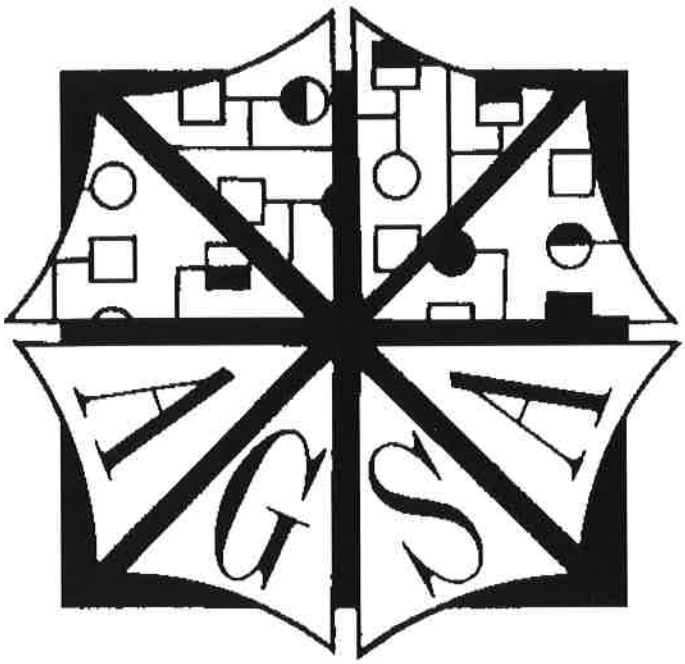

THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA INC.

FUNDED BY THE NSW HEALTH DEPARTMENT

NEWSLETTER

OCTOBER 1996 ISSUE 26

MISSION STATEMENT

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

Reg Charity CFN15481 Tax Ref AF1595C/SF8566

EDITORIAL

The past two months have presented different problems to our Association than we have had to experience before. We were broken into and our computer was dismantled. We are now in the process of improving our security system.

Having experienced the president's position for over six months now, I can begin to see AGSA's true potential. I went to the Human Genetics Conference in Adelaide, where I really felt a part of the profession due to my position in AGSA. We have the potential, as a representative consumer group, to improve the situation for those who are not yet diagnosed, for those that are newly diagnosed, and to provide ongoing support for those that need it. We can work together to improve the medical system for us.

With this in mind, we are planning a questionnaire aimed at you, our members, to see what you want now, in the future, and would have liked in the past, and what both AGSA and the professional genetics services need to do.

I am pleased to say that not only have all our committee members agreed to continue in their current positions, but we also have a new committee member, Sarah Bridge. Sarah was a committee member previously and we are pleased to have her return.

The more I work with Dianne the more I am impressed with her capability and dedication as no doubt our members are aware.

As part of our Awareness Week next year, we would like to have individuals and families available who are willing to talk to the media. If you are or someone you know is interested, please contact the office and I will discuss it with you.
Best wishes

DEBBIE REDELMAN

PEER SUPPORT/INFORMATION OFFICER'S REPORT

It is hard to believe we are on the down hill run to Christmas once again.

Last month thieves broke into the AGSA office and stole the CPU of our beloved computer. Six weeks later things are now back to normal (somebody told me recently "normal" was a setting on a hair dryer) and I apologise for the delay in producing the October newsletter.

Michael Small from the NSW Disability Discrimination Legal Centre gave an excellent talk on the Anti Discrimination Acts at our AGM in September.

On 28th September I was invited to attend the Familial Polyposis meeting at the Cancer Council. Twenty people attended and talks were given by Dr David Koorey, Gastroenterologist, Dr Kathy Tucker - Clinical Geneticist and Mrs Colleen Macic Consumer representative. The group proposed to hold another meeting in March with the view of setting up an independent support group and to create a greater awareness of FAP. Fleur Webster is the Co-ordinator of the FAP Register and works closely with the families. I would like to thank the members for contributing their family stories for this newsletter and Fleur for inviting me to attend the meeting. I look forward to meeting up with the families again in March 1997.

The Marfan's syndrome meeting on 13th October was attended by fifteen people and we thank Dr Lesley Ades, Clinical Geneticist, for her excellent talk on her research into Marfan syndrome. Marfan's syndrome will be profiled in the December newsletter. It was good to meet the new enthusiastic committee members and I know we will be hearing a lot more from this group in 1997.

