Cancer in Kids Auxiliary

Of the Royal Children's
Hospital, Melbourne

Summer 2000/01 Newsletter

History and Aims

CIKA was founded in April 1980 to increase the awareness of cancer in children and to encourage financial support to aid research into children's cancer. CIKA is an official auxiliary of the Royal Children's Hospital (RCH) and is open to any interested persons who feel that they would like to contribute to help CIKA.

Over 140 children under 15 years of age are diagnosed with cancer each year in Victoria and 90% of these children are treated at RCH. CIKA is committed to provided funding for research into solid tumours, the third most common group of childhood cancer. Solid tumours include Wilm's tumour, Neuroblastoma, Osteosarcoma and Ewings Sarcoma.

Apart from the influence of genetic factors, inherited conditions, and exposure to ionising radiation, little is known of the cause(s) of the childhood cancers and nothing can be done to prevent them. Therefore, the need to continue the financial support of research into childhood cancer is imperative.

The hopes and dreams of CIKA are to stop children from ever contracting these types of cancer, but if they do, to ensure that the treatment they receive will be successful. At present the only way to move positively towards these ideals is through Research.

CIKA has actively supported Research projects at RCH with financial assistance since its' inception and will continue to do so until these types of cancer are cured. CIKA is recognised as one of the foremost fund raising auxiliaries of the Royal Children's Hospital (RCH), Melbourne.

The CIKA logo is in memory of the children of the families who founded CIKA. One child liked birds, particularly seagulls, one child liked butterflies and the other child liked flowers, especially nasturtiums.

May the children rest in peace!

From the Editors

The members of CIKA share a common experience; we've all had a child with cancer. Some are in the early stages of the battle and the research sponsored by CIKA gives them hope. Some of us have lost the battle against cancer and deeply mourn the loss of our child. Others have "won" the battle against cancer but are still impacted by the ongoing side effects from the treatment whilst others wait and hope that remission will be one day pronounced cured. No matter what phase we are in all our lives and those of our families have been irrevocably changed.

For many of us the festive season is anything but that as we will have children in hospital during that time, some are wondering if this is the last Christmas together and some are grieving the loss of their child. To all our families we wish you peace during this difficult time.

Thanks to everyone for your positive comments on our first issue (Winter 2000).

In this issue we profile neuroblastoma which has sadly claimed the lives of a number of our precious children.

Ellen Webb
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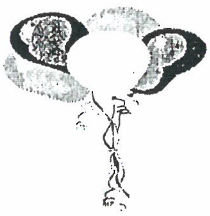
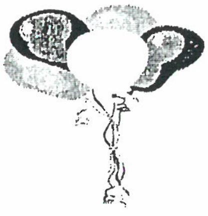
Visit our web site at www.patash.com.au/uz1083

Fundraising News

Riddells Creek Festival

On Friday, November 24th CIKA ran a raffle, sold helium balloons and handmade Christmas decoration at the Riddells Creek Festival. Steve and Susie McConville, Jim and Bernie Dawson, Dorothy Hern from the Macedon Ranges Focus Group and friend Judith worked tirelessly throughout the evening until approximately 9pm when the fireworks began.





The winners of the raffle were very excited with 1st prize being bed and breakfast for two at the Mount Macedon Inn, 2nd was an esky, 3rd was a Shell petrol voucher and four place prizes choose from $20 vouchers for fruit and veggies, meat, or a pharmacy gift pack of talc and handcream and Pingu family toys.

The total raised was $255. This is not a huge amount of money but every dollar raised brings us just that little bit closer to the doctor being able to say to the parents of newly diagnosed children "**we can cure your child**". The other important thing that activities like this do is to raise the public awareness of who CIKA are and what we are trying to achieve.

Bernie Dawson

Our Youngest Fundraiser

Michael Tomlin (one of the youngest volunteers to ever contact the auxiliaries office) wanted to raise money to help children "suffering" with cancer. With terrific support from his mum, Karen, his school and the broader community Michael organised supporters for his head shave and raised $1,144.

Good on you Michael and we hope that your new hairdo is keeping you cool this summer!

Want to raise money for CIKA?

CIKA's ability to support solid tumour research at RCH is dependent on people like you and I.

Need information on what to do?

