A G S A

NEWSLETTER

MARCH 1990 ISSUE NO. 3

THE · ASSOCIATION
OF · GENETIC · SUPPORT
OF · AUSTRALASIA

ISSN 1033 - 8624

In This Issue

EDITORIAL

In the pursuit of education about genetic disorders and awareness of genetic services, AGSA aims to forge a partnership between the consumers and the health professionals. The membership consists of both these groups and thus the first steps have been taken. Both sides of the partnership have much to gain: the consumers will benefit from access to clinical services and developments resulting from research and the health professionals will develop a greater understanding of the disorders and their effects in families. Such a partnership may not always be easy but a contribution on both sides will lead to better understanding of the roles of each.

The road that this partnership follows will sometimes be rocky and difficulties can result if personality clashes occur. On the one hand parents may direct their understandable anger and frustration at the health professional or bearer of bad news. On the other hand there are times when health professionals need to develop their communication skills and sensitivity in dealing with families.

The road towards greater understanding will be smoother if both sides work together and participate in the activities of AGSA and the individual support groups. In this way, families can be made aware of the availability of other clinical services and can learn from each other about the disorder. The health professionals can utilize the experiences of a large number of affected people who, because of the very nature of genetic disorders, will present in a variety of ways.

Inevitably this road will lead to an increase in the quality of service.

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PRESIDENT'S REPORT

March, 1990

It is with much pleasure and a great deal of pride that I write to you as the President of AGSA.

Firstly I would like to pay a personal tribute to my predecessor, Kris Barlow who vigorously led AGSA through its first year and I am indebted to her for her support and indeed her encouragement in suggesting that I should stand as your President. I am very pleased that Kris has chosen to work with me on the Committee and will, in fact, be the Chairman of the Medical Liaison Committee.

I believe that AGSA has a wonderful future ahead of it, however there is much to be done and we badly need as many helping hands as we can muster. Over the next month we will be establishing various subcommittees for membership, library, newsletter, medical liaison and education and any volunteers would be most welcome. Please contact Ros Smith if you are interested in helping.

As I said at the Annual General Meeting, our hands have been very much tied by the delays in obtaining tax deductibility and hopefully with the Federal election now over, we might be able to get the decision that we so badly need. Regrettably it is a fact of life that corporate supporters like to get a tax deduction.

We are presently seeking sponsors for the newsletter and brochures and if any of you, either through your employers or friends, know of someone who might be interested in helping, please contact me. I did say at the General Meeting that one very generous corporate sponsor had agreed to meet the cost of 5,000 educational brochures which should be ready in early April. That wonderful gesture saved us $5,000.

1990 will always be a reminder as the year that AGSA came of age and put in place its plans for the benefit of all members of the community in Australia. To do this we must educate the community and the medical fraternity and we welcome their support, we must establish a home for AGSA and we must provide a support facility not only for our member groups and last, but not least, families who need a contact point. By the time the next newsletter is published, hopefully we will have tax deductibility, in which case I will then inform you of our plans to meet our fund raising objectives.

R J M MacDiarmid
President

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CLASSIFIEDS

FOR THE PRESENT TIME
THE CONTACT NUMBER WILL BE
(02) 868 2559.

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RATES FOR THE CLASSIFIEDS

Full page — $160

1/2 page — $90

1/3 page — $60

1/4 page — $50

1/6 page — $35

Artwork and typesetting for classifieds
additional charge

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DID YOU KNOW
THAT A FREE WHEELCHAIR SERVICE EXISTS?

Free Wheelchair Service

A FREE NRMA service to wheelchair users, introduced on a trial basis last June, is now operating on a permanent basis with NRMA Road Patrolmen carrying out minor repairs to wheelchairs.

NRMA General Manager Richard Cox said the service had proved so popular in the Sydney area that it had now been extended to Newcastle, Wollongong and Canberra.

Mr Cox said that during its trial period NRMA Road Patrols had attended to an average of eight calls a week from wheelchair users who had been immobilised because of simple faults.

Said Mr Cox: "This high number of calls reinforced the need to provide the service on a permanent basis and the favourable response from the disabled and NRMA membership at large guarantees its success."

The service means that disabled people will no longer have to wait weeks to have minor repairs to their wheelchairs carried out at a special workshop.

Extract from APRIL 1990 'OPEN ROAD'

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INTERNATIONAL NEWS

2ND INTERNATIONAL SYMPOSIUM
ON THE MUCOPOLYSACCHARIDOSES
AND RELATED DISEASES
— 31st AUGUST - 3rd SEPTEMBER, 1990

This Symposium will be held at The University of Manchester Institute of Science and Technology (UMIST).

The Symposium program will include topics on the clinical presentation of MPS disorders, the management of complications and report the attempts to treat by enzyme replacement, eg bone marrow transplantation. During the biochemical section we hope to discuss the approach to diagnosis as well as recent advances in the molecular biology of the mucopolysaccharidoses and related disorders.

The Symposium has been deliberately organsied to take place on the weekend immediately preceeding the annual meeting of the Society for the Study of Inborn Errors of Metabolism (SSIEM) in Birmingham.

For further information please contact:

The Society for Mucopolysaccharide Diseases
30 Westwood Drive
Little Chalfont
BIRMINGHAM, ENGLAND
or
The Society for Mucopolysaccharide Diseases
C/- 44 Rawson Street
EPPING NSW 2121
AUSTRALIA

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CONTACT-A-FAMILY

WHAT CONTACT-A-FAMILY DOES

Contact-a-Family is a national charity which supports families who have children with different disabilities and special needs. Families with a disabled child often feel isolated and Contact-a-Family brings them together through mutual support and self-help groups.

A quarterly newsletter, Share an Idea, is circulated to a wide range of parents and professionals and provides information and advice on a range of topics. Share an Idea is available quaterly, on subscription (£5.00) per annum.

For further information about Contact-a-Family and its services, please write to:

The Information Department
Contact-a-Family
16 Sutton Ground
LONDON SWIP 2HP

LETTERS TO THE EDITOR

'Parent to Parent'

National Co-Ordinator
P.O. Box 704,
Cambridge New Zealand
Tel (071) 27 5530

30th October 1989
The Association of Genetic Support of Australasia
The Editor
C/- Hut T
Prince of Wales Childrens Hospital
High Street
Randwick NSW 2031
Australia

Recently one of our Support Parents attended the MPS Society Conference in Australia, and brought back to New Zealand a copy of your AGSA newsletter.

Here in New Zealand, Parent to Parent has over 200 Support Parents covering over 80 different disabilities and health impairments and I feel that maybe our organisation can be of help to your group, and vice versa.

Parents contact our groups throughout New Zealand requesting a match with a family who have a child similar to their own. We have many unusual syndromes that we have successfully matched, and this is a big bonus to these families, as so often they are led to believe there are no other families in New Zealand with the same syndrome. I am enclosing an updated list of the areas that we cover at the moment. (See updated list further through the newsletter).

We would like the opportunity of receiving your newsletter, could you please let me know how we go about this.

I look forward to further contact with your organisation in the very near future.

Kind regards

Shirley Wass
National Co-ordinator

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2 Chilworth Close
Beecroft 2119
23-3-90

Mrs Roslyn Smith
Association of Genetic Support of Australasia
44 Rawson Street
Epping 2121

Dear Ros,

I wish to confirm in writing my conversation at the Annual General Meeting on 4th March.

I am very interested in the Respite Care House for Salby and I would be willing to help in any way I can to make this house a reality.

Please do not hesitate to contact me when I could be of assistance with this proposed project.

