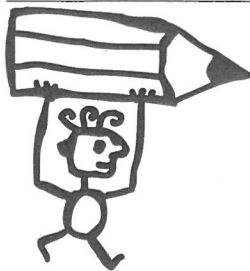




Cancer in Kids Auxiliary



of the Royal Children's Hospital, Melbourne



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.

For those of you who attended this years dinner dance, thanks for your support and we hope you had as much fun as we did. With the success of this years dinner dance under our belts we are now planning our calendar for next year.

To fund our existing commitments as well as new opportunities we need, well quite frankly, MONEY. Please let us know of your ideas for fundraising.

Thanks again for your support over the year. We wish you and your family all the best for the festive season.

The Editors

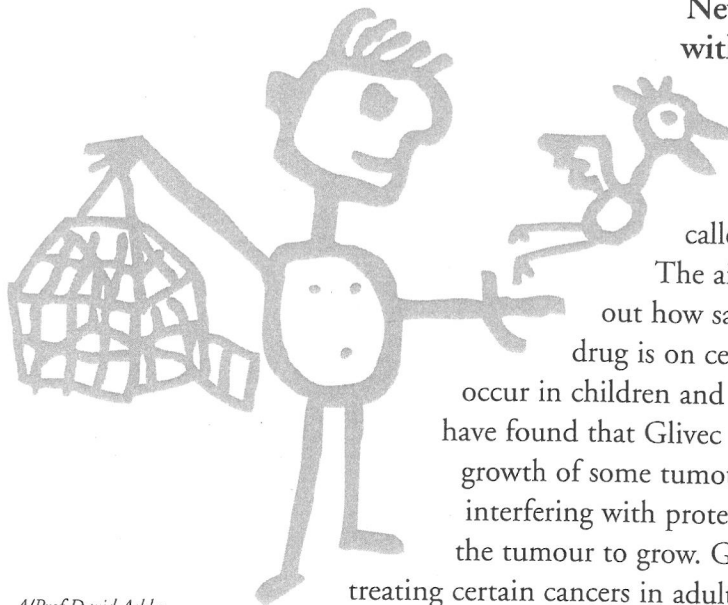
Sandra Lehrer 9696 9775
Ellen Webb 9326 0962
(Fax) 9372 0635

Research News from RCH

New Trial open for children with relapsed solid tumours:

We have just enrolled our first patient on a clinical trial involving a new drug called Glivec (Gleevec).

The aim of this study is to find out how safe and effective this new drug is on certain solid tumours that occur in children and young adults. Researchers have found that Glivec can slow down or stop the growth of some tumour cells. Glivec works by interfering with proteins in tumour cells that help the tumour to grow. Glivec is already approved for treating certain cancers in adults. However, this medication had never been tried in children with solid tumours.



AI/Prof David Ashley
DIRECTOR

Welcome new members!

Welcome to Nadia Gordon, David Morus and Yvonne Fairweather who have recently joined CIKA. Having the time and commitment to dedicate to any charity in this very busy age is a rare thing! CIKA is delighted to have these new members who have come to the Auxiliary from very different paths.

We are always keen for more members and supporters, so please call Ellen (9326 0962) or Sandra (9696 0775) if you are interested.



Thanks AXA for the generous support of this issue!

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Focus on a Bookcase



On August 30th, two of the Macedon Ranges Focus Group members, Carolyn Jefferies and Susie Laurie accompanied Jim Dawson and myself Bernie Dawson to Ward 6 East to view the long awaited bookcase that was kindly donated by the Group.

On arrival we were greeted by that friendly smile belonging of course to Mary McGowan who is 6East's Ward Manager. She lead us to the rear end of the corridor near the kitchen where we spotted a lovely powder blue lockable bookcase containing a selection of books. The top glass section of the bookcase showed

the particular titles that are available for parents to borrow and the bottom section is solid timber, which contains many more copies of those same books. A few of the titles are "Childhood Cancer", "Coping with Cancer" and "Childhood Cancer Survivors". As many of these books are very costly, it is a great advantage to parents to be able to borrow these to learn as much as they can about their child's particular condition. The Focus Group also donated some of these books.

After the routine photos, Mary showed Carolyn and Susie around the Ward. The ladies' comment

was that it felt like a happy place. We had a quick look at the Outpatients area before heading for coffee and a very enjoyable chat at McDonalds.

Who is The Macedon Ranges Focus Group?

