

# CENTRE FOR CHILDREN'S CANCER AND BLOOD DISORDERS



## FAMILY NEWSLETTER

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Number 68

December 2004

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Centre for Children's Cancer & Blood Disorders

# FROM THE EDITOR'S DESK

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Hello to all and welcome to the Christmas edition of the Family Newsletter. I hope that, while it arrives at such a busy time of the year you are able to read it and that it contains something for each of you that helps you at this time. As usual at this time I think of families who have had a child die and for whom Christmas will be so different to last year. This applies to those with children who have been diagnosed during the year also and who are wondering what the next year holds. If we can all learn one just one thing out of our child's diagnosis that should be to value the special people in our lives - our family, our friends and our colleagues in our fight for our child's life.

I would like to take this opportunity to express my sincere and heartfelt thanks, and that of many other families, to a person who has meant a great deal over the past 30 years to many families including my own family. **Prof. Marcus Vowels is retiring from clinical practice** at the end of this year and I know how much he will be missed by parents and patients alike. The impact of his dedication and compassion is seen through the continued lives of so many people, some who are now adults with their own children. There are also a great many families who had children who could not be cured and they became especially conscious of the personal pain Marcus felt when cure became impossible. His interest and willingness to develop a bone marrow transplant program saved the lives of many children and placed Sydney Children's Hospital as one of the leading transplant centres for children in the world. This interest will continue as he remains working within the Australian Cord Blood Bank.

**Thank you sincerely Marcus. You will be sorely missed.** Our very best wishes go with you however as you find more time to 'play' on and under the water.

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## Contributions

Send these at any time to  
Merron Howard,  
80 Edgecliffe Esplanade  
Seaforth 2092

Home 9948 8160  
Work 9970 1167  
Fax 9970 1197

[merron\\_howard@pittwater.nsw.gov.au](mailto:merron_howard@pittwater.nsw.gov.au)

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HighStreet  
RANDWICK NSW 2031  
Telephone: 02 9382 1111  
Facsimile: 02 9382 1179  
[www.kids-cancer.org](http://www.kids-cancer.org)  
[www.sch.edu.au](http://www.sch.edu.au)



Locked Bag 5  
RANDWICK NSW 2031  
Telephone: 02 9382 1188  
[foundation@sesahs.nsw.gov.au](mailto:foundation@sesahs.nsw.gov.au)

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?

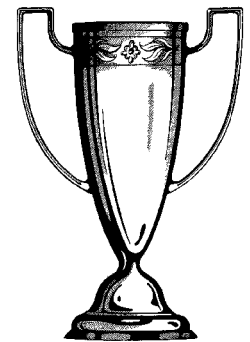
**Helen** is in Year 9 at i College at Braddan in the ACT. Helen does well academically but also enjoys rowing, dancing and outdoor pursuits. She has just completed her fourth season of soccer and spent a week skiing and snow boarding at Perisher Valley. She rows on Lake Burley Griffin and enjoys competing in regattas. Aside from her initial treatment in 1997 for non-Hodgkins lymphoma, Helen has been well and suffers no side effects from her treatment. Helen's family are doing well too. **Eldest sister Anna** is completing Year 12 and plans to work and travel next year. **Laura**, Year 11, was chosen for an international scholarship and is doing Year 11 in a northern Italian boarding school. Helen's **youngest sister Louise** is completing primary school this year and is looking forward to joining her sisters at High School next year. In March this year Helen and her sister Laura participated in Shave for a Cure. Together with 2 other Merici girls who had their locks shorn, they raised \$2000 at school and another \$1000 was collected from other private contributions. *Ed. Fantastic. Thanks for your news.*



**James** is now 11 years old and was diagnosed in July this year with ALL. When I spoke with him he was very excited because through Make a Wish he was to go on a shopping spree at Toys R Us at Hurstville the following Sunday. He and his family were to be collected from home and a party with Geoffrey the Giraffe was organised. James will be sharing some of the toys with his **brother Julian** and will select things that Julian wants.

**Sam** was diagnosed with ALL in 2001. At the time he was Captain of his school's Open Boys Basketball team. It was both a shock and a great disappointment for Sam that for some time after he was unable to play but he has been back with the team for some time now. Last year in November his team competed in the National Basketball Competition in Ballarat where they won the Bronze Medal. Sam has just begun his studies for Year 12. He does well at school and enjoys it. He says that before his diagnosis he was very difficult at school and was frequently in trouble. He didn't like it and did not work but in Year 8, just as he was starting to get over this difficult stage, he was diagnosed with ALL. Now he is doing Legal Studies, Business Studies, PDHPE, Sport and Rec, Drama and English and he would really like to go to University next year. While Sam still loves his Basketball he has another new sport he is pursuing - Boxing. He does this at Balmain Leagues Club. Just recently he was awarded "Sports Star of the Month"

by his local paper, the Village Voice. They did a short story on him with a photo and he received a \$50 gift voucher. *Ed. Keep up the great work, Sam. I think you are amazing.*



**Chelsea** was very proudly sporting 2 trophies when she visited the hospital for treatment recently. She was awarded the "Class Award for 2004" and the "All That Jazz Dance Co Award" from her Jazz dance group. She had to go up on stage to receive the awards and got a great round of applause. Chelsea attends School and she was diagnosed with ALL in October. All the children in her class sent her presents to make her feel better. She has a **brother Riley** who is 3 years old and is expecting a another brother or a sister in March. Chelsea hopes for a sister.

