

CENTRE FOR CHILDREN'S CANCER AND BLOOD DISORDERS



FAMILY NEWSLETTER

Number 65

March 2004

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Centre for Children's Cancer & Blood Disorders

FROM THE EDITOR'S DESK

Almost one third of the year has passed so it seems pointless for me to say "Happy New Year" particularly when, for many of you it has been far from a wonderful start. For those families with children recently diagnosed or those at other very difficult stages, I hope that you will find something in these pages to help you feel less alone. The Family Newsletter is aimed to provide support to families, to help them feel less isolated and alone.

For those of you who do not know me, my name is Merron Howard. I edit this Family Newsletter in a voluntary capacity while working in the management of childcare services for a Local Government. I have had 5 children, the youngest of whom is now a young adult, just started at university and full of life. As a family we enter another new stage in our growth - no longer are we parents of children at school - we are in fact grandparents of 2 young children. As a family we have had personal experience of childhood cancer, though many years ago now, and do remember clearly our concerns, hopes, fears and anxieties. But this experience, while still having a direct influence on our lives, joins so many of our other experiences as a part of who we have become. I continue to edit this newsletter as a direct result of this experience.

To ensure that the Family Newsletter does achieve its goals I do need to get contributions from families. I enclose a sheet that can be completed with information about your family. It doesn't matter if the contribution is 4 lines or 4 pages, whether it is from a child, parents or grandparents, whether it is a poem or a drawing from a child. (Photos are however difficult. I haven't come into the 21st century with my computing skills or computer hardware).

Without contributions from families and staff, the Family Newsletter is not possible. Please give serious consideration to sending some news to me. Til next time, take care,

Merron Howard

Contributions for the
Family Newsletter
urgently needed.

Closing date for
June edition
30th May 2004

See back page for more
information.



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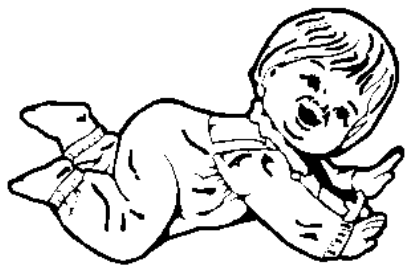
The Centre for Children's Cancer & Blood Disorders would like to say a big thank you to all our supporters

HERE THERE & EVERYWHERE

What are they up to now?

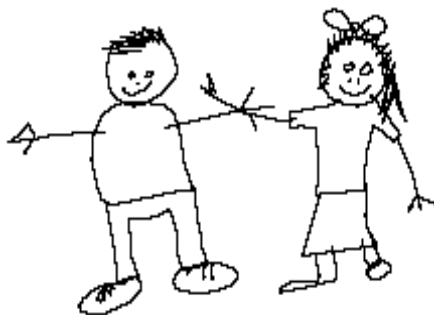
Brayden was diagnosed with non-Hodgkin's lymphoma in September 2001 and had 4 months of chemotherapy. Brayden is now 7 years old and in Year 2.1. We moved from in July last year. He enjoys swimming, playing his Playstation 2, soccer and motor-bike riding. He received a trophy for best and fairest in his first season of soccer and hopes to start racing in motorcross during winter. Brayden's **younger sister, Kaitlyn** was born at Royal Women's Hospital while Brayden received treatment. We would like to say "Hi" to all the staff at C2W, Dr Cohn, Tali and Verena, we miss you all very much. Also thanks to Ronald McDonald House. We thank you for your support when we needed it most.

Congratulations to Joseph and his family on the birth of a **little girl, Destiny**. We are sure that she will bring great joy to your family.



Sirin is now 4 years of age. She was diagnosed with ALL in November 2003 and has 8 months left of treatment. She is full of life and just loves **her little sister,**

Leila, who is now 18 months old. On a recent visit to clinic the 2 girls just couldn't get the smiles off their faces as they played games together. Sirin is already looking forward to starting school next year. Mum says that it is just wonderful to have life 'back to normal'.