Ring the Auxiliaries office at RCH on 9345 6490 and talk to the cheerful trio who work there. Sally, Rose, and Wendy will be delighted to assist you in your fund raising endeavours for CIKA.

From the CIKA committee to Sally, Rose and Wendy-a big thank you for all your support throughout the year and best wishes for the festive season and 2001!

Austrade scores a hat trick

The Austrade Social Club loves to party-and they do it for a good cause. For the 3rd year in a row Austrade selected CIKA as its charity to benefit from the proceeds raised at the annual Christmas Party. All members donate goods for hampers, which are then raffled off. The proceeds from this years event was over $800.

Thanks to the Austrade Social Club for their tremendous efforts and on going support over the last three years

Choccy Tuesday

"Choccy Tuesday is only once a year; so please think kids not kilojoules!" is one of the many slogans written by Bill and Jenny Gordon of the HeartThrob Auxiliary. They do a tremendous amount of work in making Choccy Tuesday a success and the members of CIKA appreciate their great effort. They are also a pleasure to work with.

Choccy Tuesday is held on the first Tuesday of October in the foyer of RCH and manned by the committee members of CIKA and HeartThrob. A generous range of Chocolate goodies was on offer thanks to the culinary expertise and the generous donations from the members and supporters of these two auxiliaries. As always we sold out and each auxiliary netted $522.90.

Annual Dinner Dance

Wish List for 2001

The 2000 CIKA dinner dance was a great success with 226 people attending and the result was over $22,000 was raised! We are hoping to significantly surpass that in 2001 and seeking the donation of "WOW" factor items that have universal appeal such a s a holiday to Faraway Bay!

Electrical items
White Goods-Dishwasher, Bar Fridge, etc
Brown Goods-DVD player, hi-fi, Discman, etc
Small Appliances-Kettles, toasters, hair drier, etc

Gift Vouchers
Hairdressers
Restaurant
Massage
Retail such as Myers or Sleepy Sams
Motor Car Maintenance
Zoo or Aquarium Passes

Other
Toys-commercially manufactured or hand made
Tools-Garden or Handyman
Sporting Equipment
Books
Air, Bus or Sea Travel (ie Spirit of Tasmania or Devil Cat)
Holiday Accommodation
Theatre, sporting or movie tickets
Jewellery
Works of Art
Furniture
Anything else you can think of!

Auction target $25,000-$30,000
Committed at 30/11/00 $4,500
We can do it!

Contact Sandra Lehrer for on 9696-9775 for your pledge form

Merv Lowry Memorial Benefit

When Merv Lowry, a musician, was in the hospital battling cancer he vowed to organise a Country and Western Day to benefit kids with cancer. Unfortunately Merv lost his battle. His friend Brian Allen has carried out Merv's wishes in his memory for the last 6 years and raised over $18,000.

Over 250 people attended this year's event and proceeds from the day were $3,032. The lively music provided by 10 bands was enjoyed by all evidenced by the number of people boot scooting, line dancing and even "slow" dancing. As always the Yarraville Club was an excellent venue.

Brian originally planned to stop after 5 years but due to popular demand he is now planning the 7th annual-so mark 14 October 2001 in your calendar now!

Thanks to Brian, the musicians (who donate their time), and those who helped to make this day a success.

Christmas Gift Inspiration

Wondering what to give someone for a truly memorable gift? Why not follow the example set by Australian Spa Covers who donated $1,000 to CIKA in lieu of the small gift they usually give to clients.

About Neuroblastoma

Neuroblastoma is a tumour arising from special (sympathetic) nerve cells which run in a chain like fashion up the back of a child's abdomen and chest and into the skull, following up the line of the spinal cord. The most common site for a neuroblastoma is in the abdomen. About 50% start in the adrenal gland lying above the kidney but some tumours grow at the back of the chest and occasionally even higher up towards the neck. The average age at diagnosis is two years with the majority of cases presenting before the age of 5 years.

Neuroblastoma accounts for approximately 8% of all childhood cancers and 15% of all childhood deaths from cancer. Males are diagnosed more often than females and there is slightly higher incidence among white children than black children. There appears to be no known genetic cause for neuroblastoma.