The Practicalities of Running a Support Group was attended by seven people representing four groups and much information was exchanged. Many thanks to Glenn and Geoff Fisher who presented a very informative talk on the legalities of running a support group. These meetings are usually small and informal and if you haven't attended one I urge you to come along in the New Year and learn what AGSA can do for your group.

Marlene Brightwell and myself will be canvassing the support groups this month to ascertain areas where AGSA can be of assistance and to work out a program for our Genetic Awareness Week in August 1997. AGSA's Genetic Awareness Week will focus on peer support and it is planned to have a support group luncheon with guest speakers.

In September AGSA was given the opportunity to present a poster at the Human Genetics Scientific Conference in Adelaide. This was a first time for me and I found it very worthwhile to hear first hand about the many research studies being conducted. Many studies related to the conditions represented by support groups AGSA has helped establish. The conference covered a huge range of topics with many interesting speakers. I would like to thank the HGSA for an excellent conference and for their support of AGSA.

The Parents and Professionals Loss and Grief workshop has been postponed until 22nd - 23rd March 1997 because the timing clashed with exams and the Genetic Counsellors Conference in America. This workshop will explore the grief experienced by parents of a child/individual with a genetic condition. This particular weekend has been chosen to enable genetic counsellors visiting Sydney for their Annual Genetic Counsellors Workshop an opportunity to participate. Should finances be a problem please discuss this with myself. A detailed flyer will be enclosed in the December newsletter. Please note it in your diary and I look forward to seeing you there and catching up. It is AGSA's intention to profile genetic services and counsellors in 1997 to enhance the understanding of the complexities involved.

Many thanks to all those members who have paid their membership and a special thank you to the many who gave generous donations.

Best wishes

DIANNE PETRIE

LETTER TO THE EDITOR

As you know SAFDA (Support After Fetal Diagnosis of Abnormality) is an organisation which originated in l991 to support and inform families who have experienced an abnormal prenatal diagnosis. Its members include parents, families and many health professionals. SAFDA has, over the last few years, put in place written resources for families which are designed to provide support at the time of diagnosis. If a decision is taken to terminate the pregnancy, families are referred to Shared Experience Meetings where they can find the support they need from others in similar circumstances.

As a founding member and now current member of the executive I am writing to you through the AGSA newsletter to ask for the assistance of your readers. We are anxious to develop better resources for those who opt to continue a pregnancy. They are referred to the relevant support group for the disorder which had been diagnosed to gain the necessary continuing support and information and assistance after the baby is born. However, we realise that there is a group of parents who choose to continue the pregnancy and are not able or choose not to contact a disorder - specific support group.

SAFDA has developed to date as a result of the generous and brave individuals who shared their own experiences and thus taught us something about their real needs at the time of diagnosis. We hope to appeal again to this spirit in asking any of your readers who have chosen to continue with the pregnancy after diagnosis of an abnormality, to share their experiences of the pregnancy, birth and family life in the aftermath of this decision. We hope to talk or meet with them so that we can help where possible with some of their current issues and also use their wisdom about what would have helped to assist other fellow travellers on this most difficult of journeys. Feedback is also being sought from the USA from a group which meets to support such parents.

Whatever decision is made at this distressing time there is grief and trauma for all involved and we are keen to develop equally sensitive and appropriate methods of providing information and support for all regardless of the decision taken. SAFDA is firmly committed to a position of non-judgement wishing only to offer the acknowledgment and support that can only come from those who have experienced this most difficult of life events.

Anyone interested in this issue could contact Bronwyn Butler on Tel 9926 7324 or Amanda O'Reilly on Tel 99297764 so that we can discuss a meeting and\or other opportunity to share experiences and help to develop the resources and support systems that are needed.

Thank you for your support of our work in this area.

Amanda O'Reilly, Vice President, SAFDA

ANNOUNCEMENT

A MEETING OF THE HEREDITARY HEMORRHAGIC TELANGIECTASIA SUPPORT GROUP

Saturday 16th November l996, CWA Hall, Beach Road, Bateman's Bay at 10.00 am

For details please contact Melanie Rouse on phone fax (049) 38 8122. Melanie is the Australian representative for the American HHT Foundation.