From one of the families: "Our son **Daniel** was diagnosed with ALL in March 2000, aged 2. He underwent the standard 25 months chemotherapy protocol, and was off treatment for 6 months before relapsing in November 2002. With three unrelated 6/6 matched donors here in Australia we decided to go ahead and have a bone marrow transplant and this happened in February 2003. Thankfully the transplant went very well, with the only minor complication being the 'opportunistic' appearance of shingles in May and the persistence of them still to now ... 10 months later. Daniel had his final lot of chemotherapy in January 2004, and the doctors have now told us that we do not need to come back to Sydney for the foreseeable future unless routine tests and check ups identify

anything that requires further investigation. We are excited about reaching this milestone, particularly because Daniel is now in Grade 1 at school and attending full-time. We home-schooled him until this year, and in spite of everything he has been through, his teachers felt that he had kept up with his peers and could go into Grade 1. Needless to say, he is excited about doing 'normal' things, but has also taken it all in his stride. At the end of February we had our first contact with Daniel's donor – a 30 year old man from Perth. It was fantastic to be able to thank him and try to convey what a difference he had made to our lives. We all want to keep in contact and have made plans to meet him later in the year."

It is always great to hear from some of our long term patients. Thanks to you all for taking the time to write.

"My name is **Sean**. I am 34 years old. I was diagnosed with leukaemia when I was 18 months old. Mum never actually told me I had leukaemia until I was old enough to understand. We lived in country NSW and when I was diagnosed we moved to the north shore of Sydney to be close to the Prince of Wales Hospital. My doctors were Dr. Darcy O'Gorman-Hughes, Dr. Reg Lam Po Tang and Dr Marcus Vowels. I travelled back and forth to these wonderful doctors for years. They saved my life. I had many, many down times but bounced back. I couldn't eat much after

treatments but whatever I fancied, mum would have it for me, as long as I ate something. I missed a lot of Primary School because of being ill but managed all of High School. I've always had full time employment and play golf, tennis and love fishing. I am happily married now and I'm hoping to have a family. I am more than happy to talk to anyone that would like a friend at any time."



"My name is **Michelle** and I am an Early Childhood Teacher, currently working in a preschool with 3 - 5 year old children I enjoy travelling, acting, skiing, bush walking, shopping, movies and spending time with my family and friends. I am healthy and happy - nobody would be aware that 20 years ago I was battling acute lymphoblastic leukaemia. While I remember much detail of the treatment process - the amazing thing is, nothing was ever viewed as negative. The love, care and support that was given to me from doctors, nurses, family and friends made my experience much more positive. I am determined to give back to others a lot of what I was given to me and which influenced some career decisions. I nannied a little girl with leukaemia for 8 months which was a very rewarding experience. I would like to attempt play therapy and work for the

Ronald McDonald Learning Links program within the near future."

My name is **Cara** and I was diagnosed with ALL in 1983 and finished treatment in 1985. I have therefore been off treatment for 18 long but healthy years. I didn't have any problems at school (only with maths!!). I spent 3 years at Wollongong University studying graphic design and multimedia with a minor in film and fine arts. I am currently working as a designer for a firm in Sydney and planning a working trip to Europe next year. Being sick as a little kid has made me appreciate life and not to abuse it ie no smoking and no drugs. Also I appreciate the great support and often long hours that the doctors, nurses and other staff gave to each and every individual. I have great friends from treatment times and from Camp Quality and view my past illness as a positive experience."

From the parents of a long term patient "It is now 10 years since our world was turned upside down as we learnt that our son Dean had been diagnosed with leukaemia. He was only 3 years old. At the time we wondered how we would cope but somehow, when you are thrust into this type of situation, you find the strength you need to get through each day, one day at a time. Dean is now a happy and healthy 13 year old. He is an academically gifted student. He loves to read and like most teenagers, enjoys computer games and music. Cricket is one of Dean's favourite sports and he plays in a Saturday morning competition. He also enjoys football and Tae Kwon

Do. In 2002 Dean represented the NSW Primary Catholic Schools at the Combined Primary Schools Track and Field Championships at Homebush and won the 12 years 100 mtrs final to become the NSW State Champion in this event. Dean's ambitions at this stage are to either become an oncologist or a genetic engineer." *ED. Congratulations Dean from all of us. What an outstanding achievement.*

Steven was diagnosed with acute myeloid leukaemia at the age of 8 years in February 1998. He had a bone marrow transplant. He tells us that in October 2003 he went to the NSW Combined High Schools State Carnival and ran in the 4 X 100 mtrs relay team for the North West Area. Steven lives in country NSW. *ED. It seems we have at least 2 great runners.*



Leslie was 15 years old when he was diagnosed with non-Hodgkin's lymphoma. It has been 6 years since he ceased treatment and he has had no further effects of treatment or the disease. He says "I am doing just fine. I am now pursuing my career as a pilot and do not look back."

