

CENTRE FOR CHILDREN'S CANCER AND BLOOD DISORDERS



FAMILY NEWSLETTER

Number 69

March 2005

Coles Supermarkets NSW is the proud sponsor of the
Centre for Children's Cancer & Blood Disorders

FROM THE EDITOR'S DESK



Hello again to all of you.

While we are well into the year this is the first opportunity I have had to wish most of you my best wishes for 2005. As I write these words I am starkly reminded that for many of you this year to date has been far from happy and for families has included diagnosis, relapse and the passing of a beloved child. Despite all of this families not only "cope" (what choice is there) but grow and develop. *I am constantly uplifted by observing the dedication, humour and love displayed by children, parents, other family members and staff.* In a world so driven by consumerism life in a children's hospital provides a stark reminder of the things that are so important in all our lives - love, caring and selflessness.

A few contributions to this edition show clearly this dedication and selflessness. Reprinted on Page 14 is a poem written by a member of the C2West nursing staff. This poem was printed originally in the September 2004 Family Newsletter and prompted a response from a parent. This new poem is on Page 15. I am sure this reflects the feelings of many parents most of whom are unable to express our feelings so clearly. I would like to personally thank the parent for writing such a moving response on behalf of us all.

Personal contributions I believe are the backbone of this Family Newsletter. These are certainly the aspects of the newsletter commented on the most. These do not appear unless some of you are prepared to put your thoughts on paper. I have included in this edition a tear off page in the centre. Please take time to send me your contribution which will ensure that the next edition is filled.

Til next time, Take care

Contributions

Send these at any time to

Merron Howard
80 Edgecliffe Esplanade
Seaforth 2092
or Fax to 9970 1197

Contributions can also be emailed to

merron_howard@pittwater.nsw.gov.au

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June 2005

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



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www.sch.edu.au



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HERE THERE & EVERYWHERE

What are they up to now?

New daughters and sisters have arrived

Congratulations are in order for a number of our patients and their families on the birth of new baby girls. **Chelsea** has a **sister, Abbey** born on 2nd March. **Dylan** has welcomed **Bree** into his family. **Emma** is thrilled with the **arrival of Isobel**. **Nathan** has a **sister Abbey**.

A special welcome to baby **Jessica** and our best wishes to her parents, Cassie and Mal. Jessica is **sister to Amelia** who died very recently. Congratulations and best wishes to these families



Sean completed treatment for ALL in May 2004. He and his family have just returned from a visit to Ireland with a stop off to visit Disneyland in Paris to celebrate his coming off treatment. The family was away for 6 weeks spending Christmas in Ireland. While in Ireland there was a big family reunion with other family members visiting from India, and the USA. In all Sean (6 years) and his **siblings James**

(8 years), Tara (7 years) and **Sinead (3 years)** found that they had 26 cousins all in the one place at the same time. This happens when your dad, Jim, is one of 6 children and mum, Gertie is one of 8 children. While mum and dad were happy to return to Australia the children thought that being in Ireland with so many others relatives was better than coming back home.

Joshua attends Carroll on the South Coast of NSW. Despite missing all of 2004 due to treatment he has moved into Year 11 with his form and has also been elected by them as a Year 11 representative on the SRC. The Ronald McDonald Learning Program is providing him with 6 months of tutoring to assist him to catch up with essential work that he has missed and to assist with any new work. He is finding this support very beneficial. Once he has completed his HSC he is hoping to gain a place at university doing engineering. Good luck Joshua.



News from some long term patients

Megan writes "I was diagnosed with AML at 13 years of age on 5th April 1999. I received a cord blood transplant on 8th December 1999. Five years on, at 19 years old I am very well and looking forward to the future living on the South Coast."

"My name is **Siobhan**. I was 5 years old when I was diagnosed with AML. After having a bone marrow transplant I was fine for 2 1/2 years when I relapsed. I had a second transplant and I have been well ever since. I am now 16 and enjoying life. **My sister Verity**, who was my donor, is now 18 years old and working as a hairdresser."