**Daniel** has been working very hard in the last few months fitting in as many exciting events and experiences as he can. He had a great birthday party for his 7th Birthday in October. At the Floriade in Canberra he met with Nicky Webster. He had his own personal tour of Canberra Zoo and Aquarium from the owners and went behind the scenes. He had a great day of Go-Karting, something he really

enjoys. He has visited Canberra Museum and Questacon. He had his own personal tour of the Canberra Times with the Editor during the Federal election campaign and even had a copy of the front page printed with a photograph of Daniel stating “*Daniel for Prime Minister. Daniel promises less taxes and more toys.*” Last weekend he and his family spent in Cooma on “The Snowy Ride” and this week they are off to a family weekend at Albury with Camp Quality. *Ed. Daniel, I don’t know how your parents manage to keep up with you.*



**Joseph** is a little boy with a big smile and lots of energy and enthusiasm. He was diagnosed with ALL 3 years ago and this just added to his diagnosis of Down syndrome. His dad has used this adversity to assist others from his church in Mt Annan to establish a support group for families of children with a disability in the area. This group organises joint activities and provides opportunities to socialise in an environment where families can share ideas and get emotional support and encouragement in facing the problems associated with having children with long term disabilities. *ED. Good on you. I am sure your efforts are greatly appreciated.*



**News from some attending the Long Term Follow Up Clinic**

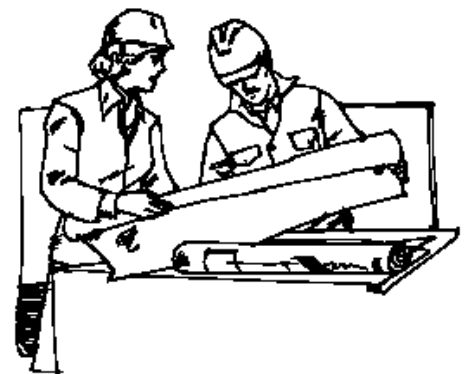
**From Peter** . “It has been 18 years of remission for me now. My illness, although never forgotten, is now only a distant memory. Life is great and I feel well and manage to keep pace with my two sons (11 years and 9 years). My eldest son will commence high school next year. I live in the country and love it. I operate my own gardening and handyman business which is going from strength to strength. I love to play golf and table tennis.” (Peter was diagnosed with Ewings sarcoma in June 1985.)

“My name is **Anthea** and I was diagnosed with ALL in 1996. Today I visited the Long Term Clinic after a year without a visit to the hospital. I have done a lot in that time. I have started Year 7 and learnt to play the tuba and I joined the school band. I also do singing lessons and have a pet dog named Xena. She is a Jack Russell with a quarter Fox Terrier. I went to Greece last year for 3 months and had a really great time with my family.”

“Hi my name is **Brad** and I am currently employed with Eagle Boys Pizza where I have been managing the store for 8 years and worked with them for 10 years. I enjoy playing guitar and just socialising with friends and family. In my

family I have 3 other brothers with myself being the oldest at 28 years. I live at home with mum and dad and I enjoy every parent of what I am doing now. I love a new challenge and I will give anything a go.”

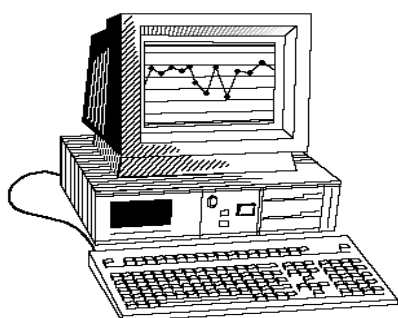
“Hi, my name is **Ricky** and I am a 22 year old male who had cancer (ALL) at the age of 3 years. I am a qualified shop fitter/cabinet maker and currently studying Residential Building at TAFE as well as working full time. In my spare time I enjoy spear fishing, taking my boat out and generally making my mum worried like an average 22 year old. I would like to thank all the staff of the hospital and Camp Quality for their support and wish you all the best for the future.”



“I am **Betul** and I was diagnosed with neuroblastoma when I was 18 months of age. I am now 17 years old, I’m in Year 12 and love studying. I enjoy sport and computers. I have a younger brother who is 10 years old and we often play soccer together. I am planning to get a good UAI mark and study Computer Engineering in the future.” *Ed. Good luck Betul. We all hope that you do very well in the HSC.*

“Hi. My name is **Sharne** and at the age of 14 months I was diagnosed with a Wilms tumour. I am now 19 years old. For 3 years I travelled from Wollongong to Sydney for treatment and operations. There were many tears shed during this period. When I was five years old I went to my first Camp Quality and I went every year after that until I was 17. I made many friends there and we all shared stories, had lots of fun and still today we keep in touch. I went on to do my HSC and study hospitality at TAFE. Today I’m back at the clinic for my 3 yearly check up. I’ve been made to run on a treadmill, answer questionnaires, have a blood test and they have weighed me...how embarrassing! Even though I don’t remember much about my illness or treatment, I still remember the nurses Judy and Carole, my doctor Prof. Vowels who is retiring shortly and who treated me and has seen me for many years. The care of these people has been greatly appreciated. I live a pretty normal life with no major effects from the illness or treatment. I wish you all the best for the future.”