Megan was diagnosed at the age of 4 years with ALL. She is now 27 years old and has been married for two and a half years. She works in administration at university. She tells us "I don't remember being ill except for needles and I still hate them. I really only remember follow up visits a little bit. My life is busy as my husband and I are currently renovating a house." *ED. Thanks Megan*



Giselle must like to work hard. Last year she completed 3 courses at TAFE - Marketing, Public Relations and Advertising. One of these was done at night and the others during the day. She passed all of them and did very well. This year she is returning to study for a Diploma in Marketing which she will do in the evenings and is currently looking for a job in the industry. Giselle was diagnosed in 1990 with ALL at the age of 6 years. Almost exactly 10 years later she relapsed, at 16 years of age. She underwent 2 further years of treatment from 2000 and hasn't looked back since.

Tricia visited the Long Term clinic early in the year. Tricia was diagnosed with ALL in September 1974 at the age of 4 years and 9 months. After 2 relapses, a bone marrow transplant was undertaken in 1982. Her brother was the donor and Tricia was only the 7th patient at the hospital to undergo the BMT. (Now there have been approximately 540 transplants undertaken at the Centre for Children's Cancer and Blood Disorders.) Tricia has been married to Craig for 12 years. She has a number of ongoing difficulties as a result of treatments but has a great fighting spirit and positive attitude. *ED. Keep it up Tricia. We are all very proud of you.*

Gianni launches "The Summer Blood Challenge"

Sydney Children's Hospital was the location for the launch of *The Summer Blood Challenge*. This is an annual challenge laid down by Red Cross to the motor cycle community and the NSW motor cycle police force to determine who can donate the most blood over the summer months. The challenge has run for 11 years now, with the police winning 6 times.

The launch took place in our lecture theatre on level 1 with Tim Webster acting as MC. Other invited guests included the Police Commissioner, his deputy, a representative from the police motor cycle squad with his bike, representatives from the motor cycle community (bikies) with one of their bikes, a bikie dog in full regalia (who alternately barked or howled whenever there was clapping) and various members of the press.

The mother of one of our thalassaemia patients spoke about her experience as a parent coming to hospital every month with her son and how thankful she is to the voluntary blood donors whose blood keeps her son well. The guest of honour was her son, Gianni who spoke of his monthly visits to SCH for blood transfusions before officially declaring the challenge "open".

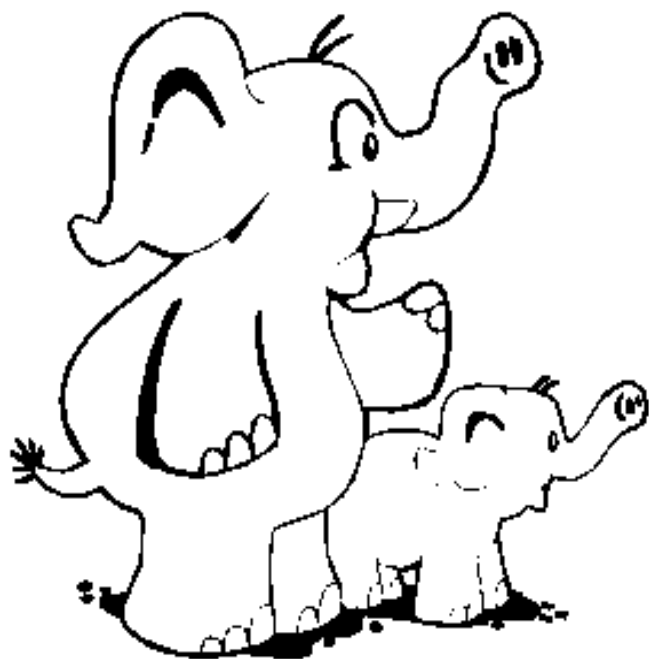
We believe that this year the police were able to donate, or have donated for them, a larger number of donations. To the police - Thanks. To the bikies - Thanks also and better luck next year.

