

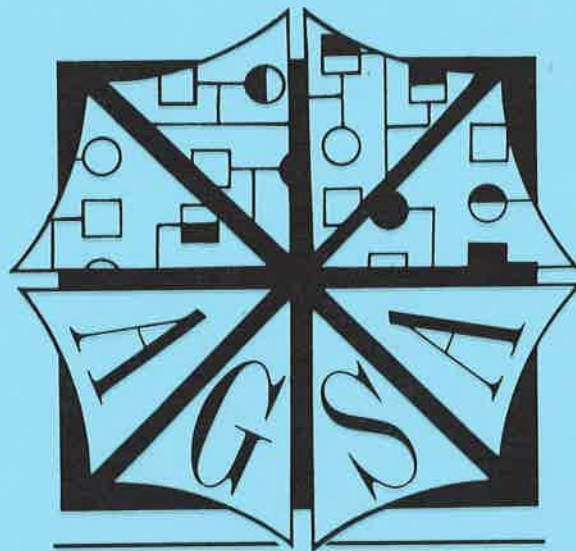
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A G S A

NEWSLETTER

MARCH 1991

ISSUE 7



THE • ASSOCIATION
OF • GENETIC • SUPPORT
OF • AUSTRALASIA

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



SUBSCRIPTIONS

Individuals — \$15.00

Groups/Organisations — \$35.00

Subscription Year — 1st October to 30th September



AGSA aims to:

- educate the medical and allied health professionals and the community about genetic disorders
- lobby government bodies, both Federal and State, for appropriate funding for genetic services
- provide a contact point for families who are affected by genetic conditions so rare that they do not have their own support group
- facilitate accessibility 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.

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AGSA gratefully acknowledges
the support of the NSW Genetic Education Program
in the production of this Newsletter

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(Insert — *Please remove if required for your files*)
 1. Tuberous Sclerosis
 2. Noonan Syndrome



*Congratulations to
the following families*



Sue and Ross Pinkerton on the arrival of a healthy son. Sue was a member of the Working Party leading to AGSA's formation and a past Executive Committee member.

Elizabeth and Ray Sloss — a daughter — Amy, who has four brothers! Elizabeth previously wrote an AGSA article relating to her difficulties with Robert.



PRESIDENT'S REPORT

25th March, 1991

I was pleased that so many of you could take the time to attend the Annual General Meeting. On behalf of the Executive Committee, I want to thank you for your support and confidence that was clearly displayed in the re-election of the Office Bearers.

At the AGM I talked at length about the financial constraints that we were facing and I should say that our ability to raise money will be severely limited. You would all be well aware of the difficulties that the Australian economy is facing and this will severely inhibit corporate Australia's ability to support charities such as ours.

We have made approaches to a number of groups seeking sponsorship for our newsletter, and again I would ask for suggestions as to companies or institutions that we can approach. In the short term however, we will have to run this charity on income derived from subscriptions.

In this newsletter you will see that names of the chairpersons of various sub-committees that have been established. These committees demonstrate our commitment to the future and I am particularly looking for support for the membership committees headed by Kris Barlow and Mandy O'Reilly. It is very important that our membership continues to grow.

This report is by nature brief as it is only a month since I last addressed you. Whilst the message might be short, the commitment is not, and I look forward to your continuing support to ensure that AGSA is successful in achieving all of its goals.

R J M MacDiarmid
President

SUB-COMMITTEES

In view of the amount of work that is anticipated in the future, it was agreed that there was a need for various sub-committees to be formed. These are as follows:

Fund Raising/Sponsorship Sub-Committee

Rob MacDiarmid,
plus one other yet to be decided.

Newsletter Sub-Committee

Ros Smith

Professional Advisory Board

Margot Latham

Interstate Membership

Kris Barlow

New South Wales Membership

Mandy O'Reilly

Library/Resources

Jan Cameron-Smith
Brenda Phillis

ANNUAL GENERAL MEETING REPORT

12th February, 1991

I am delighted to address you as your President on this, the second Annual General Meeting of The Association of Genetic Support of Australasia Inc.

When I wrote to you in the December newsletter, I expressed some frustration at our lack of progress in achieving tax deductibility. That frustration transpired into our inability to carry out a number of programs that had been priorities since the birth of AGSA, frankly without money you can do little in life these days.

So whilst 1990 proved to be a year of consolidation in AGSA, I am pleased to say that 1991 started off with the welcome news that the Tax Office had finally approved our application for tax deductibility for donations of \$2.00 or over. Regrettably this approval came at a price, in the sense that they were not prepared to grant specific tax exemption for the purposes of education. They have however, granted approval for the establishment of a respite centre which will also be the home of AGSA. It is envisaged that such a centre would not only provide accommodation, either on a long or short term basis for individuals suffering from some form of genetic disorder, but it will also house the office of AGSA, a resource library and meeting room. It is envisaged that centres would be established in all capital cities throughout the country, along the lines of Ronald McDonald House. Whilst AGSA is a National body, it is appropriate that the first centre be established here in Sydney.

At this point in time no decision has been made as to where the centre would be located and this will very much depend on the cost of acquisition of land or premises, which could be converted to suit our needs. Suffice to say that it will be extremely difficult to raise funds in the current economic environment and a fund raising program is not being considered. Whilst the Fund Raising Committee establishes its objectives, the AGSA Committee will consult with the member groups as to the needs and requirements for these centres.

Whilst the Department would not grant tax deductibility for education, we believe that newsletters, brochures etc can be funded by way of sponsorship and you may rest assured that the newsletter will continue to be published on at least a quarterly basis, and we are already approaching potential sponsors in that regard. We would welcome any contacts that you may be able to refer to us.

Education of the community has always been a priority of this Committee and will remain so, and part of the fund raising charter is to obtain sponsors to enable us to continue with this program.

In the short term, AGSA will have to operate from membership income. To increase membership, two sub-committees have been established, one to be headed by Kris Barlow to promote membership interstate, and the second by Mandy O'Reilly to promote membership amongst support groups and individuals here in New South Wales. At present, membership comprises 30 support groups and 80

individuals and we would welcome inquiries on membership from all members of the community particularly health professionals.

In the foreseeable future, we are looking to establish an AGSA Secretariat and one of the fund raising committee members has very generously agreed to provide office accommodation in the city centre at absolutely no charge to AGSA. Funds permitting, we would hope to staff this office with an Executive Director and a Secretary. Whilst the appointment of an Executive Director is unlikely for some months, we do need the services of a Secretary and we welcome inquiries from people who would be prepared to share the work or work part time.

