) 736-7115

RESOURCES AND AIDS

The Horticultural Therapy Society of N.S.W Inc. promotes the use of horticulture in recreation and rehabilitation for:

- elderly people
- people with disabilities, and those who work with them

Services includes, talks, workshops, seminars, demonstrations and the publication of a quarterly newsletter.

In association with T.A.F.E the Society offers special courses:-

* Gardening for the physically disabled
* Plant propagation for the physically disabled
* Gardening fundamentals for the developmentally disabled
* Nursery practice for the developmentally disabled
* Home gardening for the sensory impaired
* Home gardening for the elderly
* Vocational courses for special groups
* Horticulture therapy techniques (for health care workers).

For further information contact:-

The Horticultural Therapy Society of N.S.W. The Telopea Centre (in the grounds of the Ryde College of TAFE)
250 Blaxland Road,
RYDE NSW 2111
Telephone: (02) 8097 0392

Wheelchair and parking facilities are available at the centre.

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Joan Stratilatis - MPS Parent in Victoria has found DERMOFILM an effective treatment for children and adults who mouth, fingers, hands etc. DERMOFILM is non-toxic and forms a waterproof skin or false glove. It is a mousse-like substance and costs $20.00 for approximately 70 mls.

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Independent Travellers is a fully licensed and accredited travel agency structured specifically to assist travellers with special needs - people with a physical, sensory or intellectual disability, the frail, the aged and any one who requires a little more care and attention than average. Independent Travellers are used to answering the myriad of questions associated with disabled travel and finding solutions to the most difficult problems:-

* How will I manage in my wheelchair?
* Will they take my guide dog in the plane?
* How will I enjoy a trip on my own?
* I'd love to go cruising but is it suitable for me?

For further information please call their Research Consultant - Barbara Worley on their Toll Free number 008 811 355 or write to:-

Independent Travellers,
Level 7,
182 George Street,
SYDNEY NSW 2000

Telephone (02) 256 4444
Facsimile (02) 233 2273

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ABILITY TRAVEL offer carefully selected and researched holidays to ensure plenty of fun at a relaxed pace, for clients with mild to moderate disabilities. All tours are fully escorted by Cheryl Dunn or experienced staff who assist with medication and banking needs and are on 24 hour call through the tours. For further information contact Cheryl Dunn on (02) 534-5973 or write to:

Ability Travel
P.O. Box 92,
NARWEE NSW 2209

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CERTIFICATE OF LEARNING DIFFICULTIES

The program will equip school-based personnel in detection, intervention and assessment techniques designed to support and develop those students who experience difficulty in learning.

Classroom teachers as well as support teachers, counsellors, therapists, consultants and school executive responsible for students with special needs will find this program particularly suitable. It is relevant to teachers from all areas of education and for TAFE personnel.

Specific enquiries regarding the program content should be made to the Academic Director, Dr. Loretta Giorcelli, on (02) 385 9709.

Course dates:
28 February - 6 June 1995 and
25 July - 31 October 1995
Held each Tuesday from 5.00pm-7.30pm in the Clive Monk Theatre, St George Campus, UNSW.

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BOOKS

Living with Osteogenesis Imperfecta - A Guidebook for Families.

A new publication available from the OI Foundation, 5005 W.Laurel St., Suite 210, Tampa, FL 33607-3886.
Tel: 813 282-1161. Cost: $19.95 US plus $2.55 postage and handling.

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DIASTROPHIC DYSPLASIA GENE DISCOVERED

Using a combination of history, population genetics, and computational biology, a joint team of U.S. and Finnish scientists has discovered the gene responsible for diastrophic dysplasia, the second most common form of dwarfism in the United States and the most common form in Finland. Researchers employed a new method for tracking down human disease genes called linkage disequilibrium mapping, which is useful in any population in which it is possible to trace chromosomes descending from a common ancestor. The work revealed the mechanism of the disease and suggests a possible new direction for therapy.