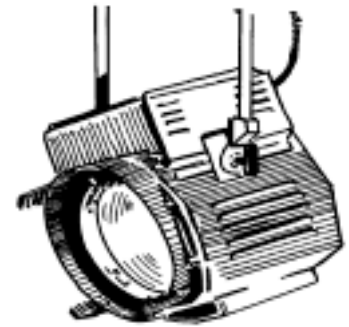
Alec is 11 years old and is in Year 5 and going well. He represented his school at the Zone athletic carnival in August last year for sprinting in the 100 metres. Alec has taken up tennis and his favorite sport is Touch Football having represented Forster/Tuncurry at the Touch Football State Cup in February 2004. He is a Sharks supporter and loves anything to do with Lord of the Rings. He is well and lives life to the full. Alec was diagnosed with ALL in July 1998.

Luke writes "I finished High School in 2001 at Port Macquarie High. During that time I was a member of the school basketball team that played at State and Nationals. I now attend the University of Newcastle and I have done so for the best part of 3 years. I will graduate at the end of 2004 with a Bachelor of Business majoring in Management and Marketing. I actively participate in soccer and basketball as well as often going to the gym. I have recently returned from a 9 month long holiday backpacking around Thailand and it was one of the best experiences of my life because I learnt and experienced so much over there. I have lived at College at Uni for 3 years and have met a lot of wonderful people from all over the world. I would recommend anyone who goes to Uni to live in college if at all possible because it enhances your total Uni experience and you meet lots of fantastic people." Luke was diagnosed in 1985 with ALL. *Ed. Luke you sound as though you have made every moment of your life count.*



Elise writes: "It's been many years since I was first diagnosed with leukaemia at the age of three. I am now 27 years old and have achieved all that I wanted to do at this stage of my life. I have just finished my Bachelor of Education in Early Childhood while working full time as a preschool teacher, a job I just love. I have recently returned from an overseas trip with my twin sister Amanda and my mum. I think that I would not have got through this whole experience if it wasn't for my loving, caring family - mum, dad, Lucinda, Amanda and Cameron and for the support of the doctors and nurses. Thank you so much to Marcus Vowels and his team at SCH.

"My name is **Emily** and I am 12 years old and looking forward to going to high school next year. At school I play indoor soccer for a sport as well as some other fun sports. My hobbies are horse riding, swimming and taking my dog for a walk. I was diagnosed with ALL in August 1996 and have now been off treatment for 8 years. I send love and best wishes to Prof Vowels for his kind care of me. I will miss you very much." *Ed. Emily wrote this late last year so I am sure all of us hope that you are finding High School terrific.*



Olivia tells us that she and her parents moved to New Zealand 18 months ago and she just loves it. She goes to a performing arts school and was accepted for singing and drama. She has been in many production and theatre companies in New Zealand and in Australia and most recently had the lead in "Robyn Hood" and "Sound of Music". She says "I have lots of friends and I am always busy - with school, friends, partying, shopping, basketball, netball, tennis and singing all the time. I have been in remission for 8 years having been diagnosed with ALL in 1994 and I am very healthy and have never felt so good."

Gary has been coming to see Prof Marcus Vowels since he was born in 1973 up until about 5 years ago when "Doc" Vowels decided that he should go to an adult doctor. He has chronic thrombocytopenia and had come up from the south coast each 2 months for the first 10 years of his life and then 6 monthly until he was about 18 years old.

When we first met Prof Vowels he told us that as Gary had such a rare condition he was very unsure of the long term outcome and that it could prove fatal. Gary is now 31 years of age and has a partner and a young son, Bailey (2 years) and a little daughter Tayla Stephanie (9 weeks). We would like to thank Prof Vowels for looking after Gary so well and wish him all the very best for his retirement.

Joshua was diagnosed 8 years ago on 16th October 1996 with Wilm's tumour. He is very well and has just completed Year 10 School Certificate. He won an Award for Citizenship on Presentation Day. He has also secured an Apprentice Chef's position with the New Brewery Restaurant on the Newcastle Harbour foreshore. Joshua has decided that becoming a Chef is much more a real prospect than a professional cricketer or soccer player. **Josh's sister, Elizabeth** has also finished her secondary schooling and achieved 90.6 UAI and hopes to

start Uni this year. We were very proud to see Josh dressed in his late Pa's dinner suite with a girl on each arm in every photo at his formal. (Very handsome) Josh would like to thank Prof Vowels not only for his years of tireless effort with all kids with cancer but also in helping to cure him. We, as a family wish him well in retirement.

Marea, Stephen, Elizabeth and Josh Niland.



The Malcolm Sargent Cancer Fund
Invites Oncology Families to a very
special event...