FROM THE CENTRE FOR CHILDREN'S CANCER & BLOOD DISORDERS

Report on American Society of Hematology Annual Meeting

The Annual Meeting of the American Society of Hematology held in San Diego in December 2003, was attended by more than 15,000 doctors, nurses and scientists working in the field, and maintained its high level of quality again.

Of particular importance to the study of child leukaemia, were two presentations by American researchers trying to understand the origin of childhood leukaemia. We know an enormous amount about the genetic and molecular building blocks which make up leukaemic cells when a child presents to their doctor with leukaemia, but know almost nothing about how and where it all starts. In a first step, these scientists are using genetic markers of leukaemia present at diagnosis and "backtracking" to find out whether the same markers are present in cells from the child at birth.



In the first study, from San Francisco, scientists showed that some markers of different types of child leukaemia were evident on blood tests taken soon after birth and others were not, suggesting that the origin in one case was pre-natal and in the other not. Through questionnaires to parents of children with leukaemia, we may be then able to link a lifestyle or environmental factor that distinguishes one leukaemia from another. These kind of studies take a long time, but are very much in line with our own research in the Centre for Children's Cancer and Blood Disorders and the Children's Cancer Institute Australia.

Children with Down's Syndrome have a very high risk of acute leukaemia (1 in 150) in childhood, and, often of a very specific type. As many as 10% of Down's Syndrome children develop a transient leukaemia-like illness in the first few months of life, which goes away without treatment. One in three children with transient neonatal leukaemia will get leukaemia 2 - 4 years later. In a second presentation paper, scientists in Chicago followed genetic clues about the type of leukaemia to show that mutations in a particular gene, called GATA1, are present in leukaemia cells when the child presents with leukaemia, and is thus causally linked to Down's leukaemia. Furthermore, they showed that GATA1 mutations were also present in blood cells from all Down's Syndrome children with transient leukaemia at birth. This indicates the leukaemia began prenatally, that the effect of GATA1 mutation begins very early in the genesis of leukaemia, and, that 2 in 3 children with a GATA1 mutation in some of their blood cells at birth do not develop leukaemia. The exciting possibility exists that we might better understand the environmental factors which either prevent or promote leukemogenesis.

A/Prof. Glenn Marshall

Important Message

Does your child need to visit OPD and then have a procedure or chemotherapy on C2N or C2W?

Staff are working hard to try to streamline your visits to OPD and ensure that you and your child get to C2N or C2W on time. To reduce delays staff would appreciate parents remembering the following information.

Blood counts - These should be either done the day before the visit or at 9 am on the day of the procedure/chemotherapy. If pathology forms are required please ask Belinda (OPD sister) or staff on C2N. Getting these forms in advance may make things easier for you.

Fasting - Children need to be fasted for fluids from 7 am and for solids from 9 am.

C2N are beginning their procedures earlier than previously and require families to be through clinic and on their ward by 12 noon.

Thank you for your co-operation.

News From C2North – The Day Unit.

Welcome to 2004!

During December and January C2N was in full swing with haematology and oncology patients, only closing on the public holidays. Those of you who came in over Christmas/New Year probably noticed that things were really busy as 5 days work was compressed into 3 days!

The “Thalassaemia Diary” that was introduced at the Thalassaemia session of the Kids Cancer Update last August is now being reviewed. All our Thalassaemia patients were given a diary and asked to record transfusions, blood counts and home treatment and also to bring it along to appointments both in Outpatients and in C2N. It is similar to the “Oncology Diary” and we are hoping it will help the children to understand their disease and its treatment.

The planned redevelopment of C2N seems to be firmly on the agenda for this year. Our current space was designed and initially used as an inpatient unit. It has served as a day unit for some years, but with the changes to day unit activity, some structural changes are necessary. At this early stage of planning the focus is on the concept, or what we would like included in the Day Unit. More news on this in the next newsletter.

From your Day Unit, C2North staff.

Staff News From C2West

A warm welcome to a number of new staff who have joined the ward in the last few months. Welcome to Tina , Tanita , Anna and Fang .

Welcome back to Wendy , Tracie (returned from Maternity Leave) and Mel .

Rachel is soon to head off on Maternity leave and we all wish her well.

Congratulations to Karina who has been married recently.

There's a Bug in My Salad!!