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A NOTE FROM THE TREASURER

At the AGM I was given the task of clarifying with the auditors an amount listed in expenditure as car expenses. The auditors have advised that this was a coding error which should have read petty cash.

Margot Latham

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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.

For your information we profile.....

RARE CHROMOSOMAL DISORDERS, HOW RARE, IS RARE, HOW COMMON IS COMMON AND WHY?

Kindly written for AGSA by Stuart Purvis-Smith, Cytogeneticist from The Prince of Wales Hospital, November 1994.

Cytogenetics (the study of chromosomes) is a somewhat esoteric subject; the cytogeneticist announcing the nature of his or her work is likely to experience a blank look and the feeling that most people do not wake in the morning thinking about chromosomes.

The fact is, that while most people would be hard pressed to describe a chromosome or the nature of chromosome abnormalities, the majority of us are familiar with Down syndrome, the condition caused by the most common chromosome abnormality. Down syndrome is caused by the presence in every cell, of an extra copy of chromosome 21, a condition known as trisomy 21.

The normal human chromosome complement consists of 46 chromosomes (23 pairs) including a pair of sex chromosomes; females have 46 chromosomes including two X chromosomes; males have 46 chromosomes including an X and a Y chromosome. The child with Down syndrome has 47 chromosomes and instead of a pair of chromosome 21 will have 3 copies of that chromosome (trisomy).

Trisomy 21 is just one of many such possible abnormalities involving other chromosomes either as trisomies or monosomies (loss of one of a chromosome pair). It is not surprising that Down syndrome is the most common of the trisomies in newborn babies. Chromosome 21 is the smallest chromosome and therefore the genetic imbalance arising from trisomy 21 is smaller than that arising from trisomy of a larger chromosome. The result is that the congenital abnormalities suffered by patients with Down syndrome are less severe than those in infants with trisomy of a large chromosome. Chromosome abnormalities are a common cause of pregnancy loss (miscarriage) and those involving large chromosomes are more likely to miscarry than those involving small chromosomes. Compared with trisomy 21 (about 1 in 700 births), trisomy 18 (1 in 6,000) and trisomy 13 (1 in 12,000) are relatively rare because the chromosomes are larger, the genetic imbalance is greater and the affected fetus is less likely to survive.
Surprisingly, cytogeneticists regard all the above chromosome disorders as being

relatively common.

The size of the chromosome or part of the chromosome involved in trisomy or monosomy is thus one of the major factors which influence the frequency of particular abnormalities - genetic imbalance of large chromosomes is seen in living individuals only rarely because the abnormalities tend to be lethal and the affected pregnancies miscarry.

Another factor influencing the frequency of chromosome abnormalities is the "genetic activity" of the chromosome involved in the imbalance. Some chromosomes or parts of chromosomes have many more active genes than others and imbalances involving these tend to produce more severe affects. An example of this phenomenon is the difference in frequency between trisomy 21 and trisomy 22, two chromosomes which are similar in size. Trisomy 21, as indicated earlier is the most common trisomy, whereas trisomy 22 is very rare; the difference between the two chromosomes is the fact that chromosome 22 has more active genes and therefore has more severe consequences when found in the trisomic or monosomic state. Nearly all fetuses with trisomy 22 are lost through miscarriage.

In addition to abnormalities involving the gain or loss of whole chromosomes, there is an almost infinite variety of abnormalities in which small parts of chromosomes are either duplicated or deleted. These are known as structural abnormalities because they usually involve chromosome breakage and rearrangement. Many such rearrangements are visible through the microscope however there are others which are so small that they are invisible and must be detected by other means.

Structural rearrangements arise by a different mechanism from that responsible for trisomy and tend to be less common. Although they are well know to geneticists, conditions such as Wolf-Hirschhorn syndrome (deletion 4p), Cri-du-chat (deletion 5p) and Prader-Willi syndrome (deletion 15q) occur in newborn babies at a frequency of only about 1/25,000 to 1/50,000.