Sydney Swans vs Western Bulldogs

Join us for a free BBQ breakfast for all the family followed by the
Big Game

Sunday 22nd May 2005 from 11am
At Cricket Centre Terrace, SCG, Driver Ave, Moore Park

Meet the celebrities before they run onto the SCG for
the Big Celebrity Game!

Be part of the guard of honour!

Be sure to wear your red and white, and bring a banner for some great prizes!

RSVP by Friday 13th May 2005 to
Arabelle on 02 9219 4000.

FROM THE CENTRE FOR CHILDREN'S CANCER & BLOOD DISORDERS

C2W (Turnbull Ward)

Not unusually C2West has been very busy over the past few months. Christmas brought lots of visitors with it including Andrew Denton, the Wiggles, the DJ Christmas characters, and Randwick Jockeys. We also had a visit from Cherie Blair last month. We are very appreciative of our visitors; it definitely brightens up the days of our children and perhaps is a distraction to the every day life of C2West for you parents.

We have had exciting times for the nursing staff of C2 West of late, Nicky Munro and Sarah Norris recently got married. Heather Laing-Peach and Megan Vlieg are both getting married in the coming weeks. In keeping with the theme Mel Buzza and Natalie Whitehouse recently announced their engagements. We wish them all lots of happiness in their exciting future ahead.

We welcome one new staff member Lorraine King and I would also like to wish the best of luck to Tina Iacono who has left us to travel and work in Europe, and to Katie Heath who left just before Christmas to work in a ski resort in Canada. Both have sent post cards and seem to be having a great time!

The CCC&BD nurses have also been busying themselves with further study. The 3rd Annual Nurses & Midwives caring for Children & families Seminar at St. George was held at the beginning of March. Alice Harvey, Kirsten Adnum, Lucy Maurice and Anne Sennar all presented papers at the conference whilst other ward nurses attended.

May I take this opportunity to acknowledge all the families who have been inpatients on C2West lately. The ward has been tremendously busy resulting in children being transferred to other wards. We recognize that this can be difficult times for you and although we endeavour to care for as many children as possible on C2West this is not always possible. So thank you for all your patience and understanding.

I would also like to thank all those families who have generously donated to the ward and on behalf of the staff on C2West send you all our best wishes.

Clinical Nurse Consultant Outreach

In December 2004 I started in the role as the second rural outreach nurse, travelling the state with Jan Hardy.

I guide parents through treatment protocols, hospital admissions and clinic visits. I liaise with rural hospitals, hospital nurses, General Practitioners and Paediatricians and visit them as necessary. I also attend our rural outreach clinics.

I will do school visits to help intergrade the children back into school and liaise with the school teachers and community carers.

Jan and I have our own patient load, and cover each other when one of us is away. There are now two of us in the rural setting, and we hope to meet you on our travels. **Ida O'Brien**

Changed your address recently?

Please make sure the the CCC&BD have your new contact details.
Please phone your specialist's office and give the changed details to the secretary.

Prof Glenn Marshall 9382 1721
Dr Richard Cohn 9382 1730
Dr Sue Russell 9382 1960
Dr Tracey O'Brien 9382 1733

Have you sent information about how your child and family is doing recently?

There are families that would love to hear what you are doing. Use this sheet to write a little about your family, a story or a poem and this contribution will be included in the next Family Newsletter of the Centre for Children's Cancer and Blood Disorders.

Please feel free to complete as much or as little of these details as you wish.


Child's Name (the patient) _____ Date of Birth _____
Diagnosis _____ Date of diagnosis _____
Address _____
Mum's Name _____ Dad's Name _____
Names and ages of other children _____

Return to

Merron Howard, 80 Edgecliffe Esplanade, Seaforth 2092. Fax 9970 1197 Email,
merron_howard@pittwater.nsw.gov.au Phone 9948 8160 (H) or 9970 1167 (W)

or to

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



Please cut out this page and return with your contribution
for the next Family Newsletter

WHEN YOUR CHILD IS DIAGNOSED WITH CANCER

Informing family and friends

This article has been taken from the CureSearch website at www.curesearch.org

When a child is diagnosed with cancer, families can feel overwhelmed and confused by all the new people, information and emotions. Extended family and friends may want to help, but may simply not know how to be of assistance. Parents may be so exhausted while caring for their child that responding to well-meaning phone calls and requests for information can feel like a burden.