Symptoms

The site of the tumour varies and may cause differing symptoms at the time of diagnosis. For example, a tumour right at the back of the abdomen, which has grown to press on the spinal cord, may cause the child to begin to walk unsteadily or to have difficulty passing urine.

A child who has a tumour in the chest may have problems with chest infections, cough, or fluid in the lung, and this may need treatment before the neuroblastoma itself is treated. The child may also have loss of appetite, vague aches and pains and sweating or a lump may be felt and seen.

Tests

Blood and urine tests, X-rays, a bone scan and bone marrow tests will be performed. A specimen of urine is collected to test for catecholamine levels. These substances, which are hormones, are generally secreted into the urine in raised levels when a child has neuroblastoma. A CT or MRI scan or ultrasound will also be done in order to show the extent or limit of the tumour (also known as staging). Usually it is necessary to take a biopsy of the tumour in order to confirm diagnosis.

The results of these tests will also be used by the oncologist to give the most appropriate treatment for an individual child, taking into consideration the child's age, the stage of the tumour, and a variety of other factors. Children with neuroblastoma are grouped into low, intermediate, and high-risk groups. To determine these risk factors several tests are used including N-myc amplification.

N-myc is a gene that is present in neuroblastoma. Research has shown that amplification, or multiple copies of this gene correlates highly with rapid tumour progression and poor prognosis

Treatment

Treatment for neuroblastoma may involve modalities, chemotherapy, surgery and radiotherapy. The extent or spread of the tumour will determine what chemotherapy will be determined. Surgery can be difficult and often not done until the tumour has been shrunk by chemotherapy to a more manageable size.

Currently at the Royal Children's Hospital there is a new study open for treatment of advanced stage neuroblastoma. This involves intensive chemotherapy, surgery, radiotherapy, and a peripheral stem cell transplant using stem cells collected from patients at the beginning of treatment.

The study also involves the use of a specially made vaccine from the patient's dendritic cells, which have been extracted from the stem cells. These cells are normally important in directing the immune system to respond to infections and other foreign proteins. If treated in the correct way they may be used to direct a patient's immune system to fight tumour cells.

Follow up care

After treatment has finished the child will be seen at regular intervals, clinical examinations, urine, blood and ultrasound scans to monitor progress will be carried out to detect any possible recurrence.

After the first few years the focus changes to monitoring growth and development and other possible side effects of treatment.

Jacqui Robinson

Neuroblastoma and our Family

Brian Webb, August 1996

On the 21st of June 1996, I noticed a large swelling on the right side of my son Brian; he was 2 years and 4 months old. The doctor confirmed that we were dealing with some sort of cancer and we were quickly admitted to hospital. Brian also had bronchiolitis at the time and was being treated for that, this resulted in us not being on 6E and feeling very isolated from the other patients and families in the ward he was in. The next few weeks were a blur of tests and confusing speculation as to what we were dealing with.

I was 41 weeks pregnant and on Brian's 2nd day in hospital I went into labour and 45 minutes later Andrew was born in the Emergency Room of RCH; to this day people tell me how excited they were to witness his birth! At least they now stock cord clamps.

It seemed to take forever to determine exactly what sort of cancer Brian had (in reality it was probably one week) and we started chemotherapy before we were absolutely sure what we were dealing with. Finally they determined that it was neuroblastoma. I'll never forget the doctor telling me that his chance of long term chance of survival was 10%. The incidence of neuroblastoma is 1:100,000, if you filled the MCG with kids mine would be the only with this disease.

I often re-read my journal and wonder how we got through that time. In reality we had no choice; Brian needed us, as did our newborn baby Andrew. The support of family and friends was tremendous.

The standard regime then called for a rotation of drugs between cyclophosphamide and cisplatin every 10 days. Because the chemo was so aggressive he was very susceptible to infections and we were often admitted to hospital in the middle of the night. Because of this Andrew was weaned much earlier than I would have liked.

Brian's prescribed treatment plan went well for the first few months. Then he had a reaction to the cyclophosphamide. He was on oxygen in hospital and when he came home. This was exceptionally frustrating as the tumour had finally shrunk enough to be surgically removed but the side effects of the chemo meant this could not proceed.