Whilst I acknowledge that it is going to be extremely difficult to raise funds in this environment, we nevertheless now have a firm direction and one which I wish to see actively pursued. I want to see AGSA's aims and objectives clearly recognised in the community by State and Federal Government and by families and support groups who will see tangible benefits in what we have to offer. I frankly do not believe that the average Australian appreciates the challenges, the hardship, the frustration, sometimes grief, sorrow, or pain, but often joy and excitement that we, as families face. I think if people have a greater understanding of our needs and our feelings, our calls will be recognised and supported.

It has been said before but needs to be said again, that AGSA is an umbrella organisation for the benefit of not only the support groups but of their individual members. We have no wish, nor have we the intention to intrude into your own domain. We hope that ultimately in time, the fulfilment of our objectives will help your support groups further your own goals.

I am truly excited about the future of our group and pledge whole-heartedly my commitment to attaining objectives that we have now set. I would welcome your support.

R J M MacDiarmid
President

* * * * *

LETTER TO THE EDITOR

Febr 1, 91
Os Kochanowskiego 4/31
43-190 Mikolow
Poland

Dear Ros,

I was very glad to get your letter and a newsletter AGSA. What a surprise it was to hear that you are the editor of newsletter AGSA. Please accept my warmest congratulations! Of course that we remember you very well. It was a great pleasure for Joanna and myself to make your acquaintance during our stay in England. Our visit was an event we will long remember with appreciation. Joanna thinks about you very often, she has like you very much.

But nice days and lovely time go past very quick and we had to come back to our everyday but difficult life. I am back to work and Joanna is looking after Kamila. She is well and a good girl now, though we live in very dusty habitat and it's easy to get an infection.

Kamila have been nine in January. Her MPS disease is developing but she doesn't suffer from other disease. She stays at home most of the time because the winter has already started in Poland (now is -20°C) and we can't go out with her on that weather. Fortunately we have got the Buggy (a gift from your MPS Society) and we take her for a walk as many times as we can.

Although she doesn't speak at all, she wets, she has more and more epilepsy attacks and she is hardly able to walk. We love her very much and we spend a lot of time on her.

Magdalena started school in September and thank God she grows up quickly and she is well. She makes well at school. I work 14 hours a day - in my job and as a president of the Polish MPS Society. As a result of difficult economic situation most of our MPS families are worse off and their children suffer even more. Well, therefore we try to help them first because they get very little social and medical care.

We hope that there will be less problems one day in Poland and through our activities MPS children in Poland will be able to live normal life.

We would like to propagate lots of the news on MPS and related diseases among the members of our Society. That's why I would be pleased to receive your "AGSA Newsletters" though I'm sorry but I haven't money to pay.

Will finish here.

Please write at the earliest opportunity you have. I shall be anxious to hear from you.

With good wishes to your Family and to all members of AGSA from us all.

With love

Marek and Joanna Popek

Editors Comment

The Conference referred to in Marek's letter was held August/September, 1990 in Manchester UK —

2nd International Symposium on
Mucopolysaccharidoses (MPS)
and Related Disorders.

A number of Australian Professionals and families attended this Symposium — 27 countries were represented.

Those professionals well known to the AGSA membership included Professor David Sillence; Dr John Nelson (NSW); Dr John Rogers (Vic) and Dr John Hopwood (SA)

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GENETIC SERVICES

Many people are interested in their family history from an historical view point. However, a family's **medical** history is also very important. Often, knowledge of a family history of a particular health problem can lead to early detection by screening tests or prevention through adjustments to lifestyle.

The New South Wales Genetic Education Program has produced the 'Family Tree Guide to Health' which is inserted in this newsletter. It may be possible to detect a health problem which is being inherited in a particular family. This information can be taken to the family physician and may be useful in the prevention of genetic disorders.

SUPPORT GROUP CATALOGUE

Third Edition (1991)

This Catalogue was developed as part of the Genetic Education Program of the New South Wales Genetics Service. It is intended as a resource for professionals and genetic support groups who are often contacted by families seeking information about genetic disorders.

This Catalogue lists support groups active in New South Wales.

AGSA, the Association of Genetic Support of Australasia, is the appropriate contact for those affected by rare conditions for which no support group is listed. AGSA or the Genetic Education Program will facilitate contact with international and interstate groups where no local group is available.

The Catalogue may be obtained by contacting the NSW Genetic Education Program on 438 7324.

MEDICAL ARTICLES

THE NOONAN SYNDROME

The word syndrome means "a pattern of features" and Noonan Syndrome (NS) is the name given to the particular pattern of features described by Dr Noonan in 1963. Dr Noonan, a cardiologist, saw children with heart problems and noticed that a group of children with an abnormal pulmonary valve looked very similar. The main features of NS are short stature, a heart problem, a broad or webbed neck and a characteristic facial appearance. Males and females can have NS which is a different and separate condition to the Turner Syndrome.

Although most often only one person in a family is thought to have NS, we know it can be passed from a parent to a child. NS is inherited in a dominant fashion which means a person with it has 1 chance in 2, (50:50), of passing it on with each child they have. When only one person, a child, has NS in a family we say it has been caused by a new change (called mutation) in a specific gene which, as yet, remains

unidentified. We know that mutations occur in the egg and the sperm all the time and are not caused by anything a parent does or does not do before, or during, a pregnancy. Sometimes a parent is very mildly affected with NS and the diagnosis in an adult may not be made until they have a child with NS. A medical geneticist can confirm the diagnosis, discuss the various aspects of NS and give counselling regarding the risk of a subsequent child having NS.

The cause of NS has not been found. Extensive studies are underway in both the UK and USA to identify the gene involved and to find out how it affects the formation of the body to cause the pattern we recognise as NS. Some doctors think fluid, called lymphoedema, builds up in the developing foetus and causes the changes. Often babies with NS have puffy hands and feet due to collected fluid. Sometimes fluid persists around the ankles, and occasionally can occur around the lungs and leak from the bowel. These observations support the theory that the fluid called lymphoedema is important in causing the pattern of features we recognise as NS.

The physical features of NS are outlined in the article by the Noonan Syndrome Association. Not every person with NS will have all the features described and it is important to know that certain features are more common at different ages, for example the eyes are more prominent when young, the neck is more webbed in childhood and adults with NS may be difficult to diagnose because the pattern seems less obvious. At least two thirds of all people with NS will have a cardiac problem and the various types that are commonly seen are outlined in the NS Association article. Many children with NS will be under the care of a cardiologist and it is important that prior to having an operation a person with NS is examined for cardiac problems including an echocardiogram.