They are a group of approximately 50 ladies, a few of whom who formed a breakaway group from the View Club about 6 years ago. They prize themselves as a very friendly group, which I can personally vouch for. From the first day I came in contact with these ladies, they made me feel very welcome. They have a meeting on the second Friday of the month, with

lunch of course but in between courses, they have a guest speaker and lots and lots of fun. There have coffee mornings and even a writers group. Best of all, the ladies manage to raise money while having all this fun. To date the Group has managed to donate approximately \$14,000 to CIKA so that the research into solid tumours in children can continue. CIKA members and their families are indebted to the Macedon Ranges Focus Group for their continued support of our aim that all children diagnosed with this terrible disease can be cured and lead a full life.

Bernie Dawson



Special mention!

We extend an extra big "thank you" to Steve and the crew at Bedshed, Hoppers Crossing. Committee member Steve Lehrer had the task of overseeing the collection of donated goods from all over Melbourne to the Carlton Crest. Steve donated his time as well as that of his staff; a great contribution from a small business.

Thanks Steve Sr., Jason, Lez, and Steve Jr..

**Need a bed?
Then head for the Shed!**

Located at:
**Bedshed Hoppers Crossing
Wyndham Homemaker Centre
Shop 7, 269-281 Old Geelong Rd.
Hoppers Crossing, VIC 3029
Phone: (03) 9748 4944
Fax: (03) 9748 4955**



I Do I Do! (actually I did I did!)

Our major fund raiser is our annual dinner dance, and this years really took the cake; the wedding cake that is! 305 attended this year and we raised just on \$37,000.

Our theme this year was "A Wedding" and it was great to see how many "brides" can still fit their dresses! Along with the blushing brides there were many handsome grooms, bridesmaids, groomsmen, mother of the bride, and many enthusiastic guests. The function room was breathtaking thanks to the creative efforts of "Weddings of Distinction" (9 Parkstone Avenue, Pascoe Vale South. 9383 5255).

We strive to make our dinner dance as enjoyable as possible whilst balancing it with the opportunity to update our supporters on the importance of the work we support and progress achieved towards our goals. Our patron, Peter Mitchell acted as our MC and we are delighted to have his support. Our president, Kaye Murphy, AKA "Mother of the Bride", gave a moving speech. Excellent background on our cause was provided by Peter Downie (oncologist with RCH). Sam Casili, eldest son of members Sam Sr and Julie gave us an insight into how he dealt with being successfully treated for Ewings Sarcoma. Sam is a fine young man, obviously very healthy and looking forward to the next phases of his life.

This years video was very moving and I was not alone in reaching for the tissues (from the Cosmetries goodies bag) whilst watching the video.

Bob Valentine and his hip crew had even the most reticent of

dancers on the floor for his mix of music which taps into all the eras represented by those attending. Thanks again to Bob and the band, especially for getting into the theme.

To help our cause we had many different types of fundraising, lucky dips, raffles, silent auction and a grand auction. The lucky dips sold for \$10 each, as people opened their boxes and realised the great value (average of \$25 per box) they went back for more and the boxes sold in a flash!

The evening could not have been the success it was without the effort put in by so many.

The Auctions and Raffle were well supported and we thank the many people who helped in many different capacities. The crew of volunteers organised by Mary McGowan did a fantastic job and looked great modelling the CIKA T-shirts (have you got yours yet?).

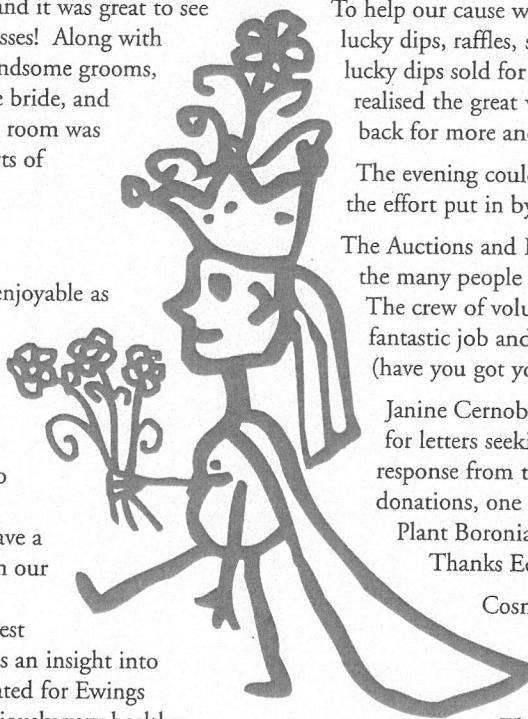
Janine Cernobrivic helped heaps addressing out envelopes for letters seeking donations. We had quite a good response from these letters. We also received many cash donations, one notable one was from Ed Fuller of Barry Plant Boronia who contributed \$2,000 to the evening. Thanks Ed!