Yours faithfully
Nola Woods (Mrs G)

The Australian Tuberous Sclerosis Society Inc.
Registered Charity No. CC25313
Incorporation No Y 07116 - 42

Re: Change of Address

I am writing to advise you that the Australasian Tuberous Sclerosis Society is now located at 22 Mason Street, Thirroul NSW 2516. Our telephone number remains unchanged — (042) 67 3992. As we are on your mailing list would you please change our address on your records accordingly.

Thank You,

Yours faithfully
Lynn McKinnon.
Lynn McKinnon
Secretary/Treasurer

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Victorian Clinical Genetics Services
Director: Professor David M. Danks

ROYAL CHILDREN'S HOSPITAL GENETICS CLINIC
Dr John G Rogers (Director) Dr Leslie J Sheffield
Dr Agnes Bankier Prof David Danks
Mrs Margaret Stebbing (Co-ordinator)

14th February, 1990

Mrs R Smith
AGSA Newsletter
44 Rawson Street
Epping 2121

Dear Ros

I have enjoyed reading the latest AGSA Newsletter. We only received it after the 1st February deadline, hence this late piece of information I would like published in your next newsletter.

We did notice that (apart from our article on "Genetic Services") most of the information and resources were NSW based, and I thought you may be interested in information about a video that I made with Garry Warne (the director of the department of Endocrinology at the Royal Children's Hospital).

I enclose a copy of the pamphlet, advertising the video.

The video is made for professionals, who are confronted with decisions on how to best communicate with a couple whose child is born with ambiguous genitalia.

I enclose a copy of my address to a Grand Round at the hospital, on the issues of communication. You may be interested to read this, and publish it in the AGSA Newsletter.

I was sorry to miss the MPS Conference last year — several parents have told me how much they enjoyed it.

Hope to see you soon.

With best wishes

Margaret

MARGARET SAHHAR

Victorian Clinical Genetics Services Limited
The Murdoch Institute, 10th Floor, Royal Children's Hospital
Flemington Road, Parkville 3052, Melbourne, Australia
Telephone: (03) 345 5157; (03) 345 5045 Fax: (03) 348 1391

GENETIC SERVICES

——— NEW VIDEO RELEASE ———

"TELL ME DOCTOR, BOY OR GIRL"

Sometimes infants are born with genitalia that make sex assignment very difficult. Staff assisting at the delivery must think very quickly, often with little or no previous experience to guide them.

The parents are waiting anxiously. How should they be counselled? Can delivery room staff prepare themselves for this emergency?

"Tell me Doctor, Boy or Girl?" focusses on:

* Vital communication procedures
* What to say and how to say it
* Parents' experiences

This acclaimed teaching video is suitable for doctors, nurses, medical and nursing students, social workers, psychologists and parent support groups.

Written and produced by
Garry L Warne
Royal Children's Hospital Paediatric Endocrinologist
Margaret Sahhar, Medical Social Worker
John M Hutson, Paediatric Surgeon
Craig Schubert, Education Resource Centre
at the Royal Children's Hospital
Melbourne, Australia

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ORDER FORM
AT THE BACK OF NEWSLETTER
SHOULD YOU REQUIRE IT

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GRAND ROUND — 13TH DECEMBER 1989

VIDEO: *"Tell me Doctor, Boy or Girl?"*

In interviewing parents for this video, the issue of communication between professional staff and parents, was identified as the major area to be addressed. Communication on both a verbal and non-verbal level, influenced parents' decisions about disclosure of the diagnosis, what to say, and to whom.

Parents all identified good communication between themselves and professional staff, as a positive factor influencing their ability to relate to their baby, and to each other. Factors of bonding and attachment, marital and family relationships are all affected by the initial communication of the diagnosis of ambiguous genitalia.

The following points should be considered. Many relate to the birth of any baby with a disability. When a baby is born with ambiguous genitalia, there are however some different and extra issues.

COMMUNICATION
at time of delivery and in the maternity hospital

12 GOLDEN RULES

— No precise formula to give

— Professionals involved need to think clearly about their reactions and responses to the situation — ie their feelings about ambiguous genitalia. Sexual issues are emotive and probably less adequately discussed generally in our society then other issues.

— Both parents, or a parent and a support person, should be present when initial information and explanation of diagnosis are given. The burden of the information is too great for one parent and **both** need to hear it.

— When talking to the parents, show care and respect for the baby — do not call the baby "it". Your respect helps the parents to value their child as an individual rather than a negative object with a disability. This is important in the bonding process.

— Reassure the parents that the baby is healthy and normal (if appropriate), that it has ambiguous sex organs, (may need to use appropriate different words) that its sex will be clarified in a few days, that a specialist in this condition will be involved and that treatment is available. It is important to reassure parents that the baby will have a **definite** sex. It is also important that the genitals are shown during this discussion. This clarifies the explanation and helps to reduce parents' fantasies. Also worth mentioning is the fact that several babies like this are born each year, ie this baby is **not** a one in a million freak. The explanation needs to present the baby as a normal child with one part that is needing medical attention, not a totally damaged child.

— **Individualise parents** — Remember that most understand only basic biology. Explain clearly and simply but not in a patronising manner. Reiterate the information often as people under stress neither **hear** nor **comprehend** information.

Education, social class, accent and appearance do not indicate the ability to cope emotionally. The middle class university graduate may not cope as well emotionally as the primary educated parent with a strong and supportive family network.

— **Refer** for counselling — Parents all indicated that they needed help in coping with friends' and families' questions. There are several strategies that parents can be taught on how to cope with questions (Deborah Fullwood "Facing the Crowd"). Parents need the chance to verbalise their fears, to have these recognised as being normal and valid and to be given support in coping with questions about their baby. Given professional support, most parents can cope — some may, however, need long term counselling for family and marital problems.

— **Recognise** that parents may feel intense **grief** for the lost perfect baby they had expected. Understand that grief can often be manifested in displays of anger, especially towards the doctor who first gives the "bad news". Allow and encourage expressions of grief. Parents who feel that professional staff could tolerate this were able to establish good, trusting relationships with those staff (Lindemann; quoted in Soza). Parents may experience **"double grief"** losing a son.

— **Support staff** eg nurses, need the chance to talk with the specialised endocrine team for clear information about treatment plans, the condition **and** the chance to verbalise their anxieties and fears. This is very important as nurses are often the professionals who will be involved with family and friends and their questions. Staff must have adequate up-to-date knowledge about the condition and feel at ease with their own feelings and reactions if they are going to be able to relate well with the parents. Otherwise staff may withdraw if they feel awkward or unsure about how to communicate. Some parents felt that they were isolated and ignored by staff. This may be irrational and related to the parents own feelings about their baby's condition, but it is often realistic.

— **Families** eg Sibs, grandparents, may benefit from simple, clear explanations from staff if the parents are agreeable. This can help relieve the parents' burden of disclosure to relations, but should only be done after discussion with the parents so that they can remain in control.

One parent explained the confusion over the baby's sex by saying that the umbilical cord had been mistaken for a penis at the birth!

— **High risk relationships** — eg single mothers, unstable relationships, should be referred for counselling and may need more help in coping with the diagnosis. This is indicated in past studies (Puck) and is supported by the interviews. Counselling should usually be long-term.

The diagnosis adds stress to an already stressed or inadequate relationship. Stress in the relationship may have been due to poor communication or inadequate understanding of each partner's needs. When a baby is born who is less then the perfect baby expected, they may be unable to offer any support or understanding to each other. Blame is often projected onto the partner. Grandparents may contribute to this. "It's not on our side of the family."