Outlined below are the few special areas for further consideration.

1. **Growth.** Feeding difficulties in infancy are very common often leading to hospitalisation for poor growth. This appears to be secondary to the poor tone and co-ordination of muscles involved in swallowing. This can be a most distressing time for new parents. Childhood growth occurs at the normal rate but the child with NS will be on or around the lowest end of the scale for age. The puberty growth spurt is reduced, delayed or occasionally absent and studies are currently underway to evaluate the pros and cons of giving growth hormone treatment. Although there has been initial limited success, some children with cardiac problems, in particular the thickening of the heart wall, have had potentiation of these problems on growth hormone treatment. For this reason further studies are currently underway. The average adult height for NS males is 162.5cm and for females 152.7cm, but of course each individual will follow their own growth pattern.
2. **Bleeding problems.** Some people with NS bruise easily and have a bleeding problem. This was mentioned by Dr Noonan who noticed that children after cardiac surgery with this particular pattern often bled longer and had more problems. Studies in the USA and the UK have found that there are various causes for this. In some NS people one or more of the clotting factors in the blood is low or missing, and others have problems with the platelets which plug up holes in the

blood vessels to stop leaks. Platelets may be low in numbers or simply function poorly. Various combinations of the above have also been found. It is important that a person with NS who is going to have an operation should alert their doctors to the fact that they have NS and that they could have a bleeding problem.

3. **Hyperpyrexia.** Another concern, although very uncommon, for people with NS is the risk of high temperature (hyperpyrexia) in association with an anaesthetic. In this unusual complication the body is unable to control its inner temperature which rises dramatically during or after an operation. This is more commonly seen in people with muscle problems but has been noted to occur in a few people with NS. Treatment is available but it is important to warn your doctors, including the anaesthetist, that you have NS and hyperpyrexia may be a problem.

Remember there is great variation within any syndrome. If you are concerned about any aspect of the articles or have further questions please get in contact with the Noonan Syndrome Support Group. They will be happy to discuss your concerns and inform you how to have an appointment with a geneticist if this could be of help to you.

By Dr Alison Colley
Clinical Geneticist
Regional Medical Genetics Unit
Hunter Area Health Service

Editors Comment

For further information see Family Stories and Removable Insert

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MARFAN SYNDROME

Research Update

The puzzle of Marfan Syndrome, an autosomal dominant disorder characterised by tall stature, and in some persons with the disorder, eye, heart or blood vessels problems is about to be solved. Scientists from Finland have recently localised the gene for the disorder to the long arm of the number 15 chromosome (*reported in the New England Journal of Medicine 1990; 323:953-9*).

A research team from Johns Hopkins Moore Clinic convened by Dr Reed Pyeritz have taken this localisation and isolated fragments of the gene. It was perhaps not surprising to find that fragments of the Marfan S. gene were fragments of the gene which codes for fibrillin an ubiquitous connective tissue protein. Fibrillin, which for some time has been potentially implicated as a candidate protein for this disorder, is distributed throughout the skin associated with elastin microfibrils. Dr Lyn Sakai with Dr David Hollister and co-workers had been able to show that cultured skin fibroblast cells from patients with Marfan S. synthesized less fibrillin than normal control fibroblasts (*New England Journal Medicine 1990; 323:152-9*).

Only 18 months ago an international consortium reported that the Marfan S. could not be localised to over 75% of the human genome. However Dr Peltonen and colleagues from Finland continued work in those areas of the genome which had not been

investigated. Recently they were successful in obtaining a chromosomal localisation. While work on the chromosomal localisation of fibrillin has been going on, other groups were working to identify the gene for fibrillin. Thus 1990 has seen a beautiful example of research in several disciplines coming together to solve the problem of Marfan Syndrome.

What will it mean for Marfan Syndrome families? The next 3-5 years will be a period of intense research in which Marfan Syndrome families in Australia through participating in research, have an unparalleled opportunity to both assist and benefit from the new knowledge that will become available. If we can characterise the mutation in many families, this will help us to understand how the disorder comes about and how we might prevent the heart and blood vessel problems as well as scoliosis.

Several types of research will have to be undertaken. Firstly we will need better clinical research ie identifying and monitoring Marfan Syndrome features in each individual and each family. Secondly we will need tissue studies probably from skin biopsies. These will need electron microscopic examination to show how the faulty protein, fibrillin, leads to damage in the tissue. These studies will then need to be correlated with the molecular genetics studies so that we can build up a whole picture. One of the puzzles of Marfan S. is that there are many more persons with partial forms of Marfan S. eg the tall stature, scoliosis and foot problems. We will need to know whether these are related or not. Some will turn out to have other tissue abnormalities. Ultimately this partnership between research workers and families with Marfan S. will lead to considerable benefits in terms of care and treatment.

Professor David Silence

For information about Marfan Syndrome Support Groups around Australia please contact

Mrs Elizabeth Lewis
PO Box 464
ST MARYS NSW 2760
Telephone: (02) 670 3600

Ms Joy Pedstone
Marfan Support Group
PO Box 176
WHITTLESEA VIC 3757

FAMILY STORIES

I could write a book, not only about my having Tuberous Sclerosis (TS) but also the experience of having a child severely affected by it. There is simply too much to include for an article such as this one but I will try to give as accurate a picture as I can give.

Tracey was 17 months old when she and I were diagnosed as having TS back in February, 1973. Thankfully I am only mildly affected. At the time we were diagnosed we were having problems with Tracey's epilepsy, her behaviour and her sleeping habits. In those days, not much was known about TS apart from the prognosis of it being largely doom

and gloom. People had never heard of TS so they did not understand anything, either about it or our situation.

Over the years Tracey's epilepsy was a major concern. Despite being on enormous doses of anticonvulsants her fits were largely uncontrolled and because of them she has endured countless injuries. Her behaviour too caused great concern. At times she would be erratic, not only injuring herself but lashing out at whoever was in range. There were times where she would go for a week or more and be lucky to sleep one hour in twenty-four but as she has grown older her sleeping pattern has improved.

We did put Tracey into residential care when she was 3 years old for 9 months and in that time her behaviour settled down to a large degree so we brought her back home again but slowly and surely, over the next few years her behaviour deteriorated to the point where we had to put her into permanent residential care when she was 7 years old. She spent 4 years at Cram House. At one stage her behaviour was so wild and erratic she was alternated between Cram House and Baringa at fortnightly intervals as she was too difficult to manage. She has lived at Baringa for 8 years now. Thankfully she has settled down a lot compared to how she used to be but she still has her moments. Her fits are much better controlled too, she only seems to have the major fits now in her sleep.