**Julie** was in clinic recently for Long Term Follow Up. She was supported by **husband Brett**, and **sons Shane (16 years) and Patrick (3 years)**. She and her family live in Wagga but have made a week long holiday out of the visit to



Sydney for clinic. Julie was diagnosed with Ewings sarcoma in 1975. The tumour was in her hip. Next year it will be 30 years since she was diagnosed and she is already planning some exciting events to celebrate. These include hiking to the top of Mt Kosiosco carrying in her backpack an expensive bottle of wine which will be opened and drunk at the top. She also plans on trying parachuting. She works as a waitress and is therefore on her feet all the time -

quite something when the tumour was in the hip. Julie has also done some voluntary work in palliative care, something that gave her very great satisfaction, and this has reinforced her determination to not put off doing things that she really wants to. *Ed. Hope the rest of the holiday went well for you all.*



**Does your child have CMML? Would you like to contact another family?**

From Pam. “Our son Todd was diagnosed with CMML in 1997 at the age of fourteen. He had been unwell since age seven and during a routine examination at the John Hunter Hospital an enlarged spleen was discovered. He was sent to Camperdown Children’s Hospital where monocystosis was found - cause unknown. He was monitored from then on by regular blood tests and continued to have numerous infections and poor physical growth. Some changes were eventually noted on his blood slides and the CMML diagnosis was made. He was then seen regularly by Dr Richard Cohn at the John Hunter Clinic and at Randwick where he had his bone marrow aspirates. When Dr Frank Alvaro was appointed paediatric oncologist in Newcastle we transferred to his care. In 1999 it was found that Todd had a non-functioning thyroid as well and lately he has been seeing a cardiologist for heart irregularities. Todd is now aged twenty one and sees Dr Seldon, a haematologist at the Mater Misericordiae Hospital in Waratah. His condition has not turned acute as predicted and with great determination he leads as full a life as he can - competitive tennis, part-time work, soon he will have completed a Social Science degree. However, he is seldom free of infections (particularly in the winter) and has a high level of fatigue. We were told when the original diagnosis was made that a marrow transplant was the only treatment and this does not seem to have changed. His older siblings are not matches and at last search there was no match on the Australian Bone Marrow Donor Register. In any case given the high level of risk associated with a transplant, this would not be considered unless his condition changed for the worse.

We know that we have much to be grateful for with Todd, but the reality is that life is very difficult for him and of course we pray for a breakthrough in the treatment of this rare disease. We would love to be in contact with another family who has a similar condition to Todd so that we are able to share our experiences. If your child has CMML and you would be happy to talk with us contact the hospital.

# FROM THE CENTRE FOR CHILDREN'S CANCER & BLOOD DISORDERS

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## C2W (Turnbull Ward)

During the past few months the ward has been quite busy. We have been fortunate to have some special visitors, who have included Reg Regan who brought back the BIFF, the crew from the Footy Show, Brad Fitler, the Holden Racing Team and of course the new Miss Universe.

Recently we have had new arrivals to the staff of C2W. They are Anna Kirby, Sinead Behan, Brigitte Montzka, May Cheng and Kirsten Adnum. I am pleased to announce that Rachael Budge who went on maternity leave in mid May had a beautiful boy named Jack. She will be returning to C2W in 2005. Also in 2005 we will have Rowena Nelson (who is currently travelling in Canada) and Kerinna Dalton (who is in Victoria) returning to C2W. I would like to also farewell one of our CNS Wendy Londal who has left C2W and returned to South Africa to work at the Red Cross Children's Hospital in their oncology unit. All the staff wish her the best and hope to see her back at the end of 2005.

Recently C2W, as part of the International Children's Day celebrations at SCH, won first prize for the Staff Art competition with a fantastic beach party theme picture. Great work guys!!

I would like to also thank Camp Quality volunteers who have generously given up their time to come to C2W and provide massages and haircuts for parents. Belinda who does the massages will be here every 2nd week and Max the hairdresser will be here every 4 weeks. Thanks for helping out guys; it's really appreciated.

As you all know Christmas is fast approaching and Santa will be making a special visit to the ward.

All the staff of C2W hope that you are well and we send our best wishes to you all.

## Dr Tracey O'Brien Returns

It is great to be back working at the Centre for Children's Cancer and Blood Disorders having spent the past two and a half years working at the largest paediatric bone marrow transplant centre in America. The experience I have gained working in such a large transplant centre will be put to good use as I take over the role of Director of the Bone Marrow Transplant program at SCH following the retirement of Professor Vowels from clinical practice.

During my time overseas I have had the opportunity to do some innovative and exciting research including extensive work on umbilical cord blood transplantation and unrelated bone marrow transplantation and prevention and management of graft versus host, a major complication of transplantation, through the use of novel gene therapy.

The future of oncology and bone marrow transplantation at SCH is very exciting as we strive to deliver excellence in care to all children and their families and I am very pleased to be a part of this future.

