

Cancer in Kids Auxiliary



Of the Royal Children's
Hospital, Melbourne

Spring 2000 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 President

Why be involved with CIKA?

CIKA is such an important organisation as it is committed to Research. It is my fervent belief that the funds we raise will enable research to be done that will make a difference in this fight against cancer and ultimately lead to a breakthrough. I'm thrilled that we are now funding Clinical Trials. It is my hope that one day we will be funding clinical trials into all Solid Tumours.

I first heard of CIKA when my daughter Kassie was being treated for Leimyosarcoma. I initially became actively involved with CIKA as a way of giving something back.

Being involved with CIKA has also been very enriching on a personal level. The networking has led to many firm friendships. Its good that something positive has come from tragedy. I have been encouraged to see members of CIKA gaining confidence and taking on more active roles.

Another positive outcome of my involvement with CIKA is that I can now walk through the doors of the Royal Children's Hospital without the dread that I once felt. I now feel really comfortable at the hospital; the wonderful staff in the Auxiliaries office has facilitated this.

I am very proud of what CIKA has achieved in the last few years and look forward to updating you on more achievements.

Kaye Murphy

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

News From 6 East

Support Groups?

The Haematology and Oncology Department are currently reviewing the need for support groups for parents, siblings, and patients.

We would like to hear from families who would be interested in establishing a support group. Below is a letter from one mother who would like to see this happen. Please contact Jacqui Robinson (9345 6975), or Deanna Angelico (Social Worker 9345 6111) to discuss.

"I feel a support group would be very useful. When your child is diagnosed with a cancerous tumour many thoughts go through your mind. Typical thoughts are:

- ❖ *Why us?*
- ❖ *Who can I talk to?*
- ❖ *What will happen next?*

The opportunity to discuss these questions (and many others) would be helpful. I believe a support group would assist in many areas and fill a gap, so that you know you're not alone. Learning strategies to help cope with and express emotions may be helpful. The sharing of experiences may be very inspirational, as well as the feeling that someone can relate to your experience."

I am happy to discuss this with other parents."

Anna Verlander 9786 3122

My trip to America



Hi, Jacqui Robinson here from the Haematology and Oncology Department at RCH. I have worked in Paediatric Oncology for the last 7 years and was appointed as clinical nurse coordinator for children with Solid Tumours in October 1999. The position involves "wearing many hats". However, its main aim is to ensure that the roller coaster ride these children and their families travel throughout treatment can be made a little easier.

In April of this year I was fortunate enough to receive funding from CIKA to attend a conference in America. This was the first meeting of the recently amalgamated Children's Oncology Group (COG) of which RCH became a member in 1998. 1200 delegates from the USA and Australia attended the meeting, which involved discussions and updates on clinical trials and advances in paediatric oncology. One of the highlights was of the conference was to meet with other nurses and share experiences, ideas and issues in this "unique" field of nursing.

A visit to both the Los Angeles Children's Hospital and the Texas Children's Hospital was on the agenda. These short visits enabled me to gain a valuable insight into new and different methods of balancing the daily clinical demands of oncology nursing, with the physical and emotional needs that children and their families have.

Visits of this nature, whilst extremely beneficial, are unlikely to attract direct hospital funding, therefore CIKA's assistance and support in these areas is vital, and result in significant improvements for solid tumour patients and their families.

Please do not hesitate to contact me if you think there is any way I can be of assistance.

Jacqui Robinson 9345 6975

Major Purchases in the last 12 months

Through our fund raising efforts the following critical equipment has been purchased by CIKA:

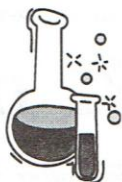
Hickman Starter Kits CIKA purchased and equipped small fishing tackle boxes, which are used as Hickman Starter Kits. Some patients have surgically implanted Hickman catheters for the administration of chemotherapy. As the catheters can stay in place for a year or more they need to be flushed on a weekly basis. Equipment for flushing includes syringes, needles, and catheter caps, sterile dressing pack, flushing solution, etc. Prior to CIKA's help parents and nurses had to organise the collection of these supplies from different sections of the hospital, parents had to pay for the equipment needed and there was no dedicated storage container. Now all a parent has to do when starting out on this process is go the Equipment Distribution Centre to obtain the kit.

Spectrophotometer Used in the analysis of DNA. Having this equipment on site has reduced the waiting time for test results that were previously processed in Sydney.

Stratagen Fluorotracker Used to analyse the biochemical events which determine the balance between cell survival and cell death, which allows the lab staff to explore the mechanisms by which some tumour cells exhibit resistance to chemotherapy and radiotherapy.