From Kate, Oncology/Haematology Dietitian

You may have heard that there have been changes to the food provided at Sydney Children's Hospital. These changes have taken place, as part of a statewide initiative to reduce the risk that food provided to patients in NSW Hospitals is contaminated with bacteria called *Listeria Monocytogenes*. Many foods naturally have bacteria such as *Listeria Monocytogenes* growing on them. Normally our immune system protects us and they cause no harm. However, in people with lowered immunity the body's defences do not work as well. When immunity is low the bacteria from food can multiply and cause sickness.

In May 2003 the Department of Health issued a circular stating that most people who are in hospital have lowered immunity.

The same circular also states that hospitals have a legal responsibility to provide food that is safe for their patients. The circular details foods more likely to have *Listeria Monocytogenes* growing on them. As a result, a number of foods, including lettuce, pre pared salads and fruit with skin that is difficult to clean or peel (e.g. strawberries, rock-melon, peaches) have been taken off the menu at Sydney Children's Hospital.

If you would like to know more about these changes or whether you should change the foods you provide to your child at home please talk to your doctor or contact the Oncology/Haematology Dietitian, Kate on 9382 1021, loretank@sesahs.nsw.gov.au

Transition Program - Working Party From paediatric patient to adult patient

In 2002 a group was formed by the Greater Metropolitan Transition Taskforce (GMTT) to develop a Sydney wide network of centres interested in the management of illnesses especially thalassaemia. A project team including paediatric and adult clinicians and consumers commenced meeting in December 2002.

It soon became evident that other young people with chronic childhood illnesses also experienced problems with transitioning from treatment at a paediatric hospital to treatment in adult services. Upon reaching adulthood and leaving the paediatric services young people with chronic childhood illnesses and their carers often have difficulties in finding out about and at times accessing, appropriate health and social services. Evidence indicates that when the care of the adolescent is transferred from a specialist paediatric hospital to a multiplicity of adult hospitals and ambulatory care services there is potential for this transfer to result in a lack of continuity of care. This reduces quality of life for the young person and their carers and results in poor health outcomes.

One project of the group is the development of a brochure of information for parents and carers of those young people heading towards transition to help prepare them for transition. The working party includes Anne from the Association for the Welfare of Child Health (AWCH) and Marea the parent of a child with chronic health problems previously treated at Sydney Children's Hospital. **This working group is looking for other members** who may be interested in assisting with the task. **The group will be able to do much of its work via email and teleconferencing.** Any one interested in this **please contact Coralie, the Patient Friend, on 9382 0680** as soon as possible. She will pass on your details to Anne. The group are keen to get the project up and running.

CURRENT RESEARCH UPDATE

“Cure is not enough” Long-Term Psychosocial Research

At the Centre for Children’s Cancer and Blood Disorders we believe that **“cure is not enough”**. We need to make a **priority of long-term emotional health needs**, both during and after treatment, and for all members of the family.

In October 2003, we started an exciting new project looking at the emotional well-being and quality of life of children who have beaten cancer. The first stage involves families completing a questionnaire booklet, given to them during a yearly follow-up visit to clinic (e.g. via Karen Johnston or Jenny Suneson) or sent by post to home. People who can take part are children who have survived cancer (i.e. no longer on treatment) and are now aged 16 years or older, their parents and their siblings.

This project, the first of its kind in Australia, is helping us to learn more about the possible on-going emotional and social impact that

cancer might have on a child and their family. Our focus is not just on “problems” such as stress and anxiety. Rather, we also want to learn more about the “positive” stories. By improving our understanding of different reactions to a cancer experience, good and bad - we are then able to plan better follow-up care for current and future families.

So far, we have enjoyed a very positive response, with lots of families completing questionnaires. If you are one of the many who have taken part, we sincerely thank you for returning your booklet. Your feedback is completely confidential and is currently being processed.

We know that some families have agreed to take part but have put their booklet aside to complete at a less busy time. **There is still time to participate by completing and returning your questionnaire - but please do this as soon as you can as the project will soon be moving into a different phase. If you haven’t received a questionnaire, can’t find your booklet and would like a new one, or if you’d simply like more information, then please contact Jenny Suneson by telephone (02-9385-1380) or email (jsuneson@psy.unsw.edu.au).**

To all of our project participants, and on behalf of CCCBD staff and families of current and future patients - thank you! Your help has been wonderful and is greatly appreciated!



