



Cancer in Kids Auxiliary

of the Royal Children's Hospital, Melbourne



Newsletter Winter 2002



As Members Lives Take New Paths

I became involved with CIKA back in November 1990 after being invited to a Laboratory Tour followed by a Christmas dinner. Our daughter Fiona was diagnosed with a Ewings Sarcoma on her pelvis in May 1989 and finished her treatment at the end of June 1990. We were very

grateful for the doctors and staff at the RCH for saving our child. By joining CIKA I felt we could repay them in some way by helping to raise funds for cancer research.

When I joined CIKA there were apart from Mary MCGowan two founding member couples and one other couple who had lost a child to cancer so in some ways I felt guilty that our child had survived although she was still having regular check ups. Some new members joined after me with surviving children and CIKA continued fundraising for research. I was asked to take on the Treasurers role in 1995 when all positions were taken on by new members at the request of the original members who had put in ten years of fundraising for CIKA. During 1997 our membership had dwindled and we looked like having to fold with only 2 members, however after a membership drive we have flourished and now have a very enthusiastic group involved in fundraising. I was able to hand over the Treasurers position 2 years ago. We have had a lot of fun times with CIKA and have made some lasting friendships with other members who all understand the emotions experienced when having a child with cancer.

Footnote: Fiona was fifteen when she started treatment at 6E RCH and age is now 28. She is a Royal District Nurse and has been happily married to Jamie for 3 years.

Faye Love

This issue of the newsletter was generously sponsored by



Thanks
AXA!

From the Editors

Dear family and friends of CIKA,

Welcome to the latest CIKA newsletter. Once again we are thrilled by the generous support of AXA who have donated the design and printing of this edition.

We appreciate your feedback on previous issues and look forward to your thoughts on this issue. In this issue we profile Osteogenic Sarcoma. Shawn Lehrer, son of committee members Sandra and Steve Lehrer, recounts his experience. Shawn, now aged 25, is indeed a survivor as he has made a full recovery following a relapse. His remarkable journey is very thought provoking.

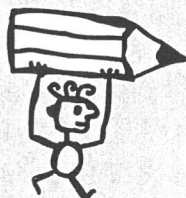
CIKA's committee is quite small and the main core consists of 9 family units. Some of these families have been involved with the group for many, many years. We are extremely grateful to these families and support their decision to move on. We are therefore hoping you or someone you know will consider joining CIKA. We are keen to share in the wisdom of your experience and enthusiasm for new initiatives. For more information please ring Kaye Murphy (President) on 0408943254 or Sandra on 9696 9775AH.

Ellen Webb 9326 0962
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Visit our website at

www.patash.com.au/uz1083



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First @ RCH

Families in Response to Solid Tumours

FIRST @ RCH was formed in August 2001. The roles and objectives of the Committee include:

- acting as a support network for parents of children with solid tumours;
- acting as an advocate for parents of children with solid tumours and to provide constructive feedback from parents to the Hospital and staff; and
- facilitation of educational seminars and informal discussion groups.

Meetings are held bi-monthly and coffee nights are held every other month. Parents from Ward 6 East are invited to attend the coffee nights and discuss relevant issues in an open and comfortable forum.

We are currently arranging educational seminars that will deal with issues such as:

- Post treatment effects of chemotherapy and radiation on children with solid tumours;

- Effectiveness of alternative therapies that may complement traditional radiation and chemotherapy treatment provided by the Hospital.
- Long term psychological and social affects on children who have received chemotherapy and radiation treatment. An opportunity will also be given for an open forum for the discussion of issues in relation to this area.

The Committee is comprised of – but not limited to – the following:

1. Department of Haematology and Oncology:
 - one Physician
 - one Nurse from the Ward
 - one Social Worker
2. Parents of children with solid tumours who:
 - are undergoing treatment
 - have completed treatment

Any queries, please contact Jacqui Robinson on 03 9345 4868.

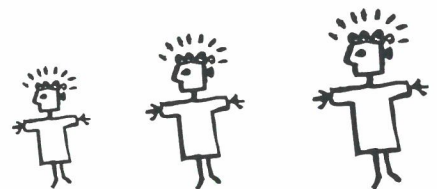
Research News

Dear supporters of CIKA,

I am pleased to report that through your sponsorship of our vaccine program, we have now been able to successfully implement three early phase studies of this technology in Outpatients. There have been 15 patients treated so far on three protocols, those with newly diagnosed neuroblastoma, a group with high risk solid tumours of childhood, and recurrent high risk brain tumours of childhood. The results to date have clearly demonstrated that we have the technical capability and are able to produce the vaccines at the highest level of quality required for human trials. This is no small undertaking, as it has required much manpower from both Denise Caruso, our post doctoral scientist and Alana Gardiner, who have been funded by Bluey Day.