Scitillation Counter

The Top Count machine is used to measure anti-tumour immune responses, including cytotoxic T cells, natural killer T cells, T cell proliferation and antigen presentation (by dendritic cells).



Lab Report

There has been a growing solid tumour research base at the Royal Children's Hospital during the year 2000. Our clinical research activities have included establishing the unit as an approved National Cancer Institute Phase I Center for testing new chemotherapies and other agents in children with refractory tumours. To date we have treated five patients on these Phase I studies with great success. As well, our clinical research program has now incorporated our first vaccine studies for neuroblastoma and these will be initiated with the next advanced stage patient diagnosed at the RCH.

Our laboratory endeavours continue. In tumour immunology our vaccine program continues to look at innovative ways of creating anti-tumour vaccines for childhood tumours and our work also continues on understanding mechanisms by which we can kill brain tumour cells. In molecular oncology, Dr Algar's work undertaking the molecular analysis of the WT1 genes has expanded to brain tumours and it may in fact, be a useful marker of the disease and involved in the basic cause of brain tumours. Work continues on examining the Beckwith-Wiedemann syndrome and its relationship to Wilms' tumour and tumour risk. We are also studying the role of the molecule stim 1 in embryonal tumours of childhood and brain tumours.

Dr David Ashley

For more information contact Jacqui Robinson (9345 6975).

Upcoming Events

11th September – Double Crossing of Australia

Beginning on September 11th 2000, Anthony Kilner and Terry Prentice will attempt to break the **Across Australia Record by 4WD** that was set back in 1994. They also intend to turn around and retrace their route to complete a second crossing of Oz, therefore setting a record for the **Double Crossing of Australia by 4WD**. All monies raised by this event will be split evenly between CIKA and the Royal Flying Doctor Service. For more info visit their website at <http://doublecrossingoz.com> or contact Jim Dawson on 5428 6019

3rd October-Chocky Tuesday

Attention chocaholics! Don't miss our annual joint event with Heart Throb in the foyer of RCH from 9am until supplies run out. All contributions gratefully received. Please note new labelling requirements are now in effect. Contact Bernie Dawson on 5428 6019 for more details.

? November-Open Day at the Laboratory

Come and see first hand what CIKA's money is being used for. Contact Kaye Murphy on 0408943254 for more details.

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.

Annual Dinner Dance

The CIKA dinner dance was a great success with 226 people attending and the result was over \$22,000 was raised!

With great energy and leadership from Kaye the very enthusiastic members of CIKA fronted up to the Carlton Crest Saturday afternoon to prepare the venue for the evening's festivities.

The CIKA members, family and friends have established a great network of supporters who donated a large and varied range of goods for the silent and overall auctions/raffles.

Peter Mitchell in his new role as patron did a fantastic job as MC for the evening. Peter spoke very profoundly about his visit to the ward and the molecular biology laboratory. His commitment to CIKA and our ideals was ably supported by our "In Hospital" video that was edited by Peter and Channel Seven.

Bob Valentine and his band had us all on the floor. A big thank you to Bob and his crew as they are always most enthusiastic about their support for CIKA.

Congratulations to Susie and Brendan Case for putting 74 "bottoms on seats"; surely a new record! Thanks to the staff at the Carlton Crest especially Danielle Jade.

Pen in 21 July for the annual CIKA ball at the Carlton Crest in 2001. More information will be provided in future newsletters.

Special Thanks

There were many people that were generous with goods donated for our annual dinner dance. Special thanks to the following:

Cosmetries of Richmond	Crown Towers
Hudson Conway	Surrey Hills Furniture
International Marketing Group	Mars Confectionary
Anne and Michael Edwards	Enfield Furniture
Lachlan and Barbara Robertson	Desktop Marketing
Suparest Bedding	

To all of our supporters-THANK YOU!



Letter from the Editors

CIKA as a group continues to grow. The committee and their supporters are committed to the goals and aspirations established by the three founding families in 1980. As we progress through the Year 2000 we have been made aware of the need to share more information and from this need has come this newsletter.

Future issues will contain profiles on solid tumours and how our brave families have dealt with and been impacted by these cancers. We invite your participation in making this newsletter a success. Please contact us with any contributions or comments.

Keep Smiling!

Ellen Webb

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Sandra Lehrer

9696 9775

The views and opinions expressed in this newsletter are those of the authors and contributors, and do not necessarily reflect the overall views nor imply endorsement by CIKA.

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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: _____