I look forward to meeting many of you and saying hello again to my 'old' patients in coming months.

Regards,

Dr Tracey O'Brien



# A/PROFESSOR MARCUS VOWELS AM Retiring from Clinical Care

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Marcus Vowels graduated in medicine from Sydney University in January 1966 and did residency terms at Prince of Wales and Prince Henry Hospitals and the department of Paediatrics at Prince of Wales Hospital. He took a fellowship in Haematology at the Royal Hospital for Sick Children in Glasgow where he spent 2 years from 1971. He returned to the Prince of Wales Children's Hospital in 1973 to take up the position of staff specialist in Paediatric Haematology.

In the 70's there was little research money for children's cancer and no facilities. In 1975 the fledgling Children's Leukaemia and Cancer Foundation was begun by Margaret French, Jack Kasses (a parent) and Marcus Vowels and officially formed in 1976. The resultant fund-raising culminated in the building of the Children's Leukaemia and Cancer Research Institute in 1983, an outcome of which Professor Vowels is extremely proud.

The opening of new wards in 1976 allowed a decision to be taken that all patients with leukaemia and cancer be nursed in one ward, an oncology unit. Involvement of all staff in unit seminars commenced in the late 1970's with the support of the Oncology Social Worker, Margaret French. The need for dedicated bereavement counselling and support services was recognised and such a position created and funded through the Malcolm Sargent Cancer Fund.

In April 1975, Professor Vowels visited the Fred Hutchinson Transplant Center in Seattle with Dr Reg Lam Po Tang and returned to establish and commence the first active transplant program in Australia, with the first transplant occurring in May 1975. The first successful bone marrow transplant performed in Australia on a child were undertaken at Sydney Children's Hospital in 1979. The transplant program became the leading program in Australia, enjoying

success of firsts in a wide range of diseases and with new technologies. Patients were referred from most parts of the globe including Russia, North and South America, Europe, Asia and the sub-continent. The lack of suitable bone marrow donors for children in need of transplant led to the exploration of cord blood as a source of stem cells culminating in the first successful related cord blood transplant in Australia in 1991. It was a natural sequence to develop an unrelated Cord Blood Bank in 1995. The first successful unrelated cord blood transplant in Australia occurred in 1995 and the first dual cord blood transplant in Australia in 2004. The achievements in the field of transplantation would not have been possible without the keen support of his close colleague, Dr Pierre Reg Lam Po Tang.

Dr Vowels took over as Head of Haematology/Oncology in 1984 and continued until his retirement of this position in 1998. He has been Chairman or Member of Committee for a range of organisations including the Australian and New Zealand Children's Cancer study group, Clinical Oncologic society of Australia and International Bone Marrow Transplant Registry.

In 1993 he was awarded an MD based on publication and promoted to Associate Professor. He has 78 publications and 7 chapters in medical texts.

In 1993 Professor Vowels was awarded an Order of Australia for his work in the field of Paediatric Oncology and Transplantation.

A/Professor Vowels retires from clinical practice at the end of 2004 but will be continuing with his work in the Cord Blood Bank. He leaves a legacy for others to build onto.

*Goodbye. Thanks  
You will be missed.*

## Your child arrives in the Emergency Department with a fever.....

### **Update on the initiative to improve the management of children who have a fever while on treatment or recently completed treatment:**

As you know, when your child has a fever it is very important to get to a doctor or Emergency Department (Casualty Department) as quickly as possible, to be examined by the nurses and doctors so that appropriate treatment can be started as quickly as possible.

In an effort to continually improve the service provided to your child, the staff in the Emergency Department and CCC&BD have worked together on an initiative to shorten the time from arrival to the first dose of antibiotics in the child who has a fever. Eighteen months ago the two departments developed a new treatment guideline or algorithm on how to manage children who have cancer or a blood disorder, who arrive in the Emergency Department (ED) at Sydney Children's Hospital, Randwick (SCH) with a fever.

The new treatment guideline was started in March of 2003. It was considered important to evaluate whether this new treatment guideline improved care. Therefore at 3 months, then again at 12 months an evaluation occurred and the results of this evaluation was compared to information collected for 3 months before the treatment guideline was introduced. Since receiving antibiotics is the crucial part of fever and neutropenia management, the team looked at the admission of each child who presented to the Emergency Department of SCH with a fever and determined how long it took for the child to receive the first dose of antibiotics. ***The exciting part of the initiative is that children are receiving antibiotics quicker than ever before. With the ongoing commitment from the nursing and medical staff in the Emergency Department at SCH, the time to starting the antibiotics has been cut in half.*** This is as a result of managing your children differently, in particular the nursing staff are accessing the central line or port-a-cath to draw blood cultures and start IV fluids as soon as possible after the child's arrival.

Since the guideline has been such a success at SCH, the outreach service wanted to have families who would not be attending the ED at SCH to receive the same quality care. Therefore the guideline which is being used at ED at SCH is now being used in the regional and rural hospitals throughout NSW who may have a child with cancer or a blood disorder present in the local paediatric ward or Emergency Department. This is organised through Jan Hardy the Outreach CNC.