Cosmetries of Richmond have long been our main sponsor for this event. Through their company Heather and Kevin Dixon have donated over \$10,000.

Thanks you both for all the effort that goes into organising the "goodie bags" as well as the

overwhelming amount of goods collected and donated to the Silent Auction.

Thanks again to all our helpers, sponsors, and "guests". We hope to see you at next years dance!



Osteogenic sarcoma

Osteogenic sarcoma is the most common type of bone cancer occurring in childhood. The peak age is between 10 to 20 years. It occurs more commonly in males (male to female ration 1.6:1). The aetiology of Osteogenic sarcoma is generally unknown, however, evidence suggests that age, sex, and its anatomical site correlate well with periods of rapid growth.

Symptoms

Bone pain is the most common mode of presentation associated with osteogenic sarcoma. This can be with or without swelling of the affected area. Systemic

metastasis are rarely seen at diagnosis, however if detected, are most commonly found in the lungs, or less commonly, commonly, other bones. Over 80% of osteogenic sarcoma cases are found within the lower limbs, most commonly around the knee. However any bone in the body may be affected.

Tests

A tissue biopsy of the affected area is the only definitive diagnosis of osteogenic sarcoma. With this in mind however, other diagnostic tests may be performed in order to gain a better understanding of the size, shape, and perhaps extent of the disease. Such tests may include Chest X

Ray, CT scan, MRI, Bone scan, etc. Collectively, the information gained provides a greater understanding of the nature of the osteogenic sarcoma, therefore determining the most appropriate course of treatment.

Treatment

Treatment of osteogenic sarcoma depends on the age of the patient, the site of the tumour and the presence or absence of metastases. Children generally receive a combined therapy including chemotherapy and surgery, with radiotherapy also being indicated in some cases.

Following numerous courses of chemotherapy, and the desired

result of a smaller tumour, surgery is often indicated. Prosthetic replacement is the preferred surgery, which involves the removal of the tumour and surrounding bone, and replacing it with an artificial bone or joint. However, if this form of surgery is not possible, amputation of the attached limb is indicated.

Chemotherapy and surgery options may vary from patient to patient according to age and tumour response.

*Information provided by
Jacqui Robinson (03 9345 4868)*



CIKA Dinner Dance



A Ellen Webb ("Matron of honour")

B Jenny Carafa ("Blushing Bride")

C Bob Valentine Band

D Julie Casilli, Jayson Joyce, Adam Oriti,
Jenny Carafa, Dr Sharon Hambly

E Steve and Sandra Lehrer



Families In Response to Solid Tumours (FIRST) @ RCH

The primary objective of FIRST is to provide support to families with children who have solid tumours.

FIRST is working with representatives from the Department of Haematology and Oncology to establish an education program for parents. Educational

seminars will be held which will deal with matters 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; and
- Long term psychological and social affects on children who have received chemotherapy and radiation treatment. (Opportunities will also be given for an open forum for the discussion of issues in relation to this area.)

The seminars will be held with other relevant parent support groups such as the Children's Brain Tumour Association (CBTA).

FIRST also acts as an advocate for parents of children with solid tumours and to provide constructive feedback to the Hospital and staff. FIRST meets with parents of children with solid tumours to keep abreast of current issues and concerns of parents.

FIRST will be holding a "Picnic at the Park" in Parkville on Sunday 10 November 2002.

For more information on FIRST please contact: Brendan Case (BH) 03 8415 9234.

Our prayers and thoughts are with Edward Hunt and James Verlander who passed away recently. Their parents are members of FIRST.



CIKA Member Profile

Mary McGowan

I am one of a family of 9 from the West of Ireland. Arrived in Australia in May 1978 and started work in the Oncology Unit of the Royal Children's Hospital and continue working there today. Known around the RCH as Mary Mc. I travel back to Ireland every 18 months to catch up with family and friends.

In my younger days in Melbourne I played competition tennis, basketball and netball. I no longer play but take a keen interest in these sports. I barrack for Hawthorn in the AFL. Having the Grand Prix in Melbourne I truly love. Living in Elwood near the beach leads for a very relaxed and pleasant lifestyle, lots of places to go for Café Lattes.