After many consultations with the oncologists and the heart doctors we were able to proceed with the surgery. Four months after diagnosis the tumour was removed and all tests indicated that he was in remission. We were so happy, relieved and exhausted.

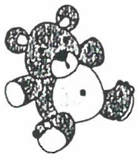
After two months the cancer came back and two months later we said goodbye for the final time. He had just turned three. I can't begin to describe how awful that time was. There can be no worse experience for a parent then to see your child waste away in agonising pain.

Brian was a gentle loving boy with an easy disposition and an engaging manner. He was a beautiful child with huge blue eyes and red hair. He loved trains and the Wiggles and was very protective of his baby brother. We miss him very much.

Ellen Webb

In memory of Olivia

It is with great sadness that we report that we lost one of our little people in October. Olivia McConville lost her battle with cancer (neuroblastoma) but never lost her battle with life. With tireless dedication from Olivia's parent's Steve and Susie and the support of the childhood cancer support group Challenge Olivia was able to experience much of what the world offers in her seven short years. She loved school and she loved life. All the members of CIKA extend our deepest sympathy to Susie, Steve, Ben and Alex.



Loving Bears, Loving Brian

Our meeting defied the odds, we believed in happily ever after.
Ensconced in my adopted country, the promise of family.
Worrying, will I be able to love this new being?
He's so beautiful, totally besotted with this small miracle.

Cheeky boy, its bath time; what's that lump?
Doctor confirms, yes, its cancer, expect the worst.
Into this chaos our second son is born.
Terrified, trying to be brave, torturous hospital stays.

Remission, hooray! No, it can't be, relapse.
My darling Brian, how can I bear living without you?
Consumed by grief, tempted to escape.
Andrew needs me, my very wonderful Andrew, my lifeline.

We need to be a family for Andrew.
Doctor again, stunned by the diagnosis, twins.
Welcome, Katie and Madeline, our precious girls.
To outsiders our family appears complete.

Wondering, always, what would he be like now?
Anguish, as his friends start school.
My arms ache to hold him, I yearn to see him.
Delighted laughter, treasured children, you complete me.

Written by Ellen Webb in memory of her son Brian who died of neuroblastoma

Questions to ask your Doctor

You should fee free to ask any question that's on your mind no matter how trivial it might seem. Some of the questions you might want to ask are:

- Has the cancer spread to other parts of the body?
- What is the stage of the cancer?
- What does the staging mean in my child's case?
- What treatment choices do we have?
- What are the chances that the cancer will recur?
- How long do you think my child will survive if there is no response to treatment of the tumour comes back?
- What side effects will my child experience from the treatment?
- Will my child experience any long term risks or complications from the disease or its treatment?
- What can be done for the side effects?
- How long will it take my child to recover from treatment?
- Does one type of treatment reduce the risk of recurrence more than another?
- What should I do to get my child ready for treatment?
- Should I get a second opinion?

Be sure to write down your questions (and the doctors' answers).

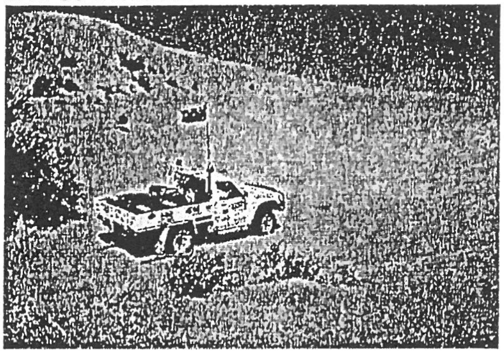
For more information on neuroblastoma contact Jacqui Robinson, Clinical Nurse Co-ordinator for Solid Tumours on 9345 6975.

Other CIKA Families impacted by Neuroblastoma

Unfortunately the children profiled in this issue are not the only ones to have lost this terrible battle. We are truly sorry for the other families who have also suffered this devastating loss. We do however have a few families whose children are now a few years past initial diagnosis and we are hopeful for their healthy future. It is for them and those still to be diagnosed that makes the research sponsored by CIKA so critical.

Double Crossing Oz

Anthony Kilner and Terry Prentice joined forces to break an existing endurance record across Australia and set a new record for a double crossing, raising a total of $12,000 which was split between CIKA and the Royal Flying Doctor Service (RFDS). They travelled a total of 10, 349 kilometres in 7 days and 26 minutes; Cape Byron to Steep Point in 3 days, 2 hours and 33 minutes and the return in 3 days 21 hours and 53 minutes.