Some deletions and duplications cause congenital abnormalities which do not fall into an easily recognised pattern and are therefore not regarded as established "syndromes". These are the ones which are regarded as truly rare and in most instances only a few similar cases have been reported worldwide. Sometimes the rearrangements in different patients may appear to be very similar, but cause a different spectrum of congenital abnormalities because the chromosome breakpoints differ between the patients. Some families may thus have affected individuals who can be considered almost unique in the world.

Overall, chromosome abnormalities of one kind or another are relatively common and can be found in about 1 in 200 newborn babies. Those specific conditions such a Down syndrome, Klinefelter syndrome and Turner syndrome which are familiar to many people may be considered as common, however the vast majority are known only to geneticists working in the field.

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FAMILY STORY

EXTRA BIT OF GENETIC MATERIAL ON CHROMOSOME 5

On the 23 June 1993, we were thrilled to have our second baby daughter - Alexandra. Her birth was uncomplicated and Alex thrived. However, from early on I felt things were all not as they should have been. Alex continued life as an unresponsive "model" baby. She did not smile at people
but started laughing aloud at pictures. It was difficult to convince anyone of my misgivings as she looked so perfect. Because of her lack of eye contact with people and with me as her mother, I felt she wasn't using her eyes. A referral to an ophthalmologist at 3 1/2 months resulted in her eyes being tested - the results were normal. This test was followed by a Cat scan, various blood tests, urine tests then a hearing test. All results pointed to normal. However, Alex's personal/social skills, fine and gross motor skills were not developing. We started physiotherapy at 4 months as she had extremely low muscle tone.

At 7 months we were referred to a neurologist at the Prince of Wales Hospital. He felt she was "different" but couldn't quite put his ideas as to what. Alex did not resemble us and looked quite different to her older sister. However, after measuring all "bits and pieces" everything fell within the norm.
He referred Alex for a chromosome test. Three weeks later results showed an extra bit of genetic material on chromosome 5. My husband and I were subsequently tested but results were negative. Further tests revealed Alex has a partial trisomy on chromosome 5q bands 13-14.

It is a very rare disorder and very little is known about her condition. We are very optimistic about her future and hand on to the words of the geneticists that "she will do everything in her own time". We felt a need to gain as much information about her condition as possible although this proved rather difficult. We also couldn't believe everything we read.

Alex taught us never to give up, and never stop pouring out the love she so deserves. Everything is so hard for her although her perseverance and determination together with lots of time and encouragement from her Mum, Dad and older
sister gets her where she has to be. Up-to-date everything she has accomplished has been in a series of "small steps" with a lot of consolidation in between.

We were thrilled to have her say "Mum mum" recently, as to date, her verbalisations consisted of a lot of clicking noises and the open vowel screeches. However these new sounds have disappeared as she seems to be concentrating on the prerequisites of walking.

Her older sister adores her and likewise in her way we are noticing signs of affection developing.

Unfortunately she is extremely prone to getting many viruses which tend to further delay her progress.

She is part of an early intervention programme consisting of a physiotherapist, occupational therapist, speech pathologist and early special education teacher. Alex is very special and has special needs.

I feel that one mustn't be overwhelmed by information. Get as much as possible but use what you can cope with at the

time. Never lose sight of your priorities and as parents never doubt your instincts as we are the best judges of our children.

We felt extremely privileged to meet up with AGSA and in the process of the formation of the Rare Chromosomal Support Group.

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ERIN'S STORY

My second pregnancy did not follow the normal course. Our daughter, Erin, was born and termed 'small for dates' along with dry skin and overlapping toes. She left hospital, still not gaining back her birth weight.

The next 12 months are very worrying - feeding problems, weight problems, lethargy, milestones slow, projectile vomiting,eczema, hearing problems etc. We had a 'gut feeling' something was wrong, but no one could tell us.