MUSIC THERAPY NEWS

Music therapy services continue to be provided for families on C2 West by myself (Verena, RMT). Younger children regularly engage in individual and group sessions; with lots of Hi-5, The Wiggles, Disney and Play School songs accompanied by loud percussion playing and singing. Parents, siblings and other relatives and family friends are all welcome to join in the musical mayhem. Occasionally staff members participate if they have a few minutes spare.

Song writing is often a popular means of creative self-expression for older kids and teenagers like Tahli (16) and Tulasi (17) who were diagnosed with non-Hodgkins Lymphoma and Neuroblastoma in the latter half of 2003. During an initial group session we wrote 3 songs together; using the "write one line - then pass it on" technique. Although we each only saw the line written immediately before, the songs made (more or less) sense. Here is an example:

"Falling Over in the Shower"
*When you're standing there alone
And it's raining tears out there
The sky is dark and icy
A storm is coming soon
Crashing into my mind
But hope grows like grass in Spring
Because we know that everything will be OK soon
Deep inside our hearts are dancing
Jumping, leaping, twirling, prancing
All over the place like jellybeans
Sitting in a row - lookin' kinda happy
Feeling kinda sappy
But knowing the end will be great
Cos we're songwriters - mate!*

This group song writing exercise became one of Tahli's favourite music therapy activities during a period of extended hospitalisation around Christmas time. Songs were written with her mother, sisters, brothers and extended family. Some lyrics were serious - others were absurd. This song writing technique facilitated the expression of feelings as well as providing a safe space to laugh and be silly. It was also an activity that creatively promoted social interaction and hopefully contributed to a more positive hospital experience for Tahli and her family.

***Thank
You
Verena.***

While the looks of joy on the faces of the children who become involved in your music sessions says "Thanks" parents also warmly thank you for bringing such happiness to their children.

SNOWY RIDE 2003

Stephen Walter's whole life revolved around motor cycles. Following his death in 2002 his family established the Stephen Walter Fund. From this was established a charity motor cycle ride to raise money toward helping children diagnosed with cancer and their families. The inaugural Snowy Ride was held in November 2001 in the Alpine region of NSW. In the middle of last year the Stephen Walter Fund, through the pages of this Family Newsletter, offered to host families for the weekend of 14 - 16 November. 20 parents and children took this opportunity. The families were invited to participate in a range of activities and events in Thredbo in conjunction with the Snowy Ride. Here is a report on the weekend by families and support staff.

The weekend began with an early morning departure from Sydney Children's Hospital. We were met by our bus driver and headed south to Canberra. We enjoyed a tour of Parliament House with a special viewing of the Prime Minister's Office. Our next stop was Jindabyne where we were welcomed by the National Parks and Wildlife Service and representatives from Jindabyne Public School. Each child was given a gift and photographs were taken for the local media. A short tour of Thredbo village followed and opportunities for a photos with Jimmy Barnes and Wayne Gardner were available.

A visit to the Snowy Mountains Hydro Electricity Scheme and a picnic lunch took place on the Saturday. The highlight of the weekend for many occurred on Saturday afternoon when each child was escorted via motorcycle to Thredbo Village to attend the official presentation ceremony. Many families spent the evening attending an open air concert starring Jimmy Barnes. Sunday, after a chairlift and bobsled ride in Thredbo we all enjoyed a ride in vintage cars to Cooma before heading home.

One of the families who enjoyed the weekend were the Hughes family. They write "The Snowy Ride was a fantastic experience for us because it was the first chance we had as a family to do something 'normal' together for a long time.

It was great to see some familiar faces and even better for the fact that we were outside the hospital environment. It was Daniel's first opportunity too, to play with other children for an extended period of time and he thoroughly enjoyed it. He also surprised us with his daring and

resilience. He rode pillion on a motorbike for the first time on the Saturday morning and we endeavored not to let him feel our fear about him possibly falling off!! To his credit he stuck like glue, being among the first to want a ride every time one was offered after that. He then also took part in the Mass Ride – sitting in an armchair equivalent on the back of this amazing bike. The owner looked after him brilliantly and it was an experience he will never forget.