The following is an excerpt of their journey.

"What started out as a great idea on paper had quickly become a bad idea - or at least a seemingly un-intelligent one. The constant concentration drained you mentally and the body received a constant pounding along the Gunbarrel Highway. The one thing that kept us going was the fact that the hard yards had to be covered so that we could raise as much money as possible for the charities.

Terry and I travelled without back up vehicles so skill and knowledge played a big part in our success, along with an amazing amount of help from many people across Australia. I lost count of the number of roos we dodged in Queensland and again in WA. The ShuRoo made a huge amount of difference to getting the roos off the road and back in the bush where they belong. We also contended with pigs, emus, rabbits, foxes, cattle and sheep.

Then there was the song I sung to Terry to keep him alert. It goes like this:
"I know a song that'll get on your nerves, get on your nerves, get on your nerves. I know a song that'll get on your nerves and this is how it goes! I know a song that'll get on your nerves." I'm sure you get the picture!

For the most part we chatted during the day, slept (in turns!), played with the radio, ate, drank, chatted, listened to each other snore and so on. **It really was boring at times!** The scenery was fantastic once we left the black top at the Olgas. Neither Terry nor myself had travelled the road between Beebyn Homestead and the Wooleen Woolshed so we were navigating off the map and GPS unit. Lack of sleep, plenty of skippies and a dwindling supply of Coke and fruit juice saw both of us in the driver's seat for an hour or so at a time.

Bleary eyes greeted the sunrise of the third day. Like a flower greeting the warm rays of first light we picked up, straightened in our seats and pushed on knowing that sometime this afternoon we'd be at Steep Point and Halfway there!

Yahoo! What an anti-climax. We reached the point, recorded the time and thought wow! We're here. Somehow the oft-repeated question of the night before - are we there yet? Felt really depressing; we still had to get back!

Watching the sunrise over the Olgas was a definite highlight of the trip. I was driving when we startled a mob of six camels at around three in the morning during our second crossing of the Simpson Desert. I'm not sure Terry appreciated the wake up call but it was a unusual change from the regular scenery.

Another night gone and another sunrise, our last, thank goodness. The run into Byron Bay was easy on good bitumen roads. Suddenly we were finished. Champagne was popped and a glass filled. Whoa, we'd made it!

Did I mention this great country of ours is a long way across?"

Thanks to the sponsors: Nissan Australia, Cooper Tires, 4x4 Australia Magazine, 4WD World, East Coast Bullbars, National 4X4 Show, WAECO fridge freezers, 4Way Suspension, Melbourne Map Centre, Piranha Off Road Products, Thomas Cook Boot & Clothing Co,Telstat Communications, Lightforce Lights, ShuRoo, Binskins 4WD
Centre and the various 4wd clubs around Oz who helped us.

CIKA is thrilled to have been a beneficiary of this great achievement and are very grateful to Anthony and Terry.

Upcoming Events

3rd Sunday of every month- CIKA Committee Meeting
We meet at the Royal Children's Hospital in the cafeteria at 4pm. All are encouraged to attend.

21st July 2001– CIKA Dinner Dance
With Bob Valentine to entertain and Peter Mitchell to M.C. at the Carlton Crest Hotel.

14th October 2001-Merv Lowry Memorial Benefit for Cancer in Kids
At the Yarraville Club

Thanks

Cassie and Kaye Murphy would like to thank to all the people that offered support during Cassie's recent surgery. It has been a very difficult time for them both and we are pleased to inform you that Cassie has recovered well.

Membership Form

If you have not already given us your name and address and wish to be on our mailing list, please return this slip to:

The Secretary, CIKA
Royal Children's Hospital
Flemington Road
Parkville, Victoria 3052
Phone 9345 9194

We have no membership fee at present but would be grateful if you consider making a donation. All donations are tax deductible and a receipt will be issued.

Name ______________________________

Address ______________________________

Telephone ______________ E-mail ______________

I would like to be on the member contact list: **Yes** **No**

Interest area: ______________________________

I would like to support CIKA by: ______________________________

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