— Plan for follow-up of both **parents** and **child** over the years. Parents need to be helped and encouraged to discuss the condition in an age-appropriate way with the developing child. The child/teenager/young adult needs the chance to discuss issues of developing body image and sexual identity as an individual, separate from the parents. Extra counselling may be necessary.

— Referral to another parent or a parent support group at any appropriate stage may be useful. Literature can also be helpful to parents.

M Sahhar
November, 1989

WORKING IN A BIOCHEMICAL GENETICS LABORATORY

Parents and relatives of patients with inherited disorders of amino acid, organic acid, carbohydrate and fatty acid metabolism and the so-called storage disorders have usually come into contact with a Biochemical Genetics Laboratory. In Australia this work has been centralised in Reference Laboratories in each state:

Princess Margaret Hospital, Perth
Adelaide Children's Hospital, North Adelaide
Royal Children's Hospital, Melbourne
Oliver Latham Laboratory, Sydney
Royal Brisbane Hospital and Mater Hospital, Brisbane

Our primary role is the detection of inherited biochemical diseases in patients - newborn babies, infants, children and adults - who have symptoms suggestive of a group of more than 150 disorders. Some of these disorders may be fatal in the newborn period and so we also provide an emergency service for neonatal intensive care units. Many disorders can be treated by dietary changes and vitamin supplements and so we provide a monitoring service which for some patients will mean a lifelong association with the laboratory. Many of the disorders become apparent in infancy, at weaning or in the case of storage disorders, when skeletal or tissue changes have become visible to the clinical eye.

We select the appropriate biochemical test most likely to detect the disorder which has resulted in these symtoms. It may be a mucopolysaccharide electrophoresis or chromatography, an organic acid separation by gas liquid chromatography and if an abnormal acid is found, confirmation by gas liquid chromatography/mass spectrometry.

The other important role is the provision of a definitive diagnosis, that is an enzyme or DNA analysis on tissue from the affected patient. This is carried out by specialist laboratories such as those at the Murdoch Institute, the Adelaide Children's Hospital and other centres overseas. Only when a definitive diagnosis is obtained can prenatal diagnosis be offered for subsequent pregnancies. We are all involved in arranging for this on-going service to affected families.

Hospital scientists working in Biochemical Genetics Laboratories are a particularly privileged group. Problems that beset our colleagues in the related field of clinical biochemistry as a result of the use of automated equipment have not yet impinged on us. Our sample numbers are low enough for us to retain the patients surname as part of our identification system throughout. And we know the particular clinical symptoms which suggest that the patient may have an inherited disorder, so it is still easy for us to relate each analytical task to the patient. Professional managers elsewhere in larger automated laboratories are trying to reintroduce the "old-fashioned" idea of making the purpose of work relevant to the analyst by arranging staff meetings on clinical topics. Our purpose is clear.

Our techniques are not fully automated and the validity of each result relies on the skills of the analyst. Even where we use an instrument with some automatic controls such as an amino acid analyser, the skill of the analyst determines the quality of the sample preparation, the complex chromatography and the measurement of at least 23 amino acids in each, in plasma, urine or other fluid.

LABORATORY PROCEDURES FOR DIAGNOSIS OF MPS DISORDERS

The analysis of a sample for mucopolysaccharide (MPS) is a good example of how we work. Firstly the high resolution electrophoretic method we use is labour intensive and takes one person a full day to complete. We usually run a batch each fortnight, but if a family have a particular need, say for example the mother is 8 weeks pregnant and wishes to continue with prenatal diagnosis, then we bring forward the batch.

We ask the clinicians to supply full details about the patient. This allows us to run a control urine from an MPS patient alongside the test sample (hence our occasional pleas for urine). Urines without adequate clinical information are stored *on hold* in the laboratory for 2 months, so that the doctor can be informed and supply details without troubling the family for more samples.

The electrophoretic method devised by Dr Hopwood in Adelaide is very reliable and has supplanted all other MPS screening tests in Australia. Quality control is checked by running an MPS urine on each electrophoresis plate. If the control is unsatisfactory then the whole batch is repeated and the cause of the problem located. We see only a band of chondroitin sulphate with a trace of heparin sulphate in urine from unaffected children and adults. Samples with bands in other positions are interpreted in the light of the clinical information and a provisional diagnosis made. Confirmation of an MPS disorder is obtained by a specific enzyme assay on a leucocyte preparation from blood sent to Dr Hopwood in Adelaide.

The reliability of testing in Biochemical Genetics is checked via two national quality assurance programs, one for urinary metabolites and one for quantitation of plasma amino acids. At OLL we also participate in the American Biochemical Genetics Proficiency Testing Program in which our analytical and interpretive skills are tested twice a year.

Judith Hammond
Senior Scientist — NSW Biochemical Genetics Service

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NSW GENETICS SERVICE

Dr K Barlow and Mrs O'Reilly have moved out of Hut T, Prince of Wales Children's Hospital and may now be contacted at the following address and telephone number:

NSW Genetics Service, (Education Program)
Royal North Shore Hospital
Pacific Highway
ST LEONARDS NSW
(02) 438 7111 (Hospital Switchboard)
(02) 438 7324

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SUBSCRIPTIONS FOR 1990 ARE NOW DUE

A MEMBERSHIP FORM IS ENCLOSED IN THIS NEWSLETTER FOR YOUR CONVENIENCE.

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NEWSLETTER DEADLINE FOR JUNE 1990

The deadline for information for the June issue of the AGSA Newsletter is **31st May, 1990.** If you wish to publish an article or item of interest in the June Newsletter, please forward relevant information to:

Mrs R Smith
44 Rawson Street, EPPING 2121

A FAMILY STORY

The following article recently appeared in the "Nursing Mothers Magazine".
Julie and her husband Rob, are featured in the AGSA Video - Julie is also Secretary of The Hunter Valley Genetic Support Group - this is their story . . .

Sheridan was eight weeks premature. A very big surprise. She weighed 1500gm and had a mass of black hair. She was a tiny fragile little doll! Sheridan had a few brain bleeds and the doctors could not work out why. This led to many tests and finally she was diagnosed as having the fifth recorded case, worldwide, of a chromosome disorder called Miller Dieker syndrome. The characteristics of this resulted in extreme mental and physical retardation.

My greatest wish was to have our baby home. Sheridan grew stronger and was moved from intensive care to special care in about three weeks. She was tubefed and graduated to bottlefeeds of my milk. I can remember the tears in my eyes the first time I fed her myself. She finally felt like my baby. At last I could do something for her no-one else could do!

The wonderful day came when she was five weeks old when we dressed her in dolls clothes and brought her home! (Finding clothes was very difficult.) We were to treat her like a normal baby and that we did. However she was cherished and loved more than that.

We took her back to the clinic for check-ups weekly and she put on small amounts of weight which was very encouraging. When she was about 10 weeks old Sheridan began to convulse. We took her to hospital and had to make some of the hardest decisions of our lives. We had to realise that Sheridan was not going to live for very long and our concern was then to ensure that the quality of her life was the best for her. We did not want her suffering in any way.

We chose to put Sheridan on a course of sedatives to help stop the convulsions. We went back home and I kept feeding her and trying to have a normal home. At the time we took Sheridan home I knew we would need professional help to explain to Tiffany what was happening.

We had made the decision that if Sheridan was to take a turn in hospital, she was not to be revived as her outlook was so poor. What agony these decisions caused us but in our hearts we knew they were the right choices for Sheridan.

