

Newsletter

Issue 1, 2007



CANCER IN KIDS AUXILIARY
of the Royal Children's Hospital, Melbourne

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Last November at the annual Living Treasures luncheon at the RCH, Bernie Dawson and Fay Love were awarded membership to this special auxiliary. Both of these women have held executive positions within CIKA and have given generously of their time to assist at the many functions that CIKA hold throughout the year. Bernie and Fay join past president Kay Murphy and current president

Living Treasures



Sandra Lehrer as our special members of Living Treasures. Our living treasures are made up of achievers without whom great things would never come to pass. They have devoted themselves to the Royal Children's Hospital Auxiliary movement and have had a huge impact on the history of auxiliaries. The people to be inducted have always been available and have made an exceptional contribution to ensure that Auxiliaries have flourished to become the highly respected and valued institution that it is today and ensure the future of the auxiliaries is vibrant.

dinner dance '07

It's on again!!! Your one night of the year, to assist us to "Cure Kids' Cancer Through Research". Our annual Dinner Dance will be held on the 18th August, at Hilton on the Park. This is CIKA's major fund-raiser for the year. The cancer research programs that CIKA fund, each cost \$100,000 per annum. **We need your support!**

Cancer in Kids @ RCH
Dinner Dance
Saturday 18th August 2007

Bushrangers! Themed Dinner Dance

If your business would like to sponsor or donate product for our dinner dance, we would welcome your enquiry.

Sandra Lehrer President ah 03 9696 9775
Ellen Webb Vice President ah 03 9326 0962
president@cika.org.au



CIKA was founded in April 1980 by 3 families, 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 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 providing funding for research into solid tumors, the most common group of childhood cancer. Solid tumors include Wilm's tumor, 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 childhood cancers and nothing can be done to prevent them. Therefore, the need to continue 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 is 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 fundraising auxiliaries of the RCH, Melbourne.

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



May the children rest in peace.

CIKA christmas party

The annual CIKA christmas breakup is always a lot of fun and this year was no different, except for the setting. The function was held at Steve and Sandra Lehrers place of business "The Decorators Warehouse" in South Melbourne. Surrounded by Chinese antique furniture and many unusual decorator items, over 160 committee and guests enjoyed an evening of chatting with other CIKA supporters and feasted on the wonderful food prepared by the committee. A big thank you to the very bubbly Jenny and Mario Carafa for their generous donation of beverages for the event.

CIKA members David Webb, Ted Taplin, Lyle Warwick and Steve Lehrer were presented with certificates of appreciation for their efforts within CIKA.

David has steered CIKA through the GST minefield and has attended to the job of treasurer with his due diligence. Having retired from that position David is hoping to spend more time developing a donation program within CIKA.

Ted Taplin, the elder statesman of the group, never ceases to amaze us with his constant resourcefulness with fundraising. He also manages the bookstalls and handles the distribution and collection of the shaker tins. Want one? Ring Ted 0411 597 672.

Lyle Warwick has helped increase the awareness of CIKA by shaking and moving with the development of our website and the production of our newsletter.

Steve Lehrer has been most generous in providing storage at his business and for the use of company vehicles and the unfailing support he gives his wife Sandra as president.

A raffle was held throughout the evening raising \$260 and another \$130 was generated through a percentage of goods sold on the night. Amongst the guests were members of Focus, The Inner Wheel, Briamar Press' Steven and Robert Crawl and partners, along with many other supporters of CIKA.

The evening was a great success and all involved with CIKA would like to thank the many wonderful folk who support our cause - finding a cure for children's Cancer.



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Contact us at cikanews@cika.org.au



... focus christmas party

The annual Focus Christmas party is always a very special event and this year was no exception. Enormous effort goes towards making this party an expression of the great fellowship that is experienced by the Macedon Ranges Focus Group.

Mary McGowan was the guest speaker. She represented the newly opened Childrens Cancer Center at the RCH. Mary delivered an update on the treatment of childhood cancer and an overview of the new cancer unit including the new labs at the hospital.

CIKA was well represented by its members, many of whom were winners in the monster Christmas raffle! Six prizes were donated by this wonderful group.

Focus is a social group whose various activities throughout the year raise money for their charity of choice which is CIKA. Once again a generous amount of \$5000 was presented to the CIKA President, Sandra Lehrer, and Secretary Bernie Dawson. The donation was, as always, given with great affection by the Focus members.

CIKA continues to be grateful for the generous support that we receive from all the members of Focus.



... MLC's "cooking for cash"

In Year 9 at Methodist Ladies College, some students choose to do a special program called Melbourne Term. This year, 15 girls were in Melbourne Term, and one of the activities that was incorporated was 'Cooking for Cash'. This is a cooking class where we mass produce different foods and sell them to members of staff. The money we raise goes to our chosen fundraising group, CIKA - Cancer in Kids @ RCH.

Some of the foods that we cooked this year included Choc Chip Cookies, White Chocolate and Raspberry Muffins, Creamy Spicy Tomato Pasta Sauce and Florentines. In some of the classes, we had to cook up to 45 dozen batches of food, package them and then send them off to the staff members who had pre-ordered them. This took between an hour and a half and three hours to do.

Throughout the term, we have worked hard making different foods to raise money for cancer research. We have raised about \$900, through selling our home made foods to staff members. We all had a great time, and loved taking part in 'Cooking For Cash'.

by Claire Impey and Adele Vandermeer





The annual “Old Time Wood Days” has always attracted many volunteers and supporters from all over the state.

The organisers rely on many folk for the donation of food for the weekend.

This year we approached long time supporter of CIKA, Rod Cohen from Rod’s Fruit and Veg at South Melbourne Market, to see if he could help, in any way, with our very large order for the two day weekend.

Rod in his very classic style said “I don’t have my glasses”. The list was read out and, without a blink, he said he would be happy to donate the lot. A ute load of fruit and veg was taken to the weekend by the Lehrer family.

All at CIKA would like to extend to Rod and his family a big thank you for his generous and continuing support for our cause.



Rod and Scott Cohen

Rod’s Fruit and Veg
Stand 40, Sth Melb Market
Cnr Cecil and Coventry Streets

rod's fruit and veg

old time wood days 2006

The preparations had been going on for quite some time but it really kicked into gear on Thursday the 9th November. Scott, Marni, Bailey and Ashlee had arrived the night before and we started loading tools, tents, camp ovens and gear onto the truck and tractor and horse gear onto the trailer. The caravan was prepared and Chris, Peta, Matthew, Cameron, Mikayla, Sam, Donna, Nicolas, Thomas and Lucas arrived with all their gear so we headed out to Milltown and unloaded everything and set up the kitchen and the camp. We all came back home for dinner and Chris mentioned that he would like to have a go at operating a dragsaw so out to the shed we went and got out the saw that Christine’s father used before he died. It was well covered and we had to move some junk!! After finding it we put some petrol in it and a few winds of the crank handle later, it fired up for the first time in seven years and ran like a charm, so we loaded it on with the next load of stuff.

Christine and I decided to go back to Milltown and sleep the night so that nothing got pinched, and because there were no beds left anyway and with eight kids in our house we probably got more sleep out in the bush. Friday morning we came back home and loaded up with horses, portable toilets and last minute odds and ends then we headed back to the bush and set up marquees, tables and chairs, before setting the dragsaw up for a working demo. By this time Nick and Kaye