The families from Cooma Apex who hosted all of us for the weekend were absolutely exceptional. Everything ran like clockwork and they catered for us magnificently – even down to hors d'oeuvres with pre-dinner drinks and a baked dinner on the Saturday night. Their attention to detail in making our lives comfortable meant that we never once wanted for anything, and it was wonderful to be 'taken care of' for a change. Snowy Hydro also pulled out all stops to make it a memorable weekend. It was an awe-inspiring sight to see over 1500 bikes, and people from all walks of life enjoying themselves harmoniously on behalf of a good cause.

There is a saying that 'out of every adversity comes a seed of equal or greater opportunity' and the Walter's family are a great example of what opportunity you can create when you take some initiative. It is no mean feat to co-ordinate an annual event of this magnitude, particularly on a totally voluntary basis, and they (and their team) deserve the utmost credit for creating an opportunity for people to come together and contribute to a greater good.

We thoroughly enjoyed the experience of the weekend and would highly recommend it to other families should the opportunity ever arising again."



LEARNING LINKS

How can they help you?

What is Learning Links?

Learning Links is a non-profit charity assisting children who have difficulty learning, and their families. They raise funds to help children from birth to 18 years by offering a range of services including the following.

Early Childhood Services for children from birth to 6 years including early intervention and support for very young children., an inclusive preschool for children with and without special needs, an assessment and consultancy service for families who are concerned about their young child's development and specialist early childhood teaching and therapy.

School aged services for children from Kindergarten to Year 12 including comprehensive assessments, small group educational services and therapy, occupational and speech programs, outreach programs and the Ronald McDonald Learning Program for seriously ill children

Family Services helping and supporting families and health professionals including centre and home based family counselling, parenting programs and case management services.

How can Learning Links help oncology/haematology families?

The Ronald McDonald Learning Program provides educational help, therapy and counselling for children who have had serious illnesses such as cancer or chronic conditions such as cystic fibrosis and as a result, missed lots of school.

It is hard for children who have been ill to return to school when they may be well behind their friends with their school work.

Learning Links offers help to children through the fully funded Ronald McDonald Learning Program to give these children the best chance to succeed at school. Learning Links has branches in six locations at Peakhurst, Peshurst, Fairfield, Miller, Dee Why and Randwick. They also offer some services to children in country NSW.

A number of our families have reported their great satisfaction at the assistance their children have received and have been very grateful for the improvements made.

For further information please contact the Head Office at Peakhurst on 02 9534 1710, Fax 02 9584 2054 or email : mail@learninglinks.org.au.

The Electronic Sarcoma Update Newsletter (ESUN)

The family of a 37 year old woman who died of Ewing's sarcoma after a 21 month battle have recently established an Electronic Sarcoma Update Newsletter.

The newsletter is designed to provide a wide range of information to those dealing with sarcoma and is designed to be of interest to patients, family members or caregivers. The first edition was launched in February this year and the editorial board consists of many doctors working in this field.

The ESUN can be found at
<http://www.liddyshrivercarcomainitiative.org/Newsletters/VO1NO1.htm>

BEREAVEMENT AND RELATED ISSUES

Men and Crying - The Unmanly Emotion?

Taken from "Fathers Grieve Too" Centering Corporation USA

"After years of saying "Big boys don't cry" we've finally learned that real men do. One of the greatest pictures of the 1970's was of Rosie Greer, the huge hulk of a football player and bodyguard to Robert Kennedy. Rosie is sitting on a bench, crying. Men like Rosie told us that it was OK to show our feelings and OK to cry.

I am exceedingly embarrassed when I cry. Intellectually, I know that it is OK and it may help me, but I feel ashamed when I cry. Then why do I cry at all? I CAN'T HELP IT? My grief becomes too intense and powerful to hold in. I feel I would burst like a balloon if I didn't let it out a little at a time. I am so full of this grief that I find it hard to believe that the balloon will ever be empty. Also when I cry I feel like a child. The barriers are down. It is then I need to be touched, hugged, held. When emotion runs so deep words aren't enough. There is a better way to communicate.