I have witnessed many changes in Paediatric Oncology Nursing over the past 20 years and cannot imagine myself doing anything different. I enjoy my work. I remain committed to my job, to the patients, their families and the staff alike. I am Nurse Unit Manager in the Oncology Unit. I enjoy a collaborative relationship with a diverse group of nurses from the very new nurses to the more experienced nurses with a smattering of agency and bank nurses in between, not to mention the number of international nurses we have.

Some of those changes witnessed in the field of paediatric oncology nursing have been dramatic. The cure rate has improved but I would like to see an even greater improvement in this figure. New drugs and equipment for treatments and supportive care, improved research, improved imaging techniques and major

advances in surgery and radiation procedures have assisted in the improvement for children diagnosed today. Many of these changes could only occur thanks to the support of groups such as CIKA.

I have an active role in CIKA (Cancer in Kids Auxiliary) and enjoy the support and camaraderie of this group. CIKA as a group is very committed to ongoing support for research and parent education. Other groups I support and are involved with include LARCH, Challenge, MY ROOM, Ronald McDonald House and The Salvation Army. I was one of the founding members of the Victorian Oncology Nurses group. Today that group is known as CNSA Victoria.

In 1997 I was awarded the White Flame Award from Save the Children Victoria in recognition of my work with our children and families over the years.

I look forward to meeting with you some time in the near future at one of CIKA's fundraising events. We need the personal and corporate support to improve the overall survival rate of Childhood Cancer in this state, in Australia and worldwide.

Mary McGowan
Unit Manager - Nursing
Haematology and Oncology Unit
Royal Children's Hospital
Flemington Road, Parkville VICTORIA 3052 Australia
Phone 61 3 9345 5649 Fax 61 3 9345 6576



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.

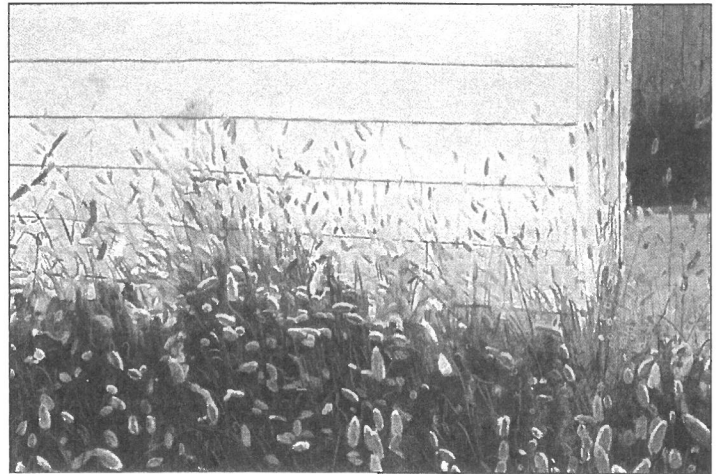
The hopes and dreams of CIKA are to stop children from ever contracting these types of cancer, but if they do, to ensure that the treatment they receive will be successful. At present the only way to move positively towards these ideals is through Research.

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!

CIKA Supporter Profile - Rick Matear



CIKA is most fortunate to have many generous supporters who come from many walks of life. One such person is well known artist Rick Matear. Rick's involvement with CIKA began with the diagnosis and treatment of his nephew for Neuroblastoma at the Royal Children's Hospital. (Rick's wife Ros is Susie Case's sister).

Rick was born in 1960 and graduated from the Victorian College of Arts in 1981. In 1982 he was awarded the Sarah Levi scholarship. Rick has travelled and painted in Europe, and lived for some time in the Grampians before settling in Melbourne. The artist spends a great deal of time at Portsea and is noted for his interpretation of the local area.

In 2002 he visited Turtle Island in Fiji and was established as Artist in Residence. Rick enjoys gardening and loves the many beachside locations he visits. Rick has exhibited numerous times in Melbourne, Canberra, Portsea, Ararat, Adelaide.

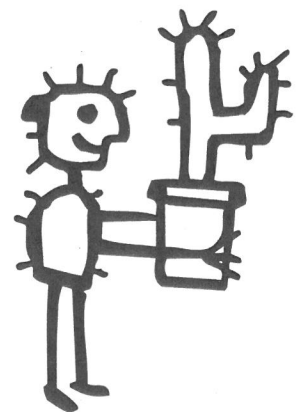
His work can be viewed at
Collins Street Gallery
411, Collins Street Melbourne
or at
www.collinsstreetgallery.com.

*These are a
few of my
favourite things'*

by Rick Matear

Rick has donated many of his beautiful paintings for auction at our annual dinner dance which has raised many thousands of dollars towards research.

To Rick and Ros many thanks for your support over the years.



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.