Because we believe parents are a child's greatest advocate, it was believed that placing the guideline in the patient diary would give you, the parent, a tool to discuss the management of your child's fever with the nurses and doctors at your local hospital.

***The CCC&BD staff would like to say "Thank you" to the nurses and doctors in the Emergency Department for the commitment to providing excellent service to our patients.***

We would be interested in any feedback you can provide. Please do not hesitate to contact your CNC or doctor if you have questions. Thank you.

Anne Senner

# TIPS FOR LIVING AND COPING

## Holiday Hope

For those who are caring for a loved one, or facing losses of any kind, the holidays can be a difficult time. Family celebrations, get togethers with friends, gift giving and religious observances all have their special meanings, but they can also bring special challenges when our time, energy or health is being taxed. Keeping the following suggestions near might enable you not only to survive the holidays, but to appreciate them for what they are.

Plan ahead. Develop a calendar of specific days for shopping, baking, visiting friends and other events. Give yourself more time to prepare. Start long before the holiday actually arrives.

If last year's holidays were not a memorable experience for you, re-evaluate them. Modify or make new traditions if it feels right. Accept a few invitations to be with close family or friends. Choose the ones that sound most appealing and avoid the ones that feel more like obligation.

Realize that things don't have to be perfect. Everything doesn't have to resemble a magazine cover. Consider your expectations. Often we lose sight of the fact that the most important aspect of the holidays is celebrating with loved ones. Learn time management techniques such as prioritizing, delegating and most importantly, saying "no" when necessary.

Draw on your faith and spirituality. For many, faith is a source of strength and comfort during stressful times. Look to your spiritual advisor and faith community to support you if needed.

Take care of yourself. Often, during the holidays, we tend to forget this is the time we need to take extra care of ourselves. Try to stick to your normal routine as much as possible; take frequent breaks, get plenty

of rest, and do not try to do everything by yourself. Something this simple will refresh you and help you enjoy the holidays that much more.

Sometimes through helping others we feel better ourselves. If you feel the desire to help, consider volunteering in a shelter, adopting a family to buy presents for, visiting a nursing home.

Make the meal preparation easier. Order in, use frozen food, have others help with the cooking, or consider going out instead. Remember it's not what you eat that is important, it's celebrating together.

**December, 2003**

**Provided by the Social Work Department of the  
American Brain Tumor Association**



Staff of the Centre for  
Children's Cancer and  
Blood Disorders extend  
their best wishes to all  
families for a safe and  
peaceful Christmas and  
New Year.

# RECOVERING FROM CHILDHOOD CANCER

## A Survivor's Story

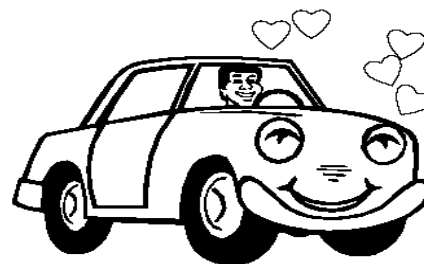
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*Taken from ICCCPO Newsletter Winter 2003*

In 1981 I was a 15 year old and in fourth form at school. For several months it had become obvious that something was seriously wrong with me. I developed impaired hearing, loss of appetite, constant vomiting after meals and poor co-ordination. Despite a battery of tests no doctor could pinpoint the cause. This was very stressful for myself and for my family. I was eventually referred to a neurosurgeon for a brain scan, and was immediately diagnosed with a pineal germinoma brain tumour. Although mine was a very rare type of tumour, it consisted of very primitive cells, which were especially sensitive to radiation therapy. My reaction to the diagnosis, and the knowledge that it could be treated successfully with radiotherapy, was one of immense relief.

On the road to recovery, I developed a positive philosophical approach. There is strength from knowing that however bad the treatment might be, it cannot be worse than not knowing what was wrong before the diagnosis. Knowing the devil and that it can be defeated, you have won half the battle. The treatment, however awful, is your friend and the medical staff are on your side. Radiation side effects such as acid saliva, loss of energy, concentration span and hair and steroid fluid bloating, are all tolerable and less of a source of stress if you know they are part of the big climb out of the pit. The trick is to associate these side effects with self-esteem (braveness, determination) and not to be afraid of them. There is always something to be gained, even in such a compromised situation. In accepting that at this point you will be out of commission for a while but have the goal of returning to the mainstream, I found the following "freeway" analogy helpful:

The freeway is the simplest, fastest, most efficient way to get from one town to another. I want to get to my destination like everyone else, but I can't use the



freeway for now. Thus I must use the secondary roads and country lanes which are slower and less efficient. There are two ways to look at the situation: (a) it's a jolly nuisance and I'm going to get terribly upset and frustrated, or (b) the situation provides the opportunity to get a better view of the countryside, visit the small towns along the way and gain a richer experience by the time I get to my destination. As opposed to a screaming rush with snarling traffic, dangerous overtaking and road rage to arrive grumpy and hassled and in which you have gained nothing but a headache.

Here is the opportunity for a re-discovery of yourself, who you are and the many things that you are still capable of doing. If you can keep your spirits up during cancer treatment, you can handle almost everything else afterwards!