Parents often need concrete help with daily tasks such as caring for their other siblings, making meals, and keeping up with the household, but struggle to find the time or energy to organize what they need. Therefore, it can help to create a plan to handle all of the calls, tasks and messages of support, while conveying information to everyone who cares about the child.

Ideas for Parents and Caregivers

- * Parents can designate one family member or friend to receive new medical information that they can in turn share with others.
- * Parents can gather together a group of people who are most supportive and involved to share new information, so the same story does not need to be repeated over and over again.
- * Medical staff can help to deliver difficult information to extended family members and siblings.
- * Honesty with siblings and other children in the family is important, but it's helpful to convey information simply, in small doses, so that they can adjust to the new reality.
- * Parents should feel free to tell loved ones that they are simply too tired to talk, but appreciate the support they are receiving.
- * Family and friends will want to help, but may not know how or what to do. Parents are encouraged to make a list of practical tasks such as laundry, shopping, sibling transport and meal preparation. This list can be given to one person who might then coordinate any others who wish to be helpful. This way, parents do not need to ask for help directly, but can get the help they truly need.
- * Parents can consider leaving a message on an answering machine thanking the caller and directing them to a person designated as the family spokesperson (or the person who is coordinating assistance).
- * Parents should remember that they decide what information to share and with whom.

Ideas for Family and Friends

Family members and friends often feel concern and compassion for a child with cancer and their family, but are uncertain about how best to reach out and help. A vague offer of "Call me if you need anything" may not be very useful because it requires that the overwhelmed parents consider their needs and articulate them. Parents need a lot of support, but in these situations they simply may not have the time or energy to call. The best support can be a concrete offer for a job or service. When possible, it may be useful to coordinate a group of helpers, so that tasks can be divided and the family's needs may be covered. There are lots of ways to be truly helpful.

- * Grocery shop for food that is easy to prepare, or already prepared. Perishables should be limited, since the family may not be home much at the time of diagnosis. Basic supplies such as paper goods are also useful.
- * Meals can be prepared and delivered to the hospital or home.
- * Family pets may need daily care.
- * Offers can be made to do laundry, clean the home, or water plants.
- * Siblings may need to be picked up from school, taken to after-school activities, or driven to the hospital. They may even need to go to another home when parents are not available.
- * Visits to the hospital are almost always appreciated, however visitors should check first with the parents. Please note that visitors should only go into patient rooms if they are feeling perfectly well. The child may not be able to fight off other illnesses while receiving chemotherapy. All visitors should be instructed to wash their hands before entering the child's room, as hands commonly carry and transmit germs.
- * Visitors can bring a movie or game to the hospital and offer to sit with the child, so that the parents can take a break or share a meal together.
- * Visitors can sit with the parents and just let them talk, even saying nothing at all, while being a caring presence. A supportive and positive ear is important. Parents are often afraid and overwhelmed. They need all the love, compassion and positive energy they can get!
- * If needed, it might be a good idea to organize a benefit in the community on behalf of the child and family.
- * Family members and friends tend to know the child and their family well, including what would soothe, ease, entertain and help them the most. Creative thinking is always welcome!

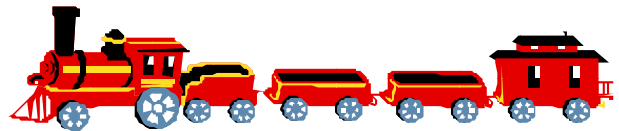
Barbara Jones, CSW, Albany Medical Center

What is Cure Search?

This organisation represents the combined efforts of the Children's Oncology Group (COG) and the National Childhood Cancer Foundation (NCCF), two organizations united by a common goal: finding a cure for childhood cancer. As partners in this search, each arm of CureSearch has vital responsibilities covering research, care, advocacy, and fund-raising.

The Centre for Children's Cancer and Blood Disorders is a member of this organisation. As such many of the treatment protocols that are used at Sydney Children's Hospital are a part of joint research projects with other Children's Oncology Group (COG) members. Data collected at SCH through clinical trials is shared internationally with other organisations.

The above article has been taken from the Cure Search website at www.curesearch.org. Check out this site. It has lots of up to date and reliable information for all members of the family.