The shock really hit us when I took her for a routine check-up at the Eye Specialist, who informed me after checking her, that she probably was 'Down' syndrome. He was out of place to tell me that, but it spurred things along. After this she had to have chromosome tests done (to discount his assumption of 'Down's') along with all the other tests they thought were necessary. Erin was diagnosed with long Arm 18 Deletion Syndrome 18q- Syndrome) - a rare chromosome abnormality. She was now 13 months old. The textbook did not paint a favourable picture - 28 severely disabled, one mild - physically and mentally. This made us more determined to do as much as possible for her. So we started with Early Intervention - speech, physiotherapy and occupational therapy, along with the many other doctors and specialist appointments. Erin coped wonderfully, even with the hospital stays. Erin also started with Respite Care, so I could have some time with my other daughter. We still use this service.

Erin progressed onto Itinerant Pre-school, then onto Pre-school with a support teacher as well as attending The Shepherd Centre for hearing impaired children. Erin is now attending a Moderately Developmentally Delayed Unit and is integrated into the mainstream classes where appropriate.

For years we were unable to trace another family in Australia with 18q-. It is not until this year that I came face to face with other 18q- children and their families - but I had to travel halfway across the world to meet them. This was at The 1st Annual Chromosome 18 Registry and Research Society Family Conference in Chicago. It was an experience I will never forget, the friendships made, the exchange of information on our children, on education and health problems were invaluable. But it is the support and understanding of family, friends and the people who have taken an interest in Erin, that has kept us going through the rough times during these years.

Time has passed so quickly, Erin is now 10 years old. Her health is much better now. Her social behaviour has improved dramatically with age, maturity and her understanding of things. We are presently experimenting with her diet, to see if it will improve her further.

Erin enjoys going to school, reading, the movies, McDonalds, walks, Kids Club and Brownies.

Erin's determination, her love and laughter has brought happiness to us and to many other people.

PROFILE

LUKE: 18p- Translocation 15p. Luke is now 4 years old and was diagnosed at 5 months.

Main problems: Low muscle tone, speech and growth. Luke walked at 19 months and has had two ptosis operations and a hydrocele operation. He is now doing really well both with speech and occupational therapy.

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"I JUST WEAR MY GENES DIFFERENTLY"

"Why am I so small, am I different?"
"No" I said realising her time had come
so we had a talk, as best we would
"Will I always be small, even with the needle that makes me grow?"
"Yes" I said sighing inside
"Why Mum?"
"Genes that gave you brown eyes and brown hair
Genes that make you, you
Small things, you can't see,
that made you before you were born.
Yours, are just mixed differently."
"Oh" she said with the wisdom 5 year olds have
"I'm still the same, I'm still me"
"Yes" I said
"I just wear my genes different"
She skipped her awkward skip
out the door
As I sat with cold hands in the winter sun
I smiled "Yes, that's all, you just wear your genes differently."

Written by Jeanine Thornton for her daughter.

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LEGAL DEPOSIT IN AUSTRALIA

What is legal deposit?

Legal deposit is a statutory provision which obliges publishers to deposit copies of their publications in libraries in the country in which they are published. Under the Copyright Act 1968 and various State Acts, a copy of any work published in Australia must be deposited with the National Library of Australia and the appropriate State library. In New South Wales, Queensland and South Australia, a copy must also be deposited with one or more other specified libraries. Legal deposit extends not only to commercial publishers but also to private individuals, clubs, churches, societies and organisations.

The Copyright Act requires all Australian publishers to deliver a copy of library material to the National Library within one month of publication. Library material means a book, periodical (eg **newsletter**, annual report), newspaper, pamphlet, sheet of letterpress, sheet music, map, plan, chart or table.

What are the benefits of legal deposit?

Legal deposit ensures that the works of authors and publishers will survive for the use of future generations, because the National Library and most other deposit libraries assume an obligation to preserve all material lodged with them. The comprehensive collections of Australian publications formed in this way provide the means for research into all aspects of Australian life , culture, and artistic, commercial, technical and scientific endeavour.

Contact your local State library for details.

Jan Cameron-Smith, Librarian

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Individual	$20.00
Group/Organisation	$40.00

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**** The views expressed in this Newsletter are not necessarily those of AGSA.***

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.