The full support of my family was instrumental in helping me to cope. We have always been a close family and when this crisis occurred everyone pitched in and helped without complaint. My brother at the same school as myself, was an important liaison between school and home. This kept me in touch with what was happening there. It is very important to know that your school is there for you to come back to and that they are thinking of you during this socially isolating time. The psychological support of my sisters was also very important. This encouraging home environment instilled an inner strength, which was vital in the difficult years to come.

After the treatment I was left with pituitary hormone deficiency, chronic tiredness, permanent moderately

severe hearing loss and minor co-ordination difficulties. One important aspect in returning to school the following year was that I was treated in the same way as others but with recognition of my special needs in certain circumstances. Returning to school was very difficult, as I had not foreseen that I would have remaining difficulties in academic thinking, concentration span and tiredness. Teachers were aware of my situation and were keen to help meet my needs, but I had to be assertive in stating my difficulties first. This resulted in altering my schedule for the first year back. I attended classes as normal but with a reduced workload and the delaying of full assessment and exams for sixth form till the following year. I attended university after six years at school spreading Stage 1 science papers over two years.

Several tactics were useful in coping at school and university;

Firstly, I consistently sat at the front of the classroom or lecture theatre in order to maximise hearing ability. Although this limited conversation with other students (who like to sit as far at the back as possible for social reasons), I had to keep in mind the primary reason I was there! I also was assertive in asking teachers or lecturers to clarify points which I had not heard or understood well.

Secondly, I organised my day so as to be aware of my tiredness and reduced concentration span. This meant taking regular breaks from study and immediately after lectures. In revising for exams (at school and university) I rewrote written material into chart-flow diagrams to aid memory. This involved recognising the pattern and sequence of ideas underlying the material. It is always easier to remember a visual pattern or direction than endless notes.

Generally in life I find the following approaches useful:

The first is the concept of assertiveness. Of not being afraid to take on new opportunities and risks as long as I am assertive to others (and myself) about my limitations and special needs. This means ensuring that I understand the situation I am encountering and what is expected of me and communicating my special needs to others.

The second approach is the concept of control. As the Chief Executive Officer of Chris Jerram Inc., I have delegated responsibility to various “divisions”. One is the Division of Medical Management and is responsible for management of my medical condition (taking medication, monitoring energy level, and reporting anything out of the ordinary.)

The Division of Awareness (managed by Hugh Watchitt!) has the task of compensating for my perceptual delay - (slow central processing and reaction to sensory input) - for example extra care crossing roads, allowing time to orient to a new situation.

The Division of Critical Analysis is responsible for decision making ie “Is this a good thing for me to be doing”, “What am I getting into and how much am I likely to get out of it?” I have to be aware that what is right for other people may not be right for me. There is no shame in making a choice which may not be the most “popular”.

Lastly there is the Department of Stress Management. I have difficulty in dealing with stressful situations at times, and have two main ways of coping. One is to use a system of gears, and to change gear up or down to suit the situation ie recognising when it is inappropriate to roar into top gear with the adrenaline pumping when you cannot do anything to make things happen any faster. A second is to compartmentalise a situation and only deal with one compartment at a time. Ignore everything else which is coming at you. Prioritising is important.

Finally I cannot say enough for the ongoing support of family, school and, in my case the Audiology Department at Auckland University in encouraging the rehabilitation of the young cancer patient to from a positive view of his or her condition. At the end of the day, he or she will have to accept, monitor and advocate for their condition in their own way, and the role for the parent, sibling, teacher or colleague is to recognise and bolster any steps which the survivor takes toward this end.

Chris Jerram, New Zealand

# "FOLLOW THE YELLOW BRICK ROAD...."

Kathy Riley

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## *Taken from The Caring Hand, Pediatric Brain Tumor Foundation*

I dreamed of a little boy with curly red hair, a boy who loved dinosaurs, Lego and me. His name was Peter. At just 5 years old, he was a master of disguise, a Teenage Mutant Ninja Turtle one day and Captain Hook the next. But through every adventure, every costume change, every hook and sword, there remained one constant - a worn pair of black cowboy boots handed down from his best friend, Ben.

Peter stole my heart. His love for each great adventure flooded my imagination with dreams of the future. I dreamed crazy, super sized dreams for his future. Dreams of Peter winning the most valuable player award in the Super Bowl or of flying as the youngest scientist aboard one of NASA's shuttles. But I also dreamed of ordinary things that now will only come by way of miracles: Peter earning a high school diploma, finding true and lasting friendships, driving a car and encountering his first love.

Five months before kindergarten, Peter was swept up in his most dangerous adventure of all, one I had never dreamed. He had been struggling with unexplained headaches and vomiting. After a long MRI and a trip to the local university hospital, a neurosurgery resident enthusiastically announced that Peter had an "impressive tumor" at the base of his brain. I learned a new, ugly word: medullablastoma. It meant brain cancer. And within days of diagnosis, my red haired future Super Bowl star had surgery to cut out that tumor. Suddenly Peter could no longer talk, he could no longer walk, he could no longer swallow his own saliva. Now even the smallest of my dreams for his future seemed lost.