At about 15 weeks Sheidan could no longer swallow without choking and so we had to stop medication and I could not get her to feed, either from me or a bottle.

Sheridan died in my arms surrounded by our loving family. I wanted so much to give her comfort until the end. We loved her dearly. Her funeral is etched on my mind. Some days I cannot erase the tiny white coffin from my sight. The loss of a baby is so tragic.

Our family is doing routine work. That means we are both back at work and Tiffany is now at pre-school.

We have yet to experience the psychological stages of the first anniversary of Sheridan's birthday or death but whatever grief we feel, we know we share with so many others. I hope our experience can help others.

Remember to seek help, let others help you in any way they can as they also feel lost or unsure how to help you cope.

Julie Ross — Broadmeadows, NSW

If you have a story to tell, please send it into the Editor at your convenience. This is your Newsletter — Health Professionals, your stories also please.

SEMINARS/WORKSHOPS

Advance notice of

A G S A

All Day Seminar

"EDUCATION - AND YOU"

All avenues of
Integration and Special Schools
to be addressed

Resources available
or lack thereof

SATURDAY — 2nd June, 1990
EPPING RSL
Oxford Street, Epping

Organiser
Mrs M Cupitt, Co-ordinator
Family Education Unit, North Ryde

Further information will be sent out shortly

THE ELIZABETH KUBLER-ROSS ASSOCIATION (AUST.) LTD

P R E S E N T S

LIFE, DEATH, & TRANSITION WORKSHOPS 1990

SYDNEY	Monday, May 28	Friday, June 1
MELBOURNE	Monday, June 4	Friday, June 8

These 5 day residential workshops are the basis
of the work and philosophy
of the internationally renowned
Dr Elizabeth Kubler-Ross
They are intense personal growth experiences
Lectures and case studies are also presented

DR LARRY LINCOLN
EKR Centre, USA
who has been training and supervising EKR staff
for 5 years
will again lead the team of facilitators

Application Forms
EKR Association (Aust) Ltd
PO Box 79
Turramurra NSW 2074

Further Information
Sydney — Faye Cameron (02) 449 5279
Melbourne — Andrea Lord (03) 288 2064

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.

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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.

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Request from New Zealand — Can anyone provide information or a contact point for a family with Carpal Tarsal Osteolysis. Mother requires contact and support for herself and son.

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Is there contact or information for a family with a 3 year old boy with Angelman or "Happy Puppet" syndrome?

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Can anyone provide information on a contact point for a family with a child with No. 2 chromosome defect, specifically in the vicinity of 2q21 to 2q32?

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Request from Country Area — Multiple Exostoses with Mental Retardation syndrome - very mild — a contact please.

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Can anyone help with a contact for Canavan's Leukodystrophy? Mother finding it hard to make contact with anyone in Brisbane — child only 9/12

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Request for contact with other families who may have had or have Trisomy 12P. Mother endeavouring to trace family members both here and overseas.

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Medical Geneticist - Queensland seeking contact with family affected with Von Hippel-Lindau Disease.

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Overseas Groups — Please note and advise if you are able to help with any of these requests.

SUPPORT GROUP

NEWS BULLETIN

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

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Newcastle areas has begun a group
"HUNTER VALLEY GENETIC SUPPORT GROUP"

This Group was formed on 9-12-89 and meets each **first** Saturday of the month, at 10.00 am at the Special Education Centre, University of Newcastle.

The aim of the group is to offer support to families and interested persons with a range of chromosomal abnormalities. A guest speaker will address the group at each meeting on a wide variety of topics. Social gatherings are also planned. The March meeting will feature a speaker on Fragile X Syndrome. For more information — Lynne Prince (049) 61 2188
Julie Ross (049) 43 3454 (AH)

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THE HUNTER VALLEY GENETIC SUPPORT GROUP was addressed at the February meeting by Pat Foster, from the Newcastle Home Care Service. This was a very interesting and informative talk as much of the information was very relevant to our members with special care problems.

Toni Penfold then spoke on behalf of the Newcastle Temporary Care Service and advised the group of the services available from this source.

Julie Ross spoke to the group on the chromosomal abnormality "Miller-Dieker Syndrome" which included experiences with terminally ill babies.

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THE FOLLOWING BRIEFLY OUTLINES
"PARENT TO PARENT"
a telephone support service for parents of children with disabilities or "special needs" in New Zealand

PARENT TO PARENT

Parent to Parent is designed to provide support and information for parents of children with disabilities or health impairments. Parents are matched with other parents who also have a child with special needs. The service is to help parents and professionals learn the importance of need for, parent support systems, how to access support networks, and the importance of providing this valuable contact to parents as early as possible in the lives of their children.

As families face the challenge of parenting a handicapped child other families are a vital source of support and information. Because of the need for such networking, parents and professionals joined together to form Parent to Parent.

Parent to Parent is a support and information network designed to put parents who have learned of their childs disability in touch with a trained Support Parent whose child has the same and/or a related disability or special need.

Parent to Parent is based on the philosophy that

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 . . .

CONGENITAL ADRENAL HYPERPLASIA (CAH)

Extracted from the booklet
"Your Child with Congenital Adrenal Hyperplasia"
G L Warne 1980

The original publication of the booklet was made possible by the Lions Club of Deer Park

REMOVABLE INSERT
Please pull gently from staple binding to remove

CONGENITAL ADRENAL HYPERPLASIA (CAH)

THE NATURE OF CAH

CAH is sometimes referred to as "the adrenogenital syndrome" (AGS). It is a congenital disorder (ie present at birth), involving the hormones of the adrenal glands.

WHAT ARE HORMONES?

Hormones are the chemical messengers in the body; they are produced in one place by an 'endocrine' or hormone-producing gland, and act somewhere else in the body. For example, female sex hormone is made in the ovaries and acts elsewhere to cause breast enlargement, broadening of the hips, menstual periods, etc. There are many different types of hormone and many endocrine glands, each of which make their own special hormones. In trying to understand CAH, the most important glands are:

(1) the adrenal glands; and

(2) the pituitary gland

WHAT ARE THE ADRENAL GLANDS?

The adrenal glands are two fleshy triangular shaped organs, each about the size of a walnut, which lie next to the kidneys on the back wall of the abdomen.

Although fairly small, the adrenal glands make some of the most important hormones, ones that cannot be done without. The important hormones are now available in tablet or injection form, so that the adrenal glands themselves can be done without if necessary. Children with CAH do have adrenal glands, but some of the complex chemical "machinery" needed to make the essential hormones is defective, and the glands make the wrong hormones.

CONTROL OF THE ADRENAL GLANDS

THE PITUITARY SWITCH

The adrenal glands are controlled by the pituitary gland, a pea sized gland at the base of the brain. It is the "master gland" which directs many of the other glands, much as the conductor of the orchestra directs the players. When the adrenal glands are not producing enough of their main hormone, the pituitary tells them to make more. When too much adrenal hormone reaches the pituitary, the adrenals are allowed to rest until the hormone level returns to normal again. Usually the pituitary and the adrenals are perfectly balanced.