CONTACT CORNER

AGSA will publish requests for contacts and letters from people searching for families with similar experiences, from those seeking or contributing specific information as well as other resource information.

Anyone who wishes to reply to a request or a letter should write direct to the individual or group concerned where an address is provided. The AGSA office may be contacted for the information to be passed on in the case of anonymous requests. Privacy and anonymity will be ensured if requested.

While AGSA aims to facilitate contacts between families it is unable to assess the suitability of these in individual cases.

It should be remembered that a shared genetic condition does to mean an equally shared value system between families. Different degrees of acceptance and different mechanisms for coping will be encountered and a non-judgmental approach is recommended in establishing contact.

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APLASIA CUTIS

Contact with another family is sort. Contact AGSA for details.

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A Melbourne family have a 4 year old with duplication of a specific segment in chromosome 17 (segment p11.2-p13.1). They would be glad to learn of any other family with a child with this same chromosome abnormality. Contact: Henryk and Eua Borkiewicz, 3 Salisbury Court, Heathmont, 3135. Phone (03) 9729 6937.

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HAJDU-CHENEY SYNDROME (ACRO-OSTEOLYSIS)

A family in Tennessee, USA, would like contact with another family. Their child is 12 years old and has a cleft palate, hearing impairment and a history of surgery to correct patent ductus arteriosus. At this time, she is experiencing some vision problems and early loss of teeth.

Please contact AGSA for details.

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SIRENOMELIA

A family who gave birth to a baby with Sirenomelia who died three years ago are keen to have contact with another family, Please contact Clara Gaff, Associate Genetic Counsellor, Royal Women's Hospital, 132 Grattan Street, Carlton 3053 - Tel: (03) 9344-2121.

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SUPPORT GROUPS

Lissencephaly Network Australia

Lissencephaly and pachygyria are brain malformations characterized by the lack of normal folds in the brain. The disorder may occur alone or as a symptom of other medical conditions. As a result the affected children have varying degrees of developmental delay, seizures, and other related medical problems. The Lissencephaly Network of Australia was set up in September 1996, it aims to provide mutual support through newsletters, telephone and letter contact, to families of children with lissencephaly or pachygyria. We also endeavour to provide up-dated medical information.

We look forward to welcoming new families into our Network.

Contact: Mrs Debbie Tuivawa
76 Whitaker Street
Guildford 2161 NSW Australia

Phone (02) 9632 5914

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METABOLIC DIETARY DISORDERS ASSOCIATION

On 13th October 1996 the association met to hear parent, teenager and sibling experiences and to discuss dietary information and recent medical information. For further information about this group please contact:-

Kerri Carboon on (03) 9720 4204 or Margaret Sahhar on (03) 9345 5157 at the Murdoch Institute Royal Children's Hospital, Melbourne.

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PROFILE
A - Z GENETIC CONDITIONS

It is the intention of AGSA to profile, in each issue, a particular Support Group/Disorder, thus increasing awareness within our membership of the range of genetic conditions. Also it hopes that where overlaps occur in conditions, support Groups may liaise with each other and thus gain a broader understanding of facilities, aids, etc. that may be of value to your individual membership.

Please ensure that all support group information is recent and reliable. It is of paramount importance that you let us know your group is "Alive and Well' and happy to take referrals.

For your information we profile.....

FAMILIAL ADENOMATOUS POLYPOSIS COLI (FAP)

It is estimated that up to 5% of all bowel cancers occur as a result of a hereditary bowel cancer condition which runs in families. Familial Adenomatous Polyposis Coli (FAP) is one of these conditions and accounts for approximately 1% of all bowel cancers. It is estimated that about 360 families are affected by FAP and 100 new cases of FAP related bowel cancer occur each year in Australia.

FAP is a condition which causes hundreds or thousands of small growths (known as polyps) to form in the bowel of the affected person. If left untreated, one of these polyps will inevitably develop into bowel cancer. There fore, it is important that people at-risk of FAP are aware of and understand their risk and undergo appropriate screening and treatment where necessary.