In addition to this feasibility and technical aspects, we have been able to show that the administration of Dendritic Cell anti-cancer vaccines to patients is safe and has not been associated with any adverse events.

One of the secondary aims of the program to-date has been to measure the patient's immune responses and their general immune capabilities. It is clear from these studies, that many of our patients enrolled on our vaccines trials are still suffering from the effects of previous treatment and have immune deficits related to this. As well, a number of patients with active tumours show abnormalities in their immune system despite the fact that they have not had any recent therapy. These abnormalities almost certainly relate to the cancer itself. These immune problems will certainly serve as



barriers to the effectiveness of the vaccine therapy and it is our intention to focus on understanding the nature of these problems in order to better formulate appropriate vaccines and come up with a rational vaccination schedule. These studies will form the basis of our research in the next few years.

Once again, I can only thank CIKA on behalf of children with cancer and the Department of Haematology/Oncology for your generous support of this program.

Many thanks.

Yours sincerely,

A/Professor David M Ashley MBSS PhD FRACP
Director
Clinical Haematology/Oncology

Shawn's Story

Most of my life I have had certain problems with my knees, due to playing a lot of sport. In October 1989 when I was 12 years old my right knee started waking me up at nighttime. After going to a few doctors I went to a specialist in Ballarat who told me I had adolescent growing pains in my joints.

I disagreed with the doctor and I asked him to X-ray my right knee. After the X-rays were taken his attitude changed a lot because he suspected I had a growth on my femur. I had to have a lot more tests done including a bone scan which confirmed that I had cancer.

That meant I was off to the kid's hospital to have more tests done including a biopsy, which showed that I had an Osteogenic Sarcoma; this was all shocking to a boy aged 13. I started chemotherapy and had methotrexate for four weeks to reduce the tumour. After they reduced the tumour they operated on my leg and I did not know if my leg would still be there when I woke up. Though the tumour was bigger than they allowed for they persisted and removed my tumour along with part of my kneecap and half of my femur. This was all replaced with a metal knee joint and femur.



Once I had recovered from my operation it was back to chemotherapy for 10 months. This was when I got quite sick but positive thinking and friends and family support along with support of organisations such as Challenge and the dedication of doctors helped get me through.

In December 1991 I had a regular follow up X-ray which showed a lump in my lung, a CT scan confirmed it was a secondary metastatic sarcoma.

I was lucky and all that was needed was removal of the tumour and some lung, I did not need to have follow up chemo.

I still have trouble with my leg and back, because of weakness and leg length differences. Within the very near future I will have to have my knee and femur replaced-I am very happy that I kept my leg.

Looking back of course I would have preferred to never have had cancer. But I did and if it wasn't for people like Keith Waters, Mary McGowan, Dave Rogers, and Bob Dickens and of course my family things would have been much harder to take.

Shawn Lehrer



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 Ewing's 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!

Annual CIKA Dinner Dance

Mark your calendar now for 10 August! Planning is well underway for a great evening of friendship, fun and fundraising. This is our 5th annual event and we know that this year's event will be the best ever. The dinner dance is our main source of fundraising, last year we raised over \$30,000 and we hope to well and truly surpass that this year.

Bookings are now open, gather your friends (don't forget your business colleagues) book a table or two, and start getting excited about this great night.

Entertainment will be provided by Bob Valentine and MC's by our sponsor, Peter Mitchell.

We have an exciting theme planned and are continuing with the Carlton Crest as a venue. If you plan to stay overnight be sure and let the hotel know you are attending the CIKA dinner dance.

Don't miss out on this gala night. Tickets are \$90 per person which covers a 3-course meal, unlimited drinks, music, spot prizes, and more!

For more information contact Kay Murphy on 0408943254 or David Webb on 9326 0962.

ADVERTISING SPACE AVAILABLE

Limited advertising space will be made available in our dinner dance program which will be presented to all attendees. Contact Steve Lehrer for sizes and prices. Steve will also be able to assist you with design and format for your advertisement.

Steve is contactable on 9768 4944 or AH 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.