The Malcolm Sargent Cancer Fund for Children
Invites Oncology Families to

FAMILY TRAIN DAY

At

Sydney Live Steam Locomotive Society
Anthony Road, West Ryde

Saturday 7th May 2005
11am – 3pm

RSVP by Friday 29th May
Phone: 02 9219 4000

*Ride the Trains...
Clowns & Entertainment...*

*Enjoy a BBQ Lunch...
Face Painting & Balloons...*

PLEASE NOTE:

For safety, enclosed shoes MUST be worn to ride the trains

JOSHUA HOLLAND LEUKAEMIA FUND CLINICAL RESEARCH FELLOWSHIP

Stephen Laughton is a Fellow at the Centre for Children's Cancer and Blood Disorders at Sydney Children's Hospital, and funded by the Joshua Holland Leukaemia Fund. He commenced his research projects that contribute towards his PhD degree in January 2002, having moved with his family, from Auckland, New Zealand. The Fellowship is the direct result of the efforts of a group of families who have been personally affected by childhood cancer and through their tireless fundraising efforts. The aim of the Fellowship is to allow a senior Paediatric Oncology trainee to undertake clinical research in the broad field of childhood cancer. Research is conducted at both the Centre for Children's Cancer and Blood Disorders, at Sydney Children's Hospital in collaboration with the Children's Cancer Institute Australia (CCIA). Sydney Children's Hospital, Randwick is in the unique position of being able to integrate basic laboratory and clinical science, with the on-site availability, and links, to the CCIA.

There are a number of aspects of childhood leukaemia (ALL in particular), that Stephen has been investigating under the supervision of Associate Professor Glenn Marshall from SCH, and Dr Lesley Ashton, Molecular Epidemiologist at the CCIA. His research is examining how a person's genetic make up influences both their chance of developing cancer and their likelihood of cure. This has implications not only in delivering the best treatment to an individual child (individualised therapy), but also more broadly in determining potentially modifiable risk factors.

His first project was examining a group of children previously treated at SCH and looking at aspects of toxicity as a result of their therapy and relating it to outcomes such as relapse. A large number of factors were considered in the analysis. One, soon to be published, finding relates relapse to the effect of the leukaemia treatment on normal bone marrow cells. While exciting, this information needs to be examined in future studies to further define its clinical usefulness. It is however, an example of the efforts in a large number of clinical trials in paediatric oncology, to identify children at high or low risk of relapse and tailoring their therapy accordingly.

Clearly the question of "what has caused the cancer?" is one that all parents whose children develop cancer, ask at some point. Stephen's second major project was to pilot questionnaires and study methods that are now the basis for the Australia-wide AUS-ALL study, involving all new cases of leukaemia in children. A number of children with the most common childhood cancer, acute lymphoblastic leukaemia (ALL), (cases), and a number without ALL from the general community, (controls), have been enrolled in what is called a case-control study. These studies have the aim of trying to determine whether there is any environmental factor that places children at a higher risk of developing leukaemia. In addition, DNA is collected from children and variations in specific genes can be identified in the laboratory. By comparing various environmental exposures between the two groups and looking at genetic variations in key enzymes that are responsible for metabolising drugs and toxins, he hopes to identify possible links to causation in childhood ALL. Special swabs, designed to collect DNA from inside the cheek, have been used and avoid the requirement to collect blood from children. It is most likely however, that leukaemia is not the result of one particular event or exposure, or even genetic make-up alone, but rather is a complex combination of many of these factors. It is important to stress that as yet, no one has discovered the cause of childhood leukaemia. This information is being analysed now, and Stephen would like to thank those who have participated for their time in completing the questionnaires.

The ongoing funding from the Sydney Children's Hospital Foundation – Joshua Holland Leukaemia Fund has allowed Stephen to continue his research studies, as well as complete his specialist clinical training in Paediatric Haematology and Oncology at Sydney Children's Hospital. Stephen will be leaving SCH later this year to take up a position as Neuro-Oncology Fellow at St Jude Children's Research Hospital in Memphis, Tennessee.

BEREAVEMENT AND RELATED ISSUES

From Kerry Nair

As I head off on Maternity Leave from 10 February I wish to advise of the coverage organised for my absence.

The Sydney Bereaved Parents Group will run bimonthly this year (following consultation with group members). Sue Hearn has kindly agreed to be available for the first half of this year to help Heidi with the group. The dates will be

27th April 29th June
31st August 26th October
14th December

Time is the usual 7.30pm. Please contact Heidi Taylor in the Social Work Department (93821021) if you would like to come or if you have questions or need directions etc.