Over the course of surgery, radiation, chemotherapy and many, many months of physical and occupational

therapy, the tumor stayed away and Peter slowly learned again how to talk, and walk and swallow. I started to believe that he was going to survive this terrible disease. But he didn't come back the same adventurous and unstoppable boy I had said good bye to months earlier when he was wheeled into the operating room.

I was grateful beyond words for Peter's life and returning health, but I felt a terrible ache in my heart. The ache grew in intensity every time I drove past a high school football practice. I yearned to see Peter on the field but knew that I never would. That ache rose during every school assembly when Peter was overlooked for an academic award even though I knew he had worked harder than anyone. And deeper questions haunted me. Questions about Peter's ability to live on his own, to find a job he loved and painful questions about the possibility of marriage and a family.

I felt guilty about the ache. How could I allow myself to feel so sad when Peter was right there beside me? Why couldn't I just be happy with what I had left? What was wrong with me? The answers came from the most unlikely place, from a mother whose son had had a brain tumor. But unlike Peter, this mother's son did not survive his illness. Her words to me were surprising and deeply healing. "You've lost something too," she said. "And no one has given you permission to grieve. I give you permission."

Permission to grieve.

The dreams I had stored up in my heart for Peter's future had indeed taken a fatal blow, and this mother was telling me that it was okay to feel sad about my loss. But her answer brought me to a new question. Would I let go of the the old and take on something new?

Psychologist Ken Moses speaks of the importance of embracing new dreams when old ones have been lost. At first, embracing new dreams for my broken boy seemed beyond my reach. But as I grieved what was lost, I discovered I was able to take my first, tentative steps toward the possibility of dreaming again. I felt like Dorothy following the yellow brick road on a journey of discovery, wonder and terrible danger. Upon reaching the end of her quest, Dorothy discovered her dream, one hidden deep in her heart all along but discovered only through peril.

What did I find at the end of my yellow brick road? I found Peter. A boy who deeply and profoundly cares about people. A boy who loves his family, his neighbours, his class mates and winning at chess. A boy with the best heart of anyone I have ever known. A boy with an unquenchable sense of humour and a keen mind stocked with dozens and dozens of knock-knock jokes. And I found a dreamer, a young man, almost seventeen now, who dreams of helping people by becoming a missionary or a teacher. And

somewhere, somehow, deep inside, if I look hard and long I can still see my astronaut and Super Bowl star. Have I completely let go of my old dreams? Mostly. But every once in a while, I imagine a handsome, ruddy football player named Peter, with his face to the wind and the ball in his grasp, being cheered toward the goal line by thousands of screaming fans.

I have come to love Tolkein's *Lord of the Rings*. I love it because Peter loves it, and because it's about some very ordinary people on a dangerous journey, people like me, who would rather be safe at home than out fighting deadly battles. Tolkein writes about what I've learned on my own long journey: "The world is indeed full of peril, and in it there are many dark places; but still there is much that is fair, and though in all the lands love is now mingled with grief, it grows perhaps the greater."

And so with Peter, I will keep loving. Keep hoping and keep dreaming.

## **COG/CureSearch Web Site**

CureSearch is the name of the combined Children's Oncology Group and the National Childhood Cancer Foundation in the United States.

Many parents will be aware that the Centre for Children's Cancer and Blood Disorders is a member of the Children's Oncology Group (COG), a large multicentre group whose protocols of treatment we follow for specific diseases. COG has member hospitals throughout North America, including Canada and in Australia.

As childhood malignancy is rare, multicentre trials offer the best chance of testing new treatments within a reasonable period of time. Each hospital sees too few patients to adequately evaluate a new treatment. By many treatment centres treating patients similarly and registering the data in a central office with consent of the parents, within a reasonable period of time one can determine statistically whether one treatment is superior to another. Earlier in November, COG started a web-page which I think will be of interest to many of the families.

The address is [www.curesearch.org](http://www.curesearch.org) If anything that you read on the web-site is different to what you have been told, please feel free to discuss it with your Oncology team.

# THE SNOWY RIDE KIDS 2004

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We escaped our “normal post cancer life” and enjoyed a weekend of fun and friendship with other families from the hospital.

The weekend was to raise money for the Children’s Cancer Institute Australia (CCIA) and the money raised will help to find a cure for cancer , an aim that is so important to every family that has been struck by the disease. The event was organised by the Steven Walter Fund.

The time away was a godsend. We felt like we did 1 1/2 years ago before Samuel was sick. The children reacquainted old hospital friendships, made new ones and enjoyed being normal and having fun with their whole families to share it with.

Fun activities were arranged, ones like learning about freshwater fish, how they are grown from tiny eggs and protected until they are old enough to be put back into the river systems. The children were taught how to cast a fishing rod and wind it back in and enjoyed this on a fresh water running river in the Snowy Mountains. It was beautiful. The dads looked like they wanted to have a go, some managed to take over for a while, but it was all done in fun and the stuff memories are made of.

Other activities included having a ride on a Honda Goldwing motor cycle along the country roads. The parents had a ride too. The freedom was so exhilarating.



We stopped for a look over a Navy helicopter and met Wayne Gardner, Jimmy Barnes and Michael Milton (a champion ‘disabled’ skier who lost his leg to childhood cancer). The children were tickled pink to see some familiar and friendly faces from the hospital as well with Prof. Marshall and Donna Drew brightening up their day with a visit.