THE ADRENAL HORMONES

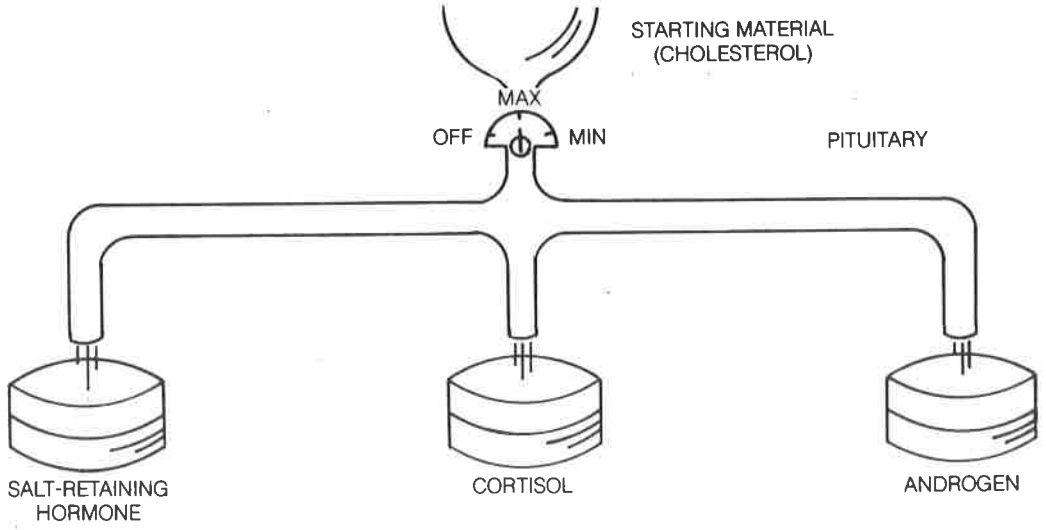
The adrenals make three important hormones. These are:

1. **CORTISOL**
   — needed as a protection against stress. Cortisol blood levels are very high during any kind of physical or emotional stress. People lacking cortisol become very ill when under stress.

2. **A SALT-RETAINING HORMONE.**
   This governs the amount of salt lost in the urine via the kidneys. In the absence of this hormone, salt is lost uncontrollably, leading to dehydration and salt-lack.

3. **MALE-TYPE SEX HORMONES ('ANDROGEN').**
   Both males and females have androgens. They are thought to aid growth in childhood and are the reason why women have pubic hair.

Not only are the adrenal glands each able to make all three hormones, but they make them all from the same starting material, cholesterol. This can be made in the body but is also found in the diet, in animal fats. To understand how the adrenal achieves this, look at the diagram below:



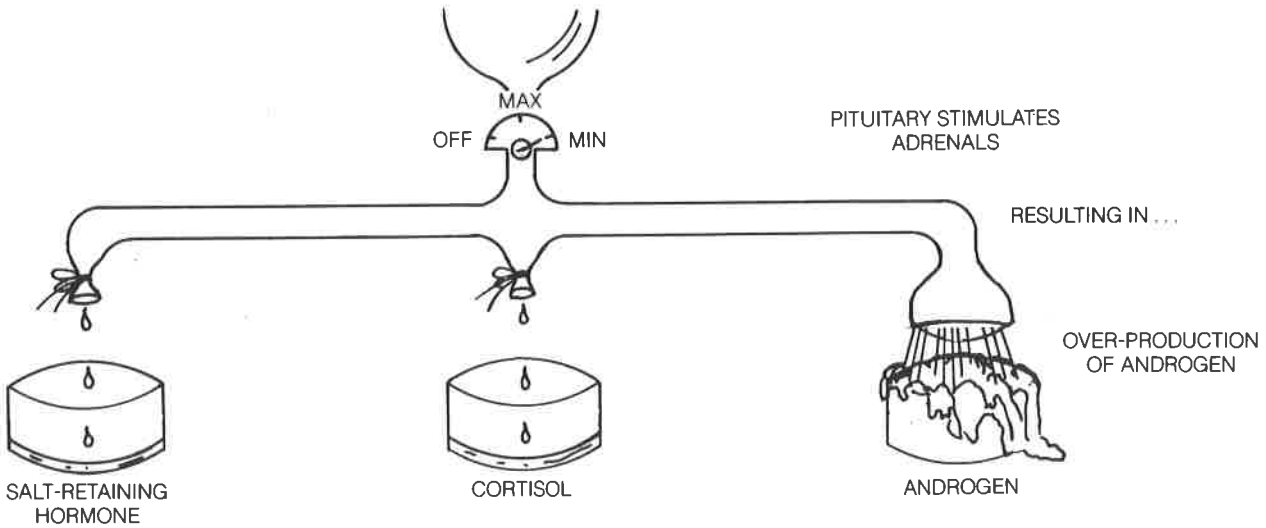
Here the starting material (cholesterol) is represented by water in a reservoir; a pipe carrying cholesterol out of the reservoir divides into three, and from each of the three branches a different hormone flows. In the body, the division of the flow is achieved by very specific chemicals called ENZYMES each of which causes a particular chemical alteration to the cholesterol. These enzymes are as necessary for the formation of the adrenal hormones as yeast is for making bread.

CAH — AN ENZYME DEFICIENCY

Whether or not a person is born with the right number of enzymes in the body is determined by genetic or hereditary factors. In CAH, one of the adrenal enzymes is missing. This can occur in more than one member of a family: CAH is a genetic disorder or "inborn error".

THE HORMONAL PROBLEM IN CAH

Compare this diagram with the previous one



Here, two of the pipes (carrying cortisol and salt-retaining hormone) are blocked. The pituitary is told atat tht enough cortisol is coming through, and more starting material (cholesterol) is allowed through. The pipes remain blocked, however, and all of the suplus cholesterol is converted into androgen.

Thus CAH results in three disturbances:

1. Lack of cortisol
2. Lack of salt retaining hormone; and
3. Too much androgen

TREATMENT OF CAH

1. **REPLACE CORTISOL**
   Cortisol can be given in either tablets or injections and in medication form it is called CORTISONE ACETATE.

   Giving cortisone acetate does two things:

   (i) it overcomes the deficiency of cortisol: and

   (ii) it switches off the pituitary galnd, and the overproduction of androgen stops.

2. **REPLACE SALT-RETAINING HORMONE**
   Not all children with CAH lack this hormone, but at least three-quarters do. The hormone can be replaced by tablets which are called FLUDROCORTISONE ACETATE or FLORINEF *(trade name of a product made by E R Squibb & Sons Pty Ltd).*

3. **CORRECT THE EFFECTS CAUSED BY EXCESS ANDROGENS**
   In early weeks after conception, the genital regions of both male and female babies look exactly the same (Figure 4a)

Figure 4a

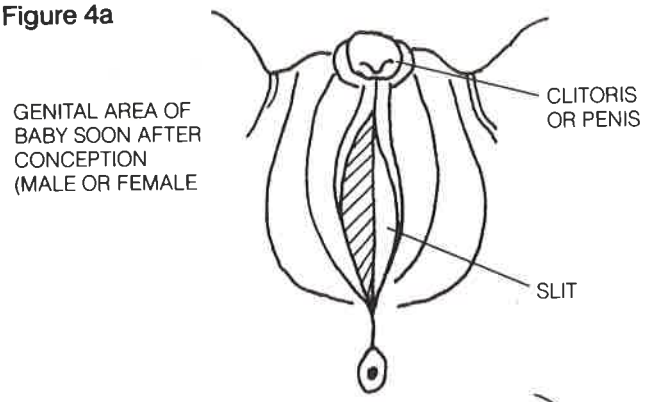
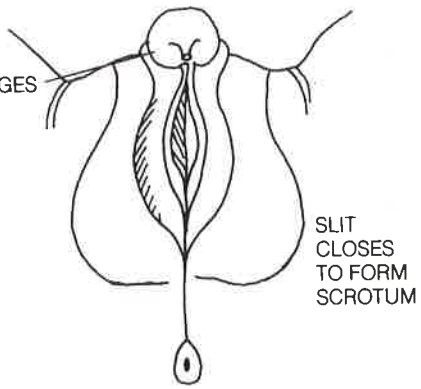
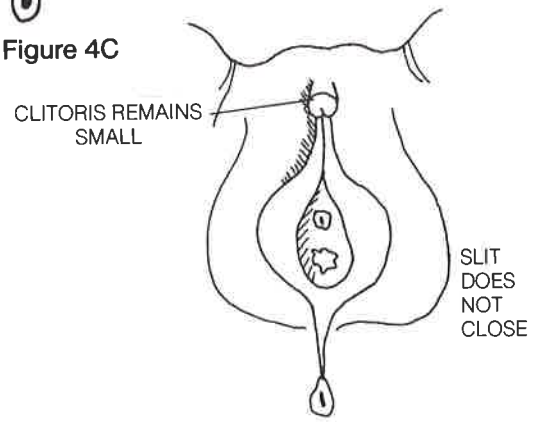


Figure 4b



Normally in male babies (Figure 4b), the testicles produce male sex hormone (androgen) which causes growth of the penis and formation of the scrotum.