FAP runs in families and is passed from a parent who has FAP to a child through a specific gene. It is dominantly inherited, so that if one parent has FAP each child has a 1 in 2 chance of inheriting the gene which leads to the condition. Most people with FAP first develop polyps during their late teens. However, polyps may first appear at any age, but rarely under the age of 10 or over the age of 55.

It is necessary for people at-risk of FAP to be screened from a young age to detect the polyposis (or multiple polyps) before one or more of these polyps develops into bowel cancer. This is because FAP usually does not produce bowel symptoms in its early stages, so by the time symptoms arise most people with AP have already developed bowel cancer. Bowel cancer usually develops when a person is in their late 20s, their 30s for their 40s. Therefore, screening must begin early, usually around the age of 12 years. Screening involves having a sigmoidoscopy once every year or two. A sigmoidoscopy is an examination done by a specialist doctor in which the lower part of the bowel is examined through a sigmoidoscope - a thin flexible instrument that works like a telescope.

As an alternative to screening, people at-risk of FAP may be gene tested. This is a relatively new technique and is now available throughout Australia. Gene testing can tell a person with a 100% certainty whether they carry the gene for FAP or not. For those who have the FAP gene, close surveillance will then be necessary to monitor the polyposis and eventual surgery will be required. For those who do not have the FAP gene, lifelong screening will no longer be necessary and their risk of bowel cancer will be that of the normal population. Gene testing is currently offered from around the age that screening for FAP would normally commence and is provided in conjunction with obligatory pre- and post- test genetic counselling. However, it is important that families are informed that gene testing often takes many months to find an answer and in only 80% of families can the change in the gene that is affecting that family be

found. For those families where gene testing is not presently possible, screening is the only option available to at-risk family members. Gene testing services are currently quite limited in Australia and there is a waiting list of people wanting to be tested.

Treatment for FAP involves preventative bowel surgery to stop bowel cancer developing. The surgery involves the removal of all or most of the large bowel (the colon and sometimes the rectum). There are different surgical options available and the choice of surgery is largely dependent on the person's age and the stage of the FAP. As polyps can also develop in the remaining rectum and other parts of the gastrointestinal tract, medical check-ups are still necessary after surgery.

To assist these families at a high risk of bowel cancer, FAP Registers have been established throughout Australia and in many parts of the world. They are usually operated by a FAP Registrar who manages the day-to-day activities of the Register and who has personal contact with the families. The main aims of these FAP Registers are to:

1. Identify and record all affected and at-risk FAP family members.

2. Facilitate regular screening of FAP family members by their clinicians by offering a free reminder service for clinicians and their patients.

3. Trace all at-risk FAP family members lost to follow-up.

4. Provide an information and support service to these family members.

For further information on FAP, you may contact the FAP Registrar in your state. Here are the contact details:

NSW FAP Register
NSW Cancer Council
Kings Cross NSW 2011 PH:: (02) 9334 1817

Queensland Familial Adenomatous Registry
Queensland Cancer Fund,
553 Gregory Terrace
Fortitude Valley QLD 4006
PH: (07) 3258 2228

Esso Familial Polyposis Register of Victoria
Anti-Cancer Council of Victoria
1 Rathdowne St
Carlton South VIC 3053 PH: (03) 9279 1176

WA Familial Polyposis Registry
WA Cancer Foundation
334 Rokeby Rd
Subiaco WA 6004 PH: (09) 346 2448

Southcorp FAP Registry
Anti-Cancer Foundation
202 Greenhill Road
Eastwood SA 5063 PH: (08) 8291 4111

This article has been written by Ms Fleur Webster who is the NSW FAP registrar, NSW Cancer Council, Sydney.

AGSA would like to thank Fleur Webster for her assistance.

FAMILY STORIES

RON'S STORY

I was born the third child in a family of four in 1928 and from early years at school I had loose (semi-formed) bowel motions. I experienced no pain or bleeding. After leaving school I gained an apprenticeship in an engineering shop, which was quite heavy work. I kept good health and was active in sports and a pastime I loved ballroom dancing.