The Phone Link Group for Bereaved Parents will also continue to run on the first Thursday of the month. Please contact Heidi again if you are interested in joining this group. The small group

of parents who use this service would dearly love to hear from other isolated parents who live far from Sydney!

In addition, Tali Foreman and Kate Lenthén, our Oncology Social Workers are available to take calls from any parents who feel they need to talk to someone while I am away. They can be contacted on 93821021.

After the success of the **Siblings Groups**, Liane Willis (Psychologist) and I would like to run some more morning groups for siblings who have lost a brother or sister. These would operate in the July School Holidays. Liane will need to have an idea of people who might be interested before she will organise anything for July. If you would like your children to attend, or would like to find out more about the programme please call Liane on 93821727 or her e.mail address is: willisl@sesahs.nsw.gov.au.

I plan to be back at work later in the year.

Warm Wishes.

Kerry Nair, Bereavement Counsellor

Condolences

Parents and staff extend their sincere sympathy to the families of the following children who have died in recent months

Sarah
Daniel
Amelia

Our thoughts are with you



ON THE DEATH OF A CHILD

Through the eyes of a nurse

We have no right to grieve, but we do.
We have no cause to love them, but we do.
These children that are not our own,
But yet each one touches our lives
Like the gentle sparkle of afternoon sun on the ocean.

We see your fear, and we cannot understand,
But we want to ease your burden.
We know the weight cannot be lifted,
But we want to help carry your cross when you feel too weak to stand.

The pain we see in your eyes
Is etched in our memories.

As carers we are expected to fulfil our duty.
But how can we possibly accept this as
Just a job?
How, when your children's faces fill our dreams
And their strength and spirit touches our hearts.

We rejoice in their victories.
Mourn the black days when the fighting seems futile
And the world is hopeless.

And how can we not love them?
These children who smile at a bobbing balloon
When their bodies are exhausted
And cry out for reprieve.
How can we not be touched by the final joy
And the unfathomable beauty of a long, overdue, restful sleep.
The rhythm of their breathing,
When we can only hope their dreams
Are full of marvels and wonders unseen.

A magical hot air balloon ride
Far, far away from this wretched place.

The brightness of their eyes shines

out from the black of night
And their small hands clasp our fingers.
They have hope.
They are filled with a sense that, come what may,
They are loved by all around them.

And that we are fighting together.
We watch your family struggling to combat the unseeable
Evil forces of hopelessness.

How can we possibly inflict pain on these children
And fill them with fear so they cry and scream
From the depths of their bodies?
How do we return, day after day,
To watch the doors open to yet another new face?

I cannot give you an answer for it is an unspeakable
Sense that somehow we are easing the pain and
Smoothing the rocky path ahead.

And when the fight is sometimes lost,
We feel each death with agonising force
And in our quietest moments
We weep.
It is absolute sadness.

We have no right to grieve, but we do.

Their chuckling at a new toy.
The gentle thank you when they are plagued with
Fever and pain.
Their sense of pride and achievement when they are
Finally
Going home for a few days.
This is the music that feeds our soul and makes us
Able to return tomorrow and tomorrow.

We do not forget their faces,
Their spirit.
As months and years pass we have them in our memories

And we feel blessed.
Blessed to have caught a glimpse of a life
That was loved and cherished and valued.
A glimpse of a soul who was not meant to walk long
On this earth.
But while they were here
They brought love and joy,
So that we who are left feel cheated and angry at their passing.

It was our job to keep them safe.
To cradle them into a billowy drowse.

We fear that wherever they are now,
they are alone and afraid.
I believe that all our children are walking hand in hand
And can be seen in the shafts of light that break the storm clouds.
Their voices are heard in a babbling mountain stream or
In the gentle rush of the wind through the autumn leaves.

And their tears have stopped falling
And their fears have subsided.

We have no right to grieve, but we do.
How can we leave this place and go home
To our families and friends?
Maybe we just hold them a little tighter now.

We begin to understand the fragility of life
And the indiscrimination of illness.

Heads or tails. The coin is in the air.

Although we cannot feel your absolute loss and pain,
We ache for every child to be well again.

And we do grieve.
We mourn.
We cry.

And we remember them.
Always.