Figure 4C



Normal female babies (Figure 4c) do not have much male sex hormone and so the clitoris is small and the labia or lips do not fuse to form a scrotum. If female babies are exposed to these hormones, however (as in CAH, when the adrenal glands make androgens), the external genital organs may come to resemble those of males. Males with CAH look normal at birth.

It is important to realise that male sex hormones only affect the ***EXTERNAL*** genital organs. Inside, the organs are still definitely male or female, depending on the true sex of the baby. Thus the external genitalia of affected females may look masculinized, but inside, the vagina, womb and ovaries are absolutely normal. The confusion is only at skin level.

Sometimes it is diffucilt to be sure about a CAH baby's true sex at the time of birth. Tests to determine what internal organs are present may be needed, as well as tests related to the adrenal glands. The results of these tests can usually be obtained within two or three days.

Female children with CAH usually require surgery to restore their external genitalia to normal and to uncover the vaginal entrance, which may be buried under the skin. At around puberty, the vagina may require stretching to allow menstruation. Female hormones made by the ovaries at puberty help this stretching in a natural way.

parents who have recently learned of their childs disability or health impairment can be helped by parents who have experienced living with and raising their own child with similar special needs. These experienced parents are willing to help other parents by being supportive listeners and by offering practical information.

No one knows exactly how an individual parent feels; however, only another parent can say, "I have been there and I understand what you are feeling". Often just learning that one is not alone can make an important difference in parents ability to cope with their own unique parenting situation.

All family and personal information of parents and their children is considered confidential and is used only to match a parent with a Support Parent. When a parent calls, the matching and follow-up process begins. The co-ordinator speaks with the parent to learn as much as possible about the parent, their child, and any major concerns they may have.

The parent is matched, by the co-ordinator with a Support Parent whose child has the same or a related disability or special need. Other family similarities and concerns of the parent are also considered in making the best match. The Support Parent undertakes to contact the family within 24 hours of receiving the call.

If the local area is unable to match the family with a Support Parent from their area, they then contact the National Co-ordinator who endeavours to find a suitable Support Parent from groups nationwide.

* * * * *

DISABILITIES, SPECIAL NEEDS,
HEALTH IMPAIRMENTS, March 1990

CONTACTS FOR

Acardis Syndrome
Achondroplasia
Alloglis Syndrome
Albinism
Allergies
Amputee
Andreno Genito Syndrome
Annaphylaxis
Apnea
Arthritis
Arthrogryposis
Asthma
Athetoid
Atrial Septal Defect
Atrio Ventricular Canal Defect
Autistic

Behavioural Problems
Battens Disease
Beckwith-Wiedemann Syndrome
Birthmark
Blind/Restricted Vision
Brain Damage/Disorder/Tumour

Cancer
Catheter
Cerebral Palsy
Chest Conditions
Cholesteatoma
Cholesterol
Cleft Lip/Palate
Club Feet
Coeliac Disease
Colostomy
Cot Death
Cri-du-Chat Syndrome
Cruzowes Syndrome
Cushions Syndrome
Cystic Fibrosis

Dandy-Walker Syndrome
Deaf
Dental Work
Depression
Dermatomyositis
Developmental Delay
Diabetes
Down Syndrome
Dyslexic

Ear Disorders
Education
Emotionally Disturbed
Eczema
Encephalocele
Encephalitis
Epilepsy
Erbs Palsy
Eye Disorders

Feeding Problems
Food Allergies
Fragile X Syndrome
Friedreichs Ataxia

Gifted Children
Grommets
Growth Hormone Deficiency

Hamman-Rich Syndrome
Head Injury
Hearing Problems
Hernia
Heart Conditions
Hemiplegia
Hip
Hirschsprungs disease
Hydrocephelus
Hyperactive
Hyperkenetic
Hypogonadism
Hypothyroidism
Hypomelanosis of Ito

Imperfecta Anus
Intellectually Handicapped

Kidney
Kyphoscoliosis

Laurence Moon Biedle Syndrome
Lung Auto Immune Disease

Marfans Syndrome
Microcephelic
Micro-opthalmia
Mucopolysaccharide Diseases
Multihandicapped
Muscular Dystrophy

Neuronal Ceriod
Nose Disorders

Orchidectomy

Pacemaker
Patent Ductus Arteriosus
Perthes Disease
Pfeiffer Syndrome
Physical Disability

DISABILITIES, SPECIAL NEEDS,
HEALTH IMPAIRMENTS, continued

Phenylketonuria (PKU)
Plastic Surgery
Prader-Willi Syndrome
Premature Birth
Protheses
Pulmonary Vascular Disease

Restricted Vision
Residential Placement
Rett Syndrome
Rickets
Ring 21
Rubella

Sanfilippo B (MPS III)
Scoliosis
Seckels Syndrome
Shunt
Smith-Lemli-Optiz Syndrome
Specific Learning Disability
Speech and Language Problems
Spina Bifida
Sturges-Weber Syndrome

Talipes
Thyroid
Transposition of Great Arteries
Tuberous Sclerosis
Turners Syndrome

Von Rechlinghausens Disease

Werdnig-Hoffmann Disease

'Parent to Parent'

National Co-ordinator
PO Box 704
Cambridge New Zealand
Telephone: (071) 27 5530
After Hours (071) 27 5488

* * * * *

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.
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

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THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

Booklets, produced on behalf of the MPS Society by parents and doctors drawing on their experience and with reference to medical literature, are available from

The MPS Society
44 Rawson Street, Epping 2121

at a nominal charge. The following titles are immediately available:

The Pattern of Inheritance
Hurler, Scheie and Hurler/Scheie Diseases
Hunter Syndrome
Morquio Syndrome
Sanfilippo Syndrome
Maroteaux Lamy Syndrome
An Introduction to Mucopolysaccharide Diseases

A further booklet containing all ML (mucolipidosis) disorders will be available in 1990.

* * * * *

very special Kids.

WHO ARE WE?
Very Special Kids is an organisation which offers to support the families of children suffering from a life threatening illness.

WHY DID WE START?
The need for an organisation such as "Very Special Kids" was recognised when families met, while visiting their children in hospital, and provided support to each other. These families realised that a great deal more help could be provided by a very organised group of volunteers with practical and professional back-up.

WE OFFER
* Support from a person who has been through a similar experience and is trained to give this support and guidance through your times of confusion, fear and uncertainty
* Practical assistance at home
* Help with hospital visits
* Information on further community support

HOW IT WORKS
The services of Very Special Kids are offered only on request. The family concerned is asked to contact us personally for assistance and we will make every endeavour to meet the needs of that family.