I met my wife Patricia in 1948 and we married in 1951. By this time I had developed haemorrhoids, but did not need medical attention nor did I seek it. I had occasional loose motions but returned to normal within a few days.
In my 30th year I had a severe case of diarrhoea. This time I saw my local doctor, he prescribed the usual medication for relief and told me to come back in two days if I was no better. I went back and he referred me to a gastroenterologist. The specialist suspected polyps and I was sent for X-rays. I took these back to the doctor and

on scrutiny he couldn't believe what he saw. I was sent back for another lot of X-rays. These was no mistake there were thousands if not millions of polyps throughout the bowel and upper rectum.

The next step was surgery. I had my first operation called a colectomy, where the large bowel is removed, also part of the rectum the small bowel is then attached to the remaining rectum. This worked successfully for 17 years. I attended out patients clinic every three months for checks with the sigmoidoscope and if any polyps were detected they were removed.

Life was good. I had been told I had an hereditary disease but as none of my siblings tested positive and my parents were alive and healthy I had no reason to believe it. Such was my ignorance 38 years ago. Our girls were healthy and we wanted another baby. Our son Bruce was born in 1965. In 1975 aged 47 my doctor, ever cautious decided it was time for an Ileostomy. The risk of the polyps turning cancerous was too great. In this operation the rectum is removed and closed. The small bowel is brought through the stomach wall and a stoma fashioned from it. On this stoma an appliance is filled to collect bowel contents. The operation was successful and convalescence lengthy, but I adapted well to my new plumbing. I am a member of the Ileostomy Association whose support I value.

Our girls became women and whilst they were aware of my condition and the signs I had experienced neither girl manifested any of these. Kay became a teacher and Ronda a secretary. Both girls married at 20 and had two children.

Ronda noticed bleeding from the bowels aged 28. On examination follow up x-rays revealed she had Familial Polyposis Coli. A hereditary condition. Within a week she was operated on, her large bowel and rectum removed, and given an ileostomy. For Ronda it was too late. She had cancerous tumours. Some chemotherapy followed, but in six months she was gone. Kay and Bruce were tested for FAP immediately. Bruce was positive aged 21. His operation followed immediately. A more modern one where an internal pouch is created from the small intestine. This procedure is only possible when there is no cancer. Bruce also has an off-shoot of the FAP condition called Gardener's syndrome. This represents a small swellings on parts of the body, sometimes they are found internally. All lumps have to be checked. He is strong and healthy and has a senior position in a Pharmaceutical Company and is undertaking a University Course. He is happily married and looks forward to having a healthy child in the near future.

In recent years our grandchildren have been tested for FAP and of the four, Ronda's eldest daughter aged 14 has the condition. She will be carefully monitored and when she is fully grown her treatment will be decided. Periodically the three other grandchildren will be examined for any evidence of the FAP condition. I am now retired keep good general health, play golf and of course with my wife go ballroom dancing.

I am so grateful we have a FAP register and the back up of doctors and advisers. Sincere thanks to a hard-working lady who keeps tabs on us all.

God Bless Fleur Webster.

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DORIS'S STORY

In the last 18 months my life has changed. In February 1995 I was diagnosed as having FAP which is Familial Adenomatous Polyposis Coli.

I can still remember the shock I felt after being told.

As the specialist told me about FAP I couldn't believe it. I had thousands of polyps throughout my large bowel and they needed to be removed. Unfortunately these polyps had commenced when I was about 15-29 year old. My large bowel was now at a dangerous stage as the polyps had become sessile or flat, meaning they were prone to becoming cancerous. I was at a high risk of malignancy at age 36. The even scarier part that it is a hereditary disease. I am the

youngest of four. My two brothers and one sister all needed to have a colonoscopy. Their tests showed no signs of polyps however a follow up test will be done every 3-5 years.

My seven year old daughter would also need to be checked out by the age 12 -15 as she has a 50% chance of getting it.

In a matter of ten minutes my whole world had come crashing around me, I was numb, confused, very frightened and angry. I sat waiting for the taxi to take me home, tears streaming down my face. How would I explain this to my daughter, when I didn't understand it myself ? What would she feel, how would she react? This must be a mistake. Here I was 36 years old, enjoying being a single parent with a loving and beautiful 7 year old child, I had a great casual job finally getting on my feet and happy with my life, and now this was all to change, but just how much no-one would ever believe.