Later that night we all went down to the market place at Thredbo and enjoyed Jimmy Barnes in concert. Security let us get up the front for an up close and personal view. There were some 2000 bikies singing along too and the place rocked.

Thredbo truly is a place where you can have 4 seasons in one day! We had snow, rain, sunshine and some strong winds. When the weather was safer the little kids had a ride in the helicopter whilst the bigger kids enjoyed bobsledding. We then picked up the littlies from Jindabyne and all went for a ride in flashy old fashioned cars organised by the Cooma Car club.

Transportation, accommodation and meals were provided by so many organisations who donated their time and services to the children. They provided healthy snacks and meals for the whole group, gave the children little gifts to remember the trip and generally made us all feel so welcome in their part of such a beautiful country. Country hospitality has got to be seen to be believed and a credit to the organisations they represent. Thank you doesn’t seem enough.

My family would like to express deep and heartfelt thanks to the very large team of volunteers who treated us like royalty, spoilt us rotten and gave us all the rest we so desperately needed.

Thank you to Sue Walter for caring enough to make a difference in helping find a cure for cancer. Steven truly left a wonderful legacy behind that is a credit to not only him but his whole family

Sincerely Craig and Beth .

# BEREAVEMENT AND RELATED ISSUES

## **Bereaved Parents Group**

As the year draws to a close we plan to hold our last group of the year on Wednesday 15th December at 7.30pm. We anticipate that discussions will be about preparing for the holiday period and traditionally a time of year when things are difficult for families.

We also plan to contact the families who have come in the last year as we prepare for the next. We have not had as many parents attending this year as we'd hoped and it would be useful to hear from people. One idea is to hold the groups bimonthly. One strong message I have had from parents so far is that they definitely want the group to continue. They find it very supportive to know it is there when they need it. I will be in touch with you if you have come in the last year. Otherwise if you would like to contact me or are interested in coming to the group my contact details are noted here.

## **Bereaved Parents Phone Link Group**

This is a group that runs once a month for parents who can't get to the group in Sydney. It is a chance to speak to other bereaved parents, at no cost without leaving home. This year we have discussed siblings, relationships with friends and families, anniversaries and creating mementos. If you are interested please contact me.

My details until the beginning of February are;

Kerry Nair,  
Bereavement Counsellor,  
CCC&BD  
Sydney Children's Hospital  
Tel (02) 93821726  
Fax(02) 93821789  
e.mail: nairk@sesahs.nsw.gov.au

I am taking some time off in the new year on Maternity Leave and plan to be back to work sometime in June. If I am in regular contact with you and your family, I will be letting you know the arrangements for my leave soon.

If you would like to speak to someone while I am away please contact

CCC&BD department on 02 93821721.

KerryNair

## **Condolences**

**Parents and staff send their sincere sympathy to the families of the following children who have died over recent months**

**Jessica  
Peter  
Tyson  
Joshua  
Justin  
Amber  
Molly**



**Our thoughts are with you.**

# GENERAL NEWS AND INFORMATION

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## **Camp Quality. You've heard about it but not sure what it is about!!**

Camp Quality is a non profit organisation that is committed to bringing hope and happiness to every child living with cancer and to their families.

There are 14 offices throughout Australia covering every state and territory. It was established in 1983 in Australia but is now found in many countries in the world.

Camp Quality provides more than just an opportunity for children with cancer to have a holiday with others, though this is one of the cornerstones of the

program and one much appreciated by children. Camp Quality also provides weekends away for families, Family Camps and the Camp Quality Puppet Program where life size puppets help children to become more aware of the need to be caring and supportive of other child who have major illnesses such as cancer.

If you think your child or family could benefit from some aspect of Camp Quality contact them on 02 9869 0588 or go to their website [www.campquality.org.au](http://www.campquality.org.au)

## **The Joshua Holland Leukaemia Fund (JHLF)**

The JHLF was established by Kate Holland in memory of her son Joshua who passed away from Chronic Myelomonositic Leukaemia (CMML) on 23<sup>rd</sup> December 1999.

Over the last 4 years the JHLF has worked tirelessly to raise funds to help in the fight against childhood cancer. Money has gone toward clinical research and into the provision of a wide range of medical equipment used in the ward. Many of you will know Stephen Laughton whose position has been funded by the JHLF. (More about his research in next issue of the Family Newsletter.) Significant funding has also gone to provide equipment to assist make the lives of families and children in the ward more comfortable.

The JHLF would like to encourage other parents or friends help us. This might be by helping sell Christmas Cards, helping at a function, raffles or just with some advice.

If you are interested please give me a call on 0412 145 655 or e-mail [powelly\\_au@optusnet.com.au](mailto:powelly_au@optusnet.com.au)

Lyndie Powell, Chairperson JHLF

## **Ronald McDonald Learning Program Learning Links**

This 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 have missed lots of school

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

Learning Links can assist. They have branches in six location at Peakhurst, Peshurst, Fairfield, Miller, Dee Why and Randwick.

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

If you think that they may be able to assist to your child contact them on 9534 1710 or [mail@learninglinks.org.au](mailto:mail@learninglinks.org.au)