VERY SPECIAL KIDS, in line with the Anti-Cancer Council guidelines does not promote any specific treatments, but provides support at the human level of feelings and emotions.

For further information contact
"Very Special Kids"
Cloyne House
12A Chapel Street
East St Kilda 3183 Telephone: (03) 51 6854

HANDITAL NSW Inc

ASSOCIATION OF ITALIAN FAMILIES & FRIENDS OF HANDICAPPED CHILDREN OF NSW
326 Norton Street, Leichhardt, 1040 Tel: 560 0494

WHAT IS HANDITAL?

Handital is a non-profit organisation established in 1983 by a parent-based group pooling their knowledge, needs and experience. Its aim is to service the disabled in the Italian community. Such as it incorporates casework, community development, advocacy, informational and referral activities.

WHAT DOES HANDITAL DO?

- it provides support for families (primarily families of Italian origin) with children with disabilities
  - cognitive support (information relating to disability)
  - social/emotional support
- it mediates on behalf of the family when they experience difficulties with government and non-government agencies and services
- it provides information about existing services for people with disabilities
- it issues a newsletter to keep members in touch with information on disability and events of interest
- it acts as a co-ordinating group for parents to provide opportunities for discussion on issues of concern
- it has a small library relating to needs of disabled people available for members to borrow
- it makes the community at large aware of its services and organised functions through regular press releases on the radio and in the local newspapers
- it identifies needs in the community and acts as a catalyst for new services

WHAT IS HESP?

Handital's Employment Skills Program was established in 1986 with a guiding principle of positive discrimination towards disabled people of different cultures, languages or ethnic backgrounds. HESP accommodates a maximum of 25 trainees with mild/moderate physical or intellectual disabilities.

WHAT DOES HESP DO?

HESP teaches work-related and social skills and improves functional literacy and numeracy skills. It seeks to access trainees to appropriate TAFE SPECIAL Courses, and where applicable, TAFE mainstream courses. Trainees are provided with work experience in an industrial setting that approximates open employment conditions. The centre also assists in finding appropriate open employment and consequently provides support in the "setting in" period of a placement.

RESOURCES & AIDS

AGSA does not evaluate or recommend any of the following aids or resources. They are included for information only.

Contact is welcomed from any individuals or organisations who may be able to provide or obtain any information through the AGSA Newsletter. Please send details of your organisation and its aims to

The Editor
AGSA
C/- 44 Rawson Street
Epping 2121
Telephone (02) 868 2559

* * * * *

FREE LEGAL SERVICE

MACQUARIE LEGAL SERVICE
48 Darcy Street, Parramatta
Telephone: 689 1777

Experienced Solicitors offer the following service to people with a developmental disability and their caregivers.

- Legal Service
- Referral to appropriate services
- Lecture/informative talks on legal matters pertaining to people with a Developmental Disability

This service operates 3 nights each month on Tuesdays from 6.30pm to 8.00pm.

Mr Stephen Booth is the Solicitor experienced in legal problems associated with people with a developmental disability. Wheelchair access can be arranged.

* * * * *

GRIEF SUPPORT INC

(02) 489 6644

24 Hr. Support Service

Reg. Charity No. CC26832

* * * * *

Kids Klub

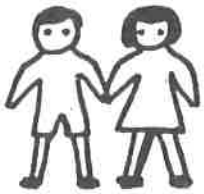
Integrated playgroup for children with disabilities as well as their brothers and sisters. It includes Music Therapy, occasional physiotherapy.

The program is structured to include a music session and craft (gross motor and fine motor) activities:

Day: Wednesday
Time: 10 - 12
Place: Uniting Church Hall,
Cnr Carlingford Road and Orchard Street,
Carlingford
Contact: Gwen Knox - phone 449 2856

* * * * *

PLAYGROUP



A playgroup is a place where children, accompanied by an Adult, learn through play.

It consists of lots of fun things for kids like painting, playdough, cutting, pasting, dressing-up, sand and water play, climbing and jumping, story-telling, singing and music, outings and much more!

Special needs officer: Jenny Stone - phone 644 9066, who can advise your nearest playgroup and make arrangements for you to attend.

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NEW RELEASE JANUARY 1990

South Australian Film Corporation
113 Tapleys Hill Road, HENDON SA 5014
Telephone (08) 45 2277 Facsimile (08) 347 0385

SO YOU WANT TO CARE FOR CHILDREN

A Videotape Series of 10 parts
Duration: 140 minutes
Price: Full Series $298.00/VHS
Sales Tax: Plus 20% *(if applicable)*
Produced: December, 1989

This is a series of 10 videotape programs aimed at raising the awareness of the responsibilities, personal qualities and skills required to care for young children up to the age of 2½ years. Throughout the series qualified staff have been used in a variety of child care settings.

Its presentation makes this program ideal for use with **new mothers** and for personnel working within the **health, welfare** and **child care** fields. It will be of particular benefit also to young adults contemplating a **career in child care.**

Availability:

SO YOU WANT TO CARE FOR CHILDREN is now available. Separate parts are available individually or you may select any number of parts for compilation on one tape. You will however, find it more economical to purchase the full ten part series on one tape for the **special price of $298.00** *(plus 20% Sales Tax if applicable).*

We invite you to preview **SO YOU WANT TO CARE FOR CHILDREN.** Preview tapes are available for evaluation only and must be returned to SAFC within the stipulated 14 day preview period. Except for the cost of returning preview material there is no charge for this service. New Zealand clients please note that the preview period is extended.

For your convenience details of each of the ten parts are listed below. However, please contact either myself or Jeanette Dunlevy should you require any further information.

HELEN GRIFFITHS
Short Film Marketing Division

**** Preview request at the back of the Newsletter ****

SO YOU WANT TO CARE FOR CHILDREN

Part 1: Introduction *14 minutes/VHS $50.00*
The introduction enforces a number of major themes addressed in the nine programs. They include respecting the uniqueness of each child and the wishes of parents; the importance of developing good communication skills and a recognition that child care involves working as part of a team which is committed to encouraging a stimulating, safe and positive environment.

Part 2: Bathing and Dressing *13 minutes/VHS $50.00*
Bathing and dressing a young child need not be stressful either for the child or the care giver. This program highlights simple but important techniques for supporting and reassuring the child.

Part 3: Play *15 minutes/VHS $50.00*
Play is a significant component in the intellectual, emotional and social development of young children. This program identifies some suitable play activities and resources in relation to development.

Part 4: Bottle Feeding *11 minutes/VHS $50.00*
Highlighted and hygenic methods of preparing bottles and procedures for making up milk formulae as well as identifying appropriate storage conditions for preparing bottle feeds. Feeding techniques and a child's individual feeding needs are also looked at.

Part 6: Assisting Babies to Eat *13 minutes/VHS $50.00*
The nutritional requirements of children and the techniques which can be used throughout the feeding stages to maintain a positive feeding environment are highlighted in this program. Eating is promoted as an enjoyable, educational and health promoting experience.

Part 7: Safety *10 minutes/VHS $50.00*
For the healthy development of children their environment needs to be both stimulating and safe. Simple safety precautions to protect children without stifling curiosity and exploration are shown.

Part 8: Nappy Changing *11 minutes/VHS $50.00*
Most children wear nappies until toilet trained. This program stresses the need for nappies to be changed regularly in an hygienic environment to keep the child clean and comfortable. Methods of folding cloth nappies and fitting both cloth and disposable nappies are demonstrated.

Part 9: Toilet Training *21 minutes/VHS $50.00*
Learning acceptable toileting procedures is dependent upon a child's physical and emotional readiness. It is emphasised that the ease with which a child becomes toilet trained is directly related to the manner in which the adult carer handles the situation.

Part 10: Hygiene *18 minutes/VHS $50.00*
The activities of small children bring them into contact with bacteria each day. The carers responsibilities in providing an hygienic environment is explained and demonstrated.

REVIEWS

RESHAPING LIFE

Key Issues in Genetic Engineering

NEW EDITION

G. J. V. Nossal and Ross L. Coppel

How far should scientists go in exploring the secrets of life? Who should decide what is an ethical and safe experiment? What concerns should influence a decision to move from a laboratory bench to commercial application or clinical practice? Above all, how will the awesome power to manipulate the very fabric of life affect our preception of the universe and of our place in it? These are just a few of the ethical, moral and philosophical questions asked by lay people understandably "jittery" at the thought of "scientists playing God".

Genetic engineering and related technologies represent the biggest single advance in the life sciences this century. Scientists can make DNA genes dance to their tune in a nearly miraculous way, with practical results of enormous significance for medicine, agriculture, industry and forensic medicine.

The first edition of this book, written by one of the world's leading biological scientists, was designed to slake the thirst of a readership titillated by sensationalist press reports of genetic engineering. This new edition, rigorously updated to reflect recent advances in technology, is evidence of continuing demand for information of a simple and authoritative kind. Far removed from the dry, overly scholarly and overly historical approach of so many other books in the field, it offers us a saner perspective from which to view our rapidly changing environment.

Gustav Nossal is one of Australia's most celebrated scientists, knighted in 1977 for his contribution to medical research. He has been Director of the Walter and Eliza Hall Institute of Medical Research since 1965 and is currently Professor of Medical Biology at the University of Melbourne.

Ross Coppel is Senior Research Officer at the Walter and Eliza Hall Institute, and Visiting Associate, University Department of Medicine at the Royal Melbourne Hospital.

216 × 140mm 192 pages 11 figures
ISBN 0 522 84381 6 **$16.95**rrp

MELBOURNE UNIVERSITY PRESS
P.O. BOX 278 CARLTON SOUTH VICTORIA AUSTRALIA 3053

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NEW IN PAPERBACK

GENETHICS

The Ethics of Engineering Life

David Suzuki and Peter Knudtson

David Suzuki is Professor of Genetics at the University of British Columbia and he is an internationally renowned radio and TV broadcaster.

Peter Knudtson is a Canadian science writer.

For the first time in history, it is within our power to design life by deliberate human intervention. In this remarkable book, David Suzuki and Peter Knudtson tell the complete story behind these scientific break-throughs and bring every reader to a clearer understanding of this most important area of scientific research today.

This work heralds the promise of a better world . . . or the horrors that an age of "genetic manipulation" could bring. Clearly, we have reached a time of dramatic and potentially dangerous change, one that requires a new vision of reality.

November 1989 230 × 155mm 384pp
ISBN 0 04 442119 2 paperback **$14.95**
Rights: Australia/New Zealand

* * * * *

"Understanding Maternal Grief"

Grief Counselling and Therapy Workshops
with

Margaret Nicol

B.Sc. (Hons), Dip.Ed., M.Psych. Clin., M.A.P.S.

Margaret Nicol is a clinical psychologist, author of **Loss of a Baby: Understand Maternal Grief,** recently released by Bantam books. The book has been widely acclaimed as a sensitive and pioneering work in this relatively neglected area of human loss.

In 1980 Margaret conducted the largest research study ever done in this area. Her research showed that the loss of a baby has as severe effects on women's physical and mental health as the death of a husband. In Australia each year 10% of women suffer some form of repoductive loss and on average by the time women reach the end of their reproductive lives they are likley to have experienced three repoductive losses.

For the past ten years Margaret has worked as a therapist with bereaved women, couples and families. She has also conducted workshops of grief counselling for the professional staff of hospitals, the health department, post graduate nurseds, child birth educators and bereaved parents.

In 1983, she was awarded the Western Australian government's Women's Fellowship Award for her outstanding contribution to the health of women in WA. This fellowship sllowed her to travel overseas to study innovations in services for the bereaved.

* * * * *

FOR CHILDREN

Beginnnings and Endings With Lifetimes in Between

Bryan, Mellonie and Robert Ingpen
(Hill of Content 1983)

A Beautiful way to explain life and death to children (to age 10)

A Child's Questions About Death

Neville A Kirkwood
(Available Baptist Supply Centre
58 Parramatta Road, Glebe 2037)

A small booklet answering the common questions young children may ask.

Explaining Death to Children

Earl A Grollman
(Beacon Press 1968)

The Outstretched Hand Foundation Windsor.
Various leaflets available dealing with the subject.

Return to: The Business Development Manager, Executive Office,
Royal Children's Hospital, Flemington Road, Parkville, Vic. 3052, Australia

"TELL ME DOCTOR, BOY OR GIRL"

ORDER FORM: Price A$50.00, US$37.50 Plus Shipping and Handling
(Victoria $3.00, Other States and Territories $5.00, International A$10.00 US$7.50)

YOUR NAME: Dr/Mr/Mrs/Miss/Ms: _____

YOUR ADDRESS: _____

STATE: _____ POSTCODE: _____ COUNTRY: _____

TELEPHONE: (BUS) _____ (A/H) _____

SYSTEM: VHS [ ]; BETA [ ]; U-MATIC [ ]; PAL [ ]; NTSC [ ];

QUANTITY REQUIRED: _____

PLEASE CHARGE TOTAL TO
BANKCARD ( ); MASTERCARD ( ); AMERICAN EXPRESS ( ); VISA ( )

CARD No: _____ EXPIRY DATE: _____

SIGNATURE: _____

OR FIND ENCLOSED: CHEQUE* ( ); BANK CHEQUE ( ); MONEY ORDER ( )
OR PLACE YOUR ORDER BY CALLING (03) 345 5116, (03) 345 5138 FAX: (03) 345 5789

** Personal cheques accepted only from recognised Australian Banks*

ORDER NOW WHILE STOCKS LAST

Return to: The Business Development Manager, Executive Office,
Royal Children's Hospital, Flemington Road, Parkville, Vic. 3052, Australia

"YOUR CHILD WITH CONGENITAL ADRENAL HYPERPLASIA"

ORDER FORM: Price A$8.00, US$6.00 Plus Shipping and Handling
(Australia: A$2.50, International A$5.00 US$3.75)

YOUR NAME: Dr/Mr/Mrs/Miss/Ms: _____

YOUR ADDRESS: _____

STATE: _____ POSTCODE: _____ COUNTRY: _____

TELEPHONE: (BUS) _____ (A/H) _____

QUANTITY REQUIRED: _____

PLEASE CHARGE TOTAL TO
BANKCARD ( ); MASTERCARD ( ); AMERICAN EXPRESS ( ); VISA ( )

CARD No: _____ EXPIRY DATE: _____

SIGNATURE: _____

OR FIND ENCLOSED: CHEQUE* ( ); BANK CHEQUE ( ); MONEY ORDER ( )
OR PLACE YOUR ORDER BY CALLING (03) 345 5116, (03) 345 5138 FAX: (03) 345 5789

** Personal cheques accepted only from recognised Australian Banks*

PREVIEW REQUEST

Short Film Marketing Division
South Australian Film Corporation
113 Tapleys Hill Road
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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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