To those trying to console I say, "Stop searching for words. Put your arms around me. Don't be afraid. Remember I'm no stranger to fear. I faced the ultimate fear of a father who is helpless to protect his child. Listening to me with total awareness is the first step. You are opening the door for me to grieve. The second step is to walk through the door with me helping me, helping hold me up with your touch, your arms around me, my shoulders, your hands in mine. If you can do that without discomfort you may be able to help me and help yourself as well"

No two men are the same. No two people grieve the same. You will experience a whole range of feelings. It is important that you find your own way of grieving with help from the caring of people who can walk with you through it. In this way the death of your child will become a significant part of your living."

Bereaved Parents Group



The Sydney Bereaved Parents Group continues with the next meeting of the group on Wednesday 28th April at 7.30pm. We have moved location now to a room in the Prince of Wales Campus, Randwick. If anybody would like to come to the group who hasn't been before or would like to begin coming again please contact me. I can explain where the room is and car parking arrangements. I can also meet you before the group if you would like.

Kerry Nair
Bereavement Counsellor
Tel (02) 93821726
Fax(02) 93821789
e.mail: nairk@sesahs.nsw.gov.au

Phone Link Support Group for Bereaved Parents

Parents who cannot access the Sydney Area Group Meeting have reported feeling isolated from this opportunity and are just as keen to talk to other parents who have shared a similar experience to them.

I am now pleased to be in a position to launch a Phone Link Support Group for Bereaved parents. This facility operates in such a way that a number of people can be on one telephone line at the one time.

The aim of this is to enable an easy and safe way for parents to listen to and share the experiences of others at no cost, at times that suit them and without having to travel. This service would be for parents who have lost a child following a chronic/enduring illness, linked to Sydney Children's Hospital.

If any parents from NSW or ACT would be interested in finding out more and how it works please contact me. I will keep you all posted on how it is going.
Kerry Nair (02 93821726)

For our extended families and friends

“Don't take my grief away”
After my brother's funeral someone told me that I was handling my grief well. “No” I responded, “I am not doing well at all. If I were, I would crumple up on the floor and let my grief flood this room. As it is, I am stoically holding it all in because there is no-one here who would be comfortable if I let it out.” Origin unknown

Condolences



Our sincere sympathy goes to the families of those children who have died over recent months.

**Rebecca
Amanda
Hannah
Viraj**

Our thoughts are with you at this very difficult time.

GENERAL NEWS AND INFORMATION

Contributions to the Family Newsletter

These can be sent at any time to
Merron Howard
80 Edgecliffe Esplanade
Seaforth 2092
Home phone 9948 8160
Work phone 9970 1167
Work fax 9970 1197

e.mail: merron_howard@pittwater.nsw.gov.au
or posted to

Centre for Children's Cancer and Blood Disorders
Sydney Children's Hospital
High Street, Randwick 2031

Contributions by

30th May 2004- June 2004 Family Newsletter
27th August 2004 - September 2004 Family Newsletter
26th November 2004 - December 2004 Family Newsletter

Dates for your Diary

Annual Bereavement Seminar

Sunday 23rd May 2004

To be held at

The Graduate School of
Management,
University of NSW

Further information will be posted
to families when further details are
available.

Sydney Bereaved Parents Group

Meeting dates for 2004

Wednesday 28th April

Wednesday 26th May

Wednesday 23rd June

Wednesday 28th July

Wednesday 25th August

Wednesday 29th September

Wednesday 27th October

Wednesday 24th November

December date yet to be advised

For further information please
contact Kerry Nair

Bereavement Counsellor

Tel (02) 93821726

Fax(02) 93821789

e.mail: nairk@sesahs.nsw.gov.au

Have you checked <http://kids-cancer.org>

This is the website for the Centre for Children's Cancer and Blood Disorders (CCC&BD). We have recently updated our link page and here there are suggested web sites to visit for more information on children's cancer. This page also has stories that have been added by families and patients. You can find this link on the "What is cancer?" page (the second yellow box on the left hand side of the main page).

For many families, having access to this type of information can be invaluable when they are going through treatment, knowing that other families have faced similar situations and made it through.

We also have a chat room so that families can get together and chat about the day to day problems of treatment and hospital life. Find this at www.kids-cancer.org/cgi-bin/ubbcgi/ultimatebb.cgi

The web committee meets 3 monthly in C2West at 6pm . If you think you can assist, contact Pam Edhouse on 9382 1693 or edhousep@sesahs.nsw.gov.au for more details.