TO THE STAFF OF C2WEST

A parent's response

You have every right to grieve
You who share the moments of
Joy, relief and churning
Painful days.

In a work weary world
Grown cynical
Your compassion is our comfort
and
Our calm.

As we wander the corridors
Of our fears
Seeking sheltered corners
To weep in
Helplessness is profound.

We have no control.

Drugs and doctors and schedules.
Tests, hypotheses and frenzied
Sometimes grinding times
Consume us like some
Evil, sucking swamp.

Who? What? Where to? When?
Which drug? What day?
Where? When? When...When.....

Questions, rarely answers
Rattle round our heads-
Give birth to fears – more tears
Who hears?

You do.

Our child cries and vomits
Writhing, wracked with pain
Pleads to leave
Or lies
In who knows what low state –
A sliding, silent drain.

But you are quietly there
Watching, thinking, caring.

We have no right to expect
Your compassion-
But we are grateful beyond words

That you defy our expectation.
And as we walk these corridors
We see and love your smiles-
Your share in life and hope.
Your laughter with our children
Is a gift
And we accept.

Your courage to come back each
day
With gentle, careful words
That seem to know our thoughts
Is solace for a screaming mind
That's silenced at the lips because
It's all too hard to say.

You seem to know
And that is our relief.

We have no right to your tears
Yet you give them freely,
Privately, painfully-
And we thank you
'Though words barely seem
enough.

Thank

You

Hi. My name is Carrie and my son Joseph, aged 12 years was diagnosed with AML in August 2003 and had a transplant in March 2004. Joseph is doing really well. But this letter isn't about Joseph but about our very good friends: Adrienne, Peter, Jason, Benny and Brad. Brad was diagnosed with ALL in March 2003 and is still a patient here at SCH. This letter isn't about Brad either but his kind and loving mother, Adrienne. Adrienne doesn't realise how special she has been to myself and I'm sure many others. I don't have money to do anything special for her, I just want her to know and everyone else to know that she is a saint and I mean that from the bottom of my heart. When times weren't looking good for us, she was never negative but always positive. Even through her tough times with Brad, Adrienne was always concerned about Joseph and myself. I could write forever about this lady and her family but I just want them to know how special they are. I always think that she deserves something good to happen in her life but she already has it, her family.

GENERAL NEWS AND INFORMATION

Rally for Recovery

Twenty five members of the Rally for Recovery group visited C2W in February. The aim of this group is to continue to support kids with cancer by raising funds for children's cancer research. It was established by Vera and Brian Entwistle, who originally established Camp Quality and has now been operating for 5 years. The Rally this year goes to Cowra with tours around the Lachlan Valley. It begins on 1st May. All those who register to participate in the Rally have to either make a donation or raise funds. There is a tremendously passionate group of supporters from all over NSW and also from Perth, South Australia and Queensland and the group have contributed over \$200,000 so far. Anyone wanting more information on the Rally is invited to view the web page: www.rallyforrecovery.com or contact Vera on 0427 576 654 and she will mail out information.

Kids Cancer Update

An information and education day for parents and other family members will again be held this year. As in 2003 we will use video conferencing to allow as many country families as possible to join in from as close to home as possible. Special parallel sessions are planned for adolescents, families of children with brain tumours and other cancers and families of children with haematology issues.

If you have suggestions for a special session you would find helpful please let Richard Cohn know directly or pass on a message to him through any other staff member.

We will inform all families of the date through the next Family Newsletter, via mail closer to the date and with poster around clinic and in C2W and C2N.

Joshua Holland Leukaemia Fund (JHLF)

The JHLF is holding a Dinner Dance at Royal Motor Yacht Club, Prince Alfred Parade on 21st May from 7pm.

The event will include Lochie Daddo as MC, the screening of a video produced by Andrew Denton and take taken on and around C2W.

There are also a great many items to be raffled including a day on Sydney Harbour aboard a boat from Yacht Sydney, a surf board signed by 40 to 50 of the top surfers of the world, a large Plasma Screen TV, a painting by Trent Nathan himself, lingerie packages, a cricket bat signed by many of Australia's top players, a significant wine collection, digital cameras and much more. Last time such an event was held many thousands of dollars were raised with all proceeds going to C2W and the CCC&BD.

If you would like any further information about this event or the Joshua Holland Leukaemia Fund please contact Lyndie Powell on 0412 145 655