At home, I rang to let my friend know I was home and could she give me some time before sending my daughter back.

I sat and stared at the report the specialist gave me, reading it over and over, I burst into tears, became angry, yelled and screamed. Why me?

I rang my G.P, in shock he listened as I read the report. He offered to call over when he had finished at the surgery. He stayed for quite some time, he was very concerned at my distressed state. He listened as I talked and comforted me when I became upset and cried. He told me that the specialist I'd been referred to was the top in the field. He left when I'd calmed down.

My boyfriend couldn't deal with this and left directly after the doctor, he could offer no support. I was left with my daughter. We sat together, hugged and talked. My friend came and stayed with us the next day, to help us through this tough time. I was grateful for her support. As my family all lived down the coast I had to ring them to tell them what was happening. They were all so shocked at the news. I still remember feeling so numb, just wandering around in a daze trying to put it out of my mind. I had a specialist's appointment in two weeks -- surely he would tell me that there had been a mistake.

Finally the day had arrived to go to the specialist, my sister came with me. The specialist was nice, very gentle and caring. He explained in more detail about FAP and as he spoke I still could not believe this was me he was talking about.

The specialist told me my polyps were pre-cancerous and I needed to have a surgical procedure - Protocolectomy - in which the large bowel (colon), rectum and anus are removed and the end of the small bowel (ileum) is brought to the surface of the abdomen. An opening (a stoma) is created in the abdomen through which the contents of the bowel are eliminated from the body. This procedure is called an ileostomy and the intestinal wastes are collected in a special, small bag attached to the abdomen.

As my polyps had changed the procedure had to be done soon. I was booked into hospital the next week. I was told I was lucky it was found now as six months more and I would not have been around.

My signs and symptoms were hidden due to an overactive thyroid gland that started in my early 20's, so the diarrhoea I was experiencing was always put down to my thyroid. I realised something was wrong when I noticed blood in my stools which increased more over a period of time.

I went home and thought about all I'd been told and what was to happen. I cried a lot, tried to act brave in front of my daughter. I didn't want to scare her too much. I remember thinking what if she didn't like how I `d look. I looked at my body naked in the mirror trying to think how I would look. I guess I was taking my last look before it changed.

My operation went well. The stoma was to be permanent - there is always a hope of creating a pouch inside but my small bowel was not long enough and they found a mass in my rectum, so everything was removed and my anus closed off

just leaving a tiny hole for drainage of blood or fluid.

I remember having a look for the first time at my stoma and the very long cut with all the staples holding it together. It made me feel a little sad. I felt ugly and scared. I also knew this needed to be done to save my life and it would heal in time. But my feelings would change.

My recovery seemed to be going well, and eight days after my surgery the specialist told me the pathology results showed that there was cancer detected on 1 of the 23 glands removed. An appointment was made to see an Oncologist the next day. I was to start chemotherapy about 6 weeks later. It was so scary to learn of the cancer I didn't believe it. The next day I was due to be discharged.

Eight days later I was admitted into hospital. I'd been sick all weekend spiking high temperatures, vomiting and bleeding a lot from my anal area. I felt sick all the time. I'd developed a haematoma and an infection in my rectal cavity. I was hospitalised for six days on I.V antibiotics and pain relief.

My chemo had to be delayed for two weeks till I was stronger. When it did start I had 5 days on and 3 weeks off. After the second day I started to feel the side effects and I had pain radiating down my left arm, chest pain and indigestion. I rang the hospital who asked me to come in to have some tests done. Some studies have shown heart problems in some patients under going this type of chemo. All test were normal.

The pains lasted for about 2-3 days after the chemo.

I was managing with my newly formed stoma . I had been staying with my family but we longed to go back to our own home, so we did.

Nine days later the infection and fevers started again, so it was back to hospital for treatment. My second bout of chemo, the same chest pains and problems. The chemo drained me of all my energy and it took me the three weeks to get a little strength, then it was time for the chemo again. I only had one day of chemo this time, as I became sick. I was admitted to hospital again and 14 weeks after my original operation I had the surgery done again and my stoma re-sited on the other side. I awoke with all the tubes, catheters, my suture line cut again, an extra drain to assist drainage of the infection that kept coming back, and an open wound where the first stoma had been. This was too much. I should be well on the road to recovery, nearly back at work, now I had to mend all over again. I was miserable but knew to mend I had to keep my positive attitude. I mended and was discharged nine days later. I decided not to continue with the chemo as I believed it was the reason why I always had the infections and couldn't heal. The specialist agreed with my choice.