If I was asked what the worst aspects of my experience were I would firstly have to say the enormous number of people, family members, friends, neighbours, professional people who, without considering me as a person who would not do such things, had me categorised as neurotic, an unfit mother, a child basher, somebody who put their child into a home because of not wanting her. Sure this hurt me a lot but I did the very best I could for Tracey, I did nothing wrong but thankfully I am not the one who has to live with my conscience.

I would then have to say the isolation I have had from family, friends and even neighbours who simply find our situation too painful. A relative once said to me that I would never be able to imagine the number of our family and friends who found our situation too painful, strangely I know each and every one of them. I am now saying to people that I am a real person with real feelings and emotions just like everyone else, I am not merely a painful situation. I have heard people with illnesses such as cancer say that they find people cannot cope with their situation and they experience incredible isolation. I can truly identify with this.

I have always said and I still sincerely believe that my salvation through everything was my wonderful husband, I have been very lucky to have had him but the stress and strain of our situation has taken its toll on my marriage, we separated 5 months ago as Andy simply needs some time out. I am thinking of this separation positively in that we can both now look at our lives and our situation for the right reasons. It is my hope that we will end up back together again but this may never happen so I must now get on with my life which is exactly what I am doing.

I would like to believe that through my experience I have become a more caring and compassionate person. I believe too that it has given me the strength to help and support other families who have members with TS.

Lynn McKinnon

Editors Comment

For further information see Removable Insert

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At this moment I wish fervently that I had recorded our children's progress in a baby book. However, the publication, Noonan Syndrome - What Is It has been a helpful memory jogger.

David, the fifth of a family of six, was born in 1956, his birthweight being in line with that of two of his siblings. No suggestion was made by the obstetrician that there were abnormalities, but a sister on the staff considered that there was some evidence of cyanosis. My own observation was that, despite weighing in at 8lbs 1oz and being full term, he had a somewhat unfinished look - fingernails and crumpled hands and ears. I do recall very clearly the scruff of skin at the back of the neck.

From the beginning, feeding was problematic. Never particularly successful at breast-feeding, I was easily persuaded to bottle-feed. The pattern was uneven. Sometimes David retained his formula; sometimes its return was immediate and projectile: but the comment that he would settle down when we returned home left his "mum" feeling that she was mismanaging him.

As the weeks passed, weight gain was minimal; he was admitted to RAHC as a failure to thrive baby, also showing signs of hydrocephaly. Following a lumbar puncture, an abscess developed near the site, and there began a long battle against golden staph. Because of it a recommended craniotomy was delayed some months. At this stage the range of antibiotics was very experimental and it was to be a long while before a complex was found to which David responded.

Though none of these factors came into the Noonan pattern, they must have had an added effect on the child's growth and development both physically and intellectually and as such deserve mention.

The first three years, therefore, were taken up coping with fighting infection and establishing feeding. We were aware that development was delayed and wondered how much of this was attributable to weakness following long illness and how much to intellectual retardation.

We were referred by the paediatric physician to an endocrinologist who monitored David's development until he was a young adult. It was he who expressed the opinion that the condition was of genetic origin and who ultimately sought the advice of an overseas specialist who diagnosed Noonan Syndrome. Our son was then eighteen years old.

At puberty he was found to have a minor heart defect. This has never limited him. Puberty was slow; the voice still ranges up and down the scales.

His health overall is good: hearing and vision have been tested from time to time. There is evidence of a "lazy eye" when David is tired and there is a degree of miopia. Tests for deafness have produced no definite results. A lowered perceptual level could be a contributor to an apparent difficulty at times. A tendency to fitting is controlled by drugs.

We feel that David has been fortunate to belong to a large family. He grew up in an environment where he was surrounded by people of all ages. We endeavoured to meet his needs, but were patently aware of the needs of his siblings too, and strove to fill these to the best of our ability and energy without putting undue stress of the extra time necessary for his medical and daily care.

As parents, it would have been a help to know other Noonan cases and their families, to swap notes with them and to discover from them the techniques they had found successful. We could only take each day as it came, being careful to find the extra time for repetition in setting speech

PROFILE

A - Z GENETIC CONDITIONS

It is the intention of AGSA to profile each Support Group/Disorder alphabetically thus increasing awareness within our membership of the range of genetic conditions. Also, it is hoped 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 . . .

TUBEROUS SCLEROSIS

AND

NOONAN SYNDROME

REMOVABLE INSERT
Please pull gently
from staple binding
to remove

TUBEROUS SCLEROSIS

WHAT IS TUBEROUS SCLEROSIS

Tuberous Sclerosis (TS) is a multi-system genetic disease causing tuber-like growths in the brain and, frequently, in other vital organs. The condition develops before birth and continues to do so during a persons lifetime. It occurs in 1-10,000 people and is incurable.

TS, also known as EPILOIA, was first diagnosed by Bournville, a French Physician over 100 years ago but it still remains poorly understood and is often misdiagnosed. Children are born with TS and it can have a devastating effect on them and their families.

SYMPTOMS OF TUBEROUS SCLEROSIS

Typical symptoms of the disease can be one, some or all of the following

Epilepsy

80% of children with TS will be epileptic, some with many types of seizures occurring. The seizures are often difficult to control.

Retardation

This does not always occur. Retardation can vary from mild to very severe. Even though text books say that TS children are retarded and epileptic 20% are free of either symptom.

Behaviour Problems

Some children with TS are very overactive and may have sleeping problems. Some may show signs of autism. Some will scream a lot or bite themselves.

Skin Signs

The earliest sign may be a white skin patch, seen even on newborn babies. These white patches are usually found on the trunk and limbs. At a later age a characteristic facial rash (Adenoma Sebaceum) may appear, especially around the nose, chin and cheeks. The rash appears in 70% of cases. At first the rash is red, pin point spots which later become small lumps.

WHAT ARE THE SIGNS

Since TS affects all systems of the body, the signs of the disease may vary according to the extent to which each system is involved. The first sign may be a white skin patch, the first neurological sign is usually epileptic fits which are difficult to control. The facial rash occurs at a later age. Abnormal growths occur in the brain and can occur in the kidney, heart, eye, bone, lung and liver. Hyperactivity, autism, screaming and excessive rage can occur.

In the past, doctors diagnosed TS from the triad of epilepsy, mental retardation, facial rash and white patches so it was those people who were severely affected that were diagnosed and those people who had skin markings alone or combined with epilepsy went through life undiagnosed. It is now recognised that it is possible to carry TS without any loss of function or dignity.

WHAT CAUSES TUBEROUS SCLEROSIS

TS is caused by an altered gene. The faulty gene causes abnormal development of some cells of the body. The name **TUBEROUS SCLEROSIS** comes from **TUBER** like growths in the brain which, with age calcify and become hard or **SCLEROTIC** hence, Tuberosclerosis.

TS is an hereditary disease carried by a dominant gene. It is estimated that TS occurs as a spontaneous mutation in 80% of cases. In this situation neither parent has TS. Where one parent has TS there is a 50% chance that each child will also have the disease.

PROGNOSIS AND TREATMENT

TS varies in severity of symptoms. People with the mild form can lead full, satisfying lives without any loss of function or dignity. In the more severe forms of TS the disabilities can be very handicapping and an early death can occur as a result of seizures, infections or tumors in vital organs. Although there is still no known cure for TS the outlook continues to improve as medical advances are made in earlier problems, argon laser for the skin problems and special education for those who need it.

AUSTRALASIAN TUBEROUS SCLEROSIS SOCIETY INC

Australasian Tuberous Sclerosis Society Inc was founded in 1982 by Lynn McKinnon. It acts as a mutual support group for parents, sufferers, relatives, health professionals and other interested people, sharing problems and information. It provides national and international information to families, professionals and anybody else interested in TS. It is a member of Tuberous Sclerosis International which was founded in London in October, 1986.

For further information about Tuberous Sclerosis please contact

Mrs Lynn McKinnon
Secretary/Treasurer
22 Mason Street
THIRROUL NSW 2515
Telephone: (042) 67 3992

All donations of \$2 and over are Tax Deductible

NOONAN SYNDROME

Noonan Syndrome is a condition affecting both children and adults, which can cause heart defects and alter physical development. Its exact cause remains unknown.

It is believed that 1 in 2,000 children worldwide are born with this condition.

Many individuals do not receive adequate counselling because the wide variety of features make it difficult to recognise.

PHYSICAL CHARACTERISTICS

Not all Noonan Syndrome children will have all of these features but will present with some of them. They tend to become less obvious with maturity.

Facial

- Eyes Hypertelorism — widely spaced eyes
- Ptosis — drooping eyelids
- Prominent downslanting eyes

Many of these children have visual problems, most commonly squints and myopia.

- Nose Flat broad nose bridge, especially when young.

This can contribute to poor nose breathing.

- Mouth Pronounced top lip below a deep midline groove.
- High arched palate
- Malocclusion due to small jaw.

Many children have delayed teething and an increased occurrence of dental cavities.

- Ears Low set and tipped back
- Thick outer rim
- Turned up ear lobe

There is a high incidence of glue ear leading to mild hearing loss. Sporadic occurrence of sensory neural deafness.

- Hair Very low hairline
- Wooley hair

- Neck Short neck
- Excess skin at back of neck - infancy
- Broad or webbed neck - childhood and adulthood.

Muscular Skeletal System

- Chest Elevated or depressed sternum
- Widely spaced nipples
- Square chest
- Sloping shoulders

- Spine Scoliosis in a minority of cases

- Elbows Cubitus valgus - increase in carrying angle of elbows

Poor muscle tone and hyperextension of some joints are common features.

CARDIAC

A high proportion of Noonan Syndrome patients have an abnormal echogram. The most common abnormalities are:

Pulmonary Valve Stenosis

A narrowing and sometimes a malformation of the valve that takes the blood from the heart to the lungs for oxygenation. This can usually be corrected by open heart surgery or cardiac catheterisation, the former appearing to be the more successful in these children.

Hypertrophic Cardiomyopathy

Thickening of the heart muscles with possible disorganisation of the muscle cells. In some cases, there appears to be a spontaneous improvement in this condition. Drug therapy has also shown some success.

Atrial Septal Defect

A hole between the two upper chambers of the heart.

Ventricular Septal Defect

A hole between the two lower chambers of the heart.

Both these defects are usually surgically correctable.

GENITO URINARY SYSTEM**Undescended Testes**

A high proportion of boys need surgical intervention for this condition.

HEMATOLOGY**Abnormal Clotting Factors**

Deficiencies are common in factors VIII, IX and XII but various deficiencies have been found.

Tendency to Bruise Easily

It is essential that these children are tested prior to surgery.

GROWTH AND PHYSICAL DEVELOPMENT**Feeding Difficulties**

Poor sucking

Frequent forceful vomiting

Failure to thrive

This can lead to some of these children needing to be tube fed

Inability to tolerate solids

There appears to be a delay in co-ordination of palate and muscles of swallowing. By school age, most of these children will have improved.

Shortness of Stature

A large proportion are at the lower end of the growth scale.

Delayed bone maturity

Delayed Puberty

A 3-4 year delay is quite common in both males and females.

Most females have a normal cycle

A delayed growth spurt in late teens or early twenties may occur.

INTELLIGENCE AND BEHAVIOUR

90% of Noonan Syndrome children are in normal schools. Some have learning disabilities in specific areas. There does not appear to be a pattern as to which area will present as a problem. They may be of average intelligence but compared with siblings are usually slower in grasping concepts.

Delayed Speech — Delayed Language

Speech therapy is often necessary for these children.

Social Development

Due to their delayed puberty and short stature, some children can have emotional difficulties during adolescence.

Research is now being done to try to come to a better understanding of this Syndrome, and it is with thanks to the Noonan Syndrome Foundation in the United Kingdom that I have been able to compile this information.

Judy Cork

Noonan Syndrome Association of NSW

303 Rowe Street

EASTWOOD NSW 2122

Telephone: (02) 804 6759

and behaviour patterns. With no idea of likely long term goals, it was impossible to set targets for him. Now we believe that was an asset.

Schooling came in three stages. Two years at pre-school, followed by two in kindergarten at the local P.S., then to Cromehurst Special School for the balance of his education and training. Practical skills are low average, formal learning ability is small, reading and writing being at best immature. He is able to travel efficiently in public transport, taking himself to his open industry job each day. This job he prefers to the limited range of tasks available at earlier workshop placements.

David is a warm, gregarious person with a delicious sense of the ridiculous. TV gives him immense pleasure. We never cease to be amazed at his ability to absorb information from "the Box". Let us say that his physical disabilities for the main part have receded into history and David is very much his own man.

Ros Mein, Kangaroo Valley

Editors Comment

For further information see medical Article and Removable insert.

Dear Ros,

I thank you very much for the newsletters. I was surprised to find that they were so informative, and I am looking forward to receiving the next one.

I would like to tell you something of my daughter's syndrome (Smith-Magenis) 17p. so as you have some understanding about it.

Candice is 3 years and 9 months. From a baby milestones in her development were quite delayed: smiled - 3 months; crawling - 16 months; walking - 2 years. Candice developed 18 viruses and infections in the first 18 months. This apparently has no relation to the syndrome, but it has been found that most patients have developed recurring ear infections requiring tubes to be inserted due to hearing loss.

Candice lost 60% of her hearing and had tubes inserted at the age of 2 years. This, was then thought to be contributing to her delayed development, but there was no improvement. She is also a chronic asthmatic.

Candice has woken every night since birth unless given high doses of sedative. This is also believed to be another manifestation of this syndrome. Her speech is limited to single words. Basic signing has been a great benefit for her to eliminate some of the frustration.

Another manifestation of this syndrome is extreme behavioural problems and sudden mood changes. There is no reasoning with Candice at all. We wait for it to pass and then we wait for it to begin again. Some days are a real struggle.

This is a newly recognised Syndrome. At present studies are being done in California to discover why sleep problems occur. They are also doing studies in Houston, Texas. They are interested in studying this area because it is believed that a gene for a neurological disease called Charcot-Marie-Tooth may be in this region (chromosome 17p).

I have been invited to a meeting sometime in February at the Royal Childrens Hospital. Hopefully we will learn more about this Syndrome and how the Charcot-Marie-Tooth disease bears any relation to this syndrome. I hope that you find the case studies most interesting.

Thank you again.

Yours sincerely

L R Alexander

SUPPORT GROUP

NEWS BULLETIN

Your chance to publicise and provide information about your Society's or organisation's upcoming events and new developments.

The following is a list (of AGSA Member Support Groups) for your information:

Spina Bifida Association of NSW
Cornelia De Lange Syndrome Support Group
The Little People's Association of Australia
Fragile (X) Support Group
The Williams Syndrome Association
The Australian Tuberous Sclerosis Society
The OI Society of NSW
The Neurofibromatosis Assoc. of Australia
Spinal Muscular Atrophy Support Group
The Dystrophic Epidermolysis Bullosa Research Association
The Society for Mucopolysaccharide Disease (MPS)
The Turner's Syndrome Assoc. of NSW
Retinitis Pigmentosa Society of NSW
Coeliac Society
Australian Huntington's Disease Assoc. (NSW)
Australian Huntington's Disease Assoc. (QLD) Inc.
Australian Marfan Syndrome Association
Cystic Fibrosis Association of NSW
Muscular Dystrophy Association of NSW
Haemophilia Society of NSW
ALS — Motor Neurone Disease Association Inc.
Friedreichs Ataxia
Handital (Association for Italian Families and Friends of Handicapped Children)
Down Syndrome of NSW Inc.
Ehler's-Danlos Syndrome Association
Lowe's Syndrome Association Inc.
Thalassaemia Society of NSW
Albino Support Group
Spina Bifida Association of WA (Inc.)
Wellington Huntingtons Disease Association (Inc.)
Prader-Willi Syndrome Association
Charcot-Marie-Tooth Disease/Peroneal Muscular Atrophy International - Canada
Victorian Marfans Syndrome Support Group
Rett Syndrome Association of Australia Inc.
Charcot-Marie-Tooth Disease (CMT) of Australia Inc.
Batten's Disease Support Group

Address Correction

Charcot-Marie-Tooth Disease (CMT)
of Australia Inc

Secretary
No. 7 / 30 Glenarvon Street
STRATHFIELD NSW 2135

OSTEOPETROSIS CONTACT GROUP

Osteopetrosis is a rare disease characterised by a generalised increase in bone density. Bones are well calcified with little or no marrow space.

Dental problems and fractures are common and the liver, spleen and head may be enlarged. Many affected infants do not survive childhood although some have survived into their teens. The severity of the condition is variable.

Osteopetrosis is caused by an autosomal recessive pattern of inheritance ie. both parents carry the same defective gene which is passed on to the affected child. Both male and female children may be affected.

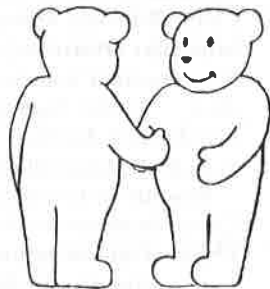
Experimental treatment of osteopetrosis includes bone marrow transplantation. The most seriously affected children are also being treated experimentally with a combination of steroids (prednisone) and a low calcium, high phosphate diet.

Much more research is needed to determine if these treatments may be helpful.

The Osteopetrosis Contact Group is for parents of children with the infantile form of the disease. It is a small personal group offering mutual support to one another and particularly to parents of newly diagnosed children. They have contacts in Ireland, USA, South Africa as well as ten families in the UK.

A doctor in Manchester is very interested in doing some research into the condition but they really need more families to be involved to support them. If there are any parents who would like to join the Osteopetrosis Contact Group please write or telephone.

Margaret Wright
10 Cumberland Avenue
Fixby
Huddersfield HD2 2JJ
Telephone: (0484) 54 5974



Editors Comment

Whilst in the UK last year, Margaret approached me to see whether anyone in Australia would be interested in participating in the Manchester Research Project.

Please contact Margaret at the above address, if interested.

* * * * *

*Please ensure that ALL State Branches
of your Support Group
are advised of AGSA's existence
through your Newsletters.*

* * * * *

SUBSCRIPTIONS ARE NOW DUE

Individuals — \$15.00

Groups — \$35.00

* * * * *

ATTENTION

PROPOSED NEW SUPPORT GROUP

AGSA (The Association of Genetic Support of Australasia) and the NSW Genetic Education Program have received an increasing number of enquiries concerning the need for a support group for families facing termination of pregnancy for genetic disorders.

Although there are groups such as SANDS (Stillbirths and Neonatal Deaths Support) and SAMS (Stillbirths and Miscarriages Support), it appears that the needs of families and couples with genetic disorders are not being met. Such families may face somewhat different difficulties given their involvement in the decision-making process and choice of termination. They also face a future reproductive risk and there are implications for the extended family which are not addressed by existing groups. In addition, we believe the issues and implications that arise for families will be of increasing importance to a wider section of the population as prenatal screening of the general population becomes more readily available.

Apart from the difficult decisions which must be faced by families where a condition is known to be present as a result of prenatal diagnosis, we believe there is a great lack of information and support available to families who face either termination, stillbirth or the continuation of an affected pregnancy for any reasons, genetic or otherwise.

We have recently obtained material from Scottish and English support groups which is excellent and could perhaps form the basis of a similar organization here in Australia.

The following issues would need to be addressed:

1. It would be essential that any such group offer support and information which is completely non-judgmental to its members. Ideally, it should work as a partnership between professionals and families, providing accurate information, counselling and on-going support.
2. The opportunity to express individual concerns, as well as perhaps supporting a wider examination of the moral, ethical and legal implications both in the decision making process and in the coping experience of families, must be examined in depth.

Overseas groups have also maintained an active interest in legal, moral and ethical implications in the Government and scientific decision-making that concerns genetic and related areas such as research and fertility, termination and religious issues.

As a result of the foregoing, and the interest expressed in the formation of a support group for those affected by a prenatal diagnosis of genetic abnormality a Seminar has been proposed for 30th June, 1991, at

Royal North Shore Hospital
Large Conference Room
Level 1, Block 4
Pacific Highway
ST LEONARDS NSW 2065

Ros Smith
Vice-President
AGSA

Amanda O'Reilly
Assistant Co-ordinator
NSW Genetic Education Program

A.G.S.A.

(The Association of Genetic Support of Australasia)
and the

NSW Genetic Education Program

are holding a seminar
on

Sunday, 30th June, 1991

to examine

**The Impact of Prenatal Diagnosis
of Genetic Abnormality**

and

**The Options/Formation of
a Support Group**

VENUE: Large Conference Room
Level 1, Block 4
Royal North Shore Hospital
Pacific Highway
ST LEONARDS

TIME: 9.30 am

SPEAKERS: Parents and Professionals

Morning tea and lunch provided

Further information telephone:

AGSA NSW Genetic Education Program
(02) 868 2559 (02) 438 7324

★ DRAFT PROGRAM ★

IMPACT AND OPTIONS

9.30- 9.45 am Registration and Welcome

9.45-10.15 am **THE IMPACT - THE DIAGNOSIS**

Speakers Genetic Counsellor
Parent

10.15-10.45 am **THE OPTIONS - THE DECISION**

Speakers Geneticist/Obstetrician
Parent
Midwife

MORNING TEA BREAK - 15 Minutes

11.00-11.30 am **AFTERWARDS**

Speakers Grief Speaker
Parent
Social Worker/Psychologist

11.30-12.00 pm **AN OVERVIEW - ETHICS**

Speakers Ethics
Clergy

2.00-12.30 pm Panel Discussion

2.30-1.30 pm **LUNCH**

1.30-3.00 pm **THE FUTURE**

Parent to Parent
Professional Involvement

Please complete
Registration Form inserted in this Newsletter
if wishing to attend seminar

*The following article is from the
Exceptional Parent Journal — USA*

Parents Are Like Tea Bags

by Betty Pendler

As one of the readers of EXCEPTIONAL PARENT since 1973 and a current member of the Editorial Advisory Board, I want to attest to the fact that over 15 years ago, both editors felt strongly that "Parents are Experts in Family Life," just as they espouse in the editorial of the September 1989 issue. I remember being energized in 1973 by an editorial called "Parent Power", which literally got me started as a parent advocate and made me proof today for other parents that each of us can make a difference. For too long, parents of children with developmental disabilities have been content with second rate services and have been afraid to speak up for what is rightfully ours.

I constantly remind parents that we are a unique kind of "professional", cutting across many disciplines and including areas sometimes unknown to professionals. So is it any wonder that I continue to be excited when I see how consistent the EXCEPTIONAL PARENT has been on the importance of parents and family.

In the September editorial, I noted the reference to the need for training on the part of both parents and professionals to work with each other. Now, with legislation on our side, this is more crucial than ever. More and more articles are appearing in professional magazines on the subject of parent-professional relationships and this is heartening. For years, professionals would speak to parents. Now they are learning to speak with parents. They are learning new listening skills, with the understanding that parents, indeed, have a great deal to contribute. Traditionally,

*"Professionals must learn to
speak to parents and
hear the melody —
not just the words."*

parents have felt they were not the experts and could not contribute. All too often parents allowed themselves to be intimidated. Happily, this trend is changing in both directions.

In the parent training programs listed in the September *Annual Directory of Organizations*, parents are learning to be assertive, to speak up, and to know their rights. And, they are learning how to talk to professionals. We parents are like tea bags — we don't know our own strength until we get into hot water. Professionals are now beginning to admire our strength and our coping mechanisms.

*"We parents are like tea bags —
we don't know our own strength
until we get into hot water."*

We parents know that teachers and other

professionals are just as concerned with the success of our children as we are, but we come with different agendas. It is important for professionals to take us from where we are — not from where they would like us to be — and to believe that we can give them meaningful information. I think it is helpful if both professionals and parents admit that we are all sometimes vulnerable and don't know all the answers — but together, we can work it out.

Professionals can help parents to identify the positive contributions that they are making towards their child's development by emphasizing their strengths. Parents and professionals are going through a process of mutual learning; and, as stated in an earlier EXCEPTIONAL PARENT editorial, professionals must learn to speak to parents and hear the melody — not just the words.

We must remember that parents make the best advocates — we have a sense of urgency and are more motivated to do what is necessary to move bureaucracies. We have the motivation to keep us going even when the going is rough. When professionals say that parents are too emotional or too closely involved to be effective, we must point out to them that because we are so closely and personally involved, we can be more effective because we have the most at stake.

With faith in the knowledge that we, as parents, are experts in our own unique way, and that professionals are experts in their area, we will reach a mutual admiration relationship which will work towards the benefit of all of us.



Editors Comment

I would like to thank both "The Exceptional Parent" Journal and Parent to Parent, New Zealand for the foregoing article.

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 Editor 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-judgemental approach is recommended in establishing contact.

* * * * *

Editors Comment

If you have requested contact and a contact address has been published, we would appreciate you following this through as soon as possible. Failure to do this will lead to loss of credibility at this end — remember, these families are equally anxious for support. Penfriends, by dint of disorder, may, in fact, become a long-term friendship.

* * * * *

199 Osborne Street
Nowra NSW 2541

17th February, 1991

Dear Ros,

Many thanks for the back-issues of the Newsletter along with your letter. I do enjoy reading every issue.

I would certainly like you to place my request once more into the 'Contact Column'.

I am keeping relatively well and am somehow able to carry on. I am still very anxious to communicate/meet anyone with my condition (CEREBELLAR ATAXIA/SPINO CEREBELLAR DEGENERATION) or anyone who has any suggestions or advice for me. Meanwhile my husband and myself are continuing to do our own research into this condition.

Thanks for all your help.

Regards

Barbara

Mrs Barbara Miles
199 Osborne Street
Nowra NSW 2541
Phone: (044) 21 2765

Cerebellar Ataxia/Spino Cerebellar Degeneration

* * * * *

Request from Victoria — Mother of 3½ year old girl with Smith-Magenis Syndrome 17 (p11.2 p11.2) seeking contact with families in Australia and Overseas similarly affected.

* * * * *

Genetic Counsellor, Central West, has family with Ring Chromosome on 22, looking for contact.

* * * * *

Prader-Willi family with a 9½ year old son recently diagnosed — would like contact with a family with a child of similar age.

* * * * *

Contact a Family

16 Strutton Ground • London SW1P 2HP
Tel 071-222 2695 • Fax 071-222 3969

Support for Families
who Care for Children
with Special Needs

AGSA
44 Rawson Street
EPPING NSW 2121
AUSTRALIA

February 26 1991

Dear Ros,

On going through the latest edition of the AGSA newsletter, I find that there are a number of requests for contacts with which we could help if the families would like to correspond with a family in the UK.

I notice that you are publicising the RTMDC 10th Anniversary Conference. Families wanting contacts for Adrenal Hypoplasia should contact:

Lesley Greene
RTMDC
53 Beam Street
Nantwich
Cheshire. CW5 5NF.

The Sturge Weber Foundation UK is now developing well and you could pass on details to the family requesting contact. The family enquiring about Klippel Trenaunay Weber might also gain from this contact:

Karen Slack
Sturge Weber Foundation UK
18 Wentworth Drive
Bromborough
Wirral
Merseyside L63 0JA

Lisa Cooksey is our contact for Klippel Fiel. Her address is

21 Danzey Grove
Kings Heath
Birmingham
West Midlands B14 6JY

For Opitz Syndrome, Deletion P6 and XYY Syndrome, please contact me if you wish to follow these up.

Best Wishes

Yours sincerely

Deve Barnett
Kristine Lavery
National Development Officer for Rare
Handicaps Groups



RESOURCES & AIDS

If you are interested
in knowing more,
wish to make a referral
to the
Service or become
a host family,
please contact
the co-ordinator.
(02) 809 6595

RIVERLINK INTERCHANGE INC.

Community based
respite care for children
and young people
with disabilities.

Please Note NEW Address

THE ARGYLE
COMMUNITY CENTRE
35-41 BLAXLAND ROAD
RYDE NSW 2112
PO BOX 378
RYDE NSW 2112

A home and community care
funded project.

Board of Directors • John Shelley (Chairman) • Ruth Eisenberg • Paul Ennals
• Matthew Griffiths • Janet Ouston • Andrew Purkis • Philippa Russell • Elinor Wigley
Executive Director Harry March • Patron Esther Rantzen OBE • Charity No. 284912

Family Education Unit

We are happy to announce that **Judy Ellis** has been appointed the new Director of FEU.

Judy may be well-known to some people in one of her many roles —

- as the past Executive Officer of Action for Citizens with Disabilities
(which is a parents' support, information and advocacy group on the North Shore)
- as a representative of family/parent interest on National and State advisory councils such as the Disability Advisory Council of Australia
- as the past Director of the Office of Disability

Judy has a son Matthew, who has an intellectual disability.

Margaret Cupitt, who was the Co-ordinator of the Family Education Unit for over five years left us at Christmas for the greener pastures of a ten-acre property near Tamworth. We were very sad to see her go and miss her friendly informality but she is enjoying country life. (We're all extremely envious!!!).

Newsletter

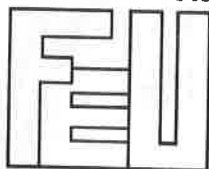
For some time we have been considering starting a newsletter which would go out mainly to the parents who have participated in groups run by FEU.

A working title is '**Family and Friends**'.

We are interested in:

- ★ your feedback (positive or negative) about FEU groups you have attended
- ★ ideas about new groups that could be run, or suggestions and ideas in general
- ★ any articles/newspaper clippings that you think others may find relevant.

Please either phone us at the office (02) 805 0233 or write to us at the address below.



for families who have a member with an intellectual disability

H118 Cox's Rd., North Ryde 2113 Ph. (02) 805 0233

School Integration

The Family Education Unit's Kit No. 9 on integrating children with disabilities into preschools and schools is now available.

Of interest to parents and teachers of children with disabilities and related workers, this kit provides background information, background reading and resources, and current (1990) information on educational alternatives in New South Wales.

KIT CONTENTS

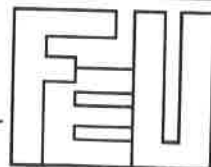
- ☞ Some Thoughts on Integrating Children with Disabilities into Schools
- ☞ A Parent's Perspective
- ☞ Some New South Wales Parents' and Students' Experiences of Integrated Education — their stories
- ☞ A Teacher's Perspective
- ☞ "Education and You" FEU Workshop — reports and policies
- ☞ Resources
- ☞ Recommended Reading

All kits are \$20 each which includes postage. Family of a person with a disability need only pay postage if their school, group or organisation does not have a copy.

Contact FEU for details

Other kits available from FEU include:

- | | |
|------------------------------|---|
| * No. 1 Behaviour Management | * No. 5 Leisure Ideas and Resources |
| * No. 2 Siblings Groups | * No. 6 How to Get the Best Services (update) |
| * No. 3 Family Relationships | * No. 7 Social Development |
| * No. 4 Speech and Language | * No. 8 Menstruation Management |



FAMILY EDUCATION UNIT

for families who have a member with an intellectual disability

H118 Cox's Rd., North Ryde 2113 Ph. (02) 805 0233



Poem

Are we aware of what sprouts these years
Under the surface of things?
Meekly emerged behind failures and fears
A will to succeed takes wings.

Humanity's enemies do not consist
In cells, or humans or nations,
But in our weakness for thinking in mist
And dealing in deadly evasions.

Invisible foes are the hardest to fight:
Ignorance, sloth and illusions.
We ignore their existence - the cause of our plight,
The sources of global confusions.

We were always alert to cooperate
In the face of a forceful rival.
We begin to wake up to the choice of a fate
Of harmony, health and survival.

We must rise to the challenge - and follow the call
Of a Sanity's commonwealth.
Let us welcome a future of Health for All
By an action of All for Health.

Health is not bought with a chemist's pills
Nor saved by the surgeon's knife.
Health is not only the absence of ills,
But the fight for the fullness of life.

Piet Hein

*From the World Federation of Haemophilia Journal
"Life Paths", January 1990 - Vol 2, No 1.*

Thanks to Haemophilia Foundation of Australia