Two weeks later I came in for a check up. I needed to come in for an overnight stay so I could have a drain put in again, as an abscess was forming on the old drain site. All went well and one week later the drain was removed. Ten weeks later it flared up again and burst. This time it was treated and finally healed. I was getting distressed will all the abscesses that kept happening and the specialist said it was because my immune system was run down from all the surgery and chemo and would build itself up eventually. I was managing well with my stoma. For three months all was going well when an abscess formed around the stoma area. Once again it was treated and settled for a short while then over the next ten months the abscess flared up on and off. After putting up with being told it would settle, I pushed to have something done. The stoma was cut out to reveal an infection underneath it. It was refitted and sewn into place.

That was four months ago now and I am slowly getting to do things. I still need to take it easy and both my daughter and I hope that we will get a nice long break before any more complications set in. Having a stoma isn't too bad. I have met some wonderful people every time I have been in hospital.

I am also lucky to have met Fleur Webster, when this first happened to me. Fleur has been very helpful and supportive and kept me up to date on

every aspect of FAP. Worked hard and managed to get a group of us together. It is great to talk to others with this and their families, and try to get a support group going.

CONFERENCES

DONOR INSEMINATION SUPPORT GROUP

DONOR ISSUES FORUM

SATURDAY, 16TH NOVEMBER 1996

9.00 AM TO 5.00 PM

Metcalfe Auditorium, State Library of New South Wales, Macquarie Street, Sydney 2000

The Donor Issues Forum is the first of its type to be held in New South Wales. It will give participants a unique opportunity to listen to a wide range of speakers and participate in discussions on issues surrounding donor conception.

Topics to be covered will include:

* What is the effect of secrecy versus openness on the family?

* What is the current situation with legislation for reproductive technology in NSW?

* Do donor offspring really need access to information on their donors?

* What will the effect be on donor programs of openness?

* Do we need a central register of donor and recipient information?

* Will there be less need for donor conception in the future?

* How do other countries handle donor conception?

Speakers:

* Ken Daniels: Associate Professor of Social Work at the University of Canterbury in New Zealand. Professor Daniels is a renowned researcher into the effects of donor conception on the family.

* Margaret McDonald: Worker in the Adoption field

* Graeme Hughes: Gynaecologist from the Royal Hospital for Women, Paddington

* Kerrie McGowan: Counsellor from King George V Hospital, Camperdown

* Henry Wellsmore: Counsellor from Lingard Hospital, Newcastle

* Lauren & Nicky: adult donor offspring

* Terry Crookie & Karen Body: parents of donor embryo twins.

* Dave a sperm donor

* Peter Hennessy: from the NSW Law Reform Commission.

Cost: $15.00 members, $20.00 non members , $30.00 professionals.

Contact: Leonie Hewitt (02) 9724 1366, Caroline Lorbach (02) 9624-5110

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1997 BIENNIAL NATIONAL AUTISM CONFERENCE 13 - 16 MARCH 1997 'THE WIDENING SPECTRUM'

Fairmont Resort, Leura, Blue Mountains NSW

Contact: Anthea Mulready, Secretariat Ph: (02) 9956 83333

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JOINT NATIONAL CONFERENCE 1997
NALAG ACISA ASTSS

WED. MAY 7 - SAT. MAY 10, 1997

THE UNIVERSITY OF SYDNEY

"TRAUMA, GRIEF & GROWTH - finding a path to healing"

Keynote Speakers: Dr Atle Dyregrov, Centre for Crisis Psychology, Bergen, Norway; **Professor Bonnie Gree,** Dept. of Psychiatry, Georgetown University, Washington DC, USA; **Professor Zahava Solomon,** School of Social Work, Tel Aviv University, Israel

Contact the Conference Manager, PO Box 79, Turramurra NSW 2071 Australia PH: (02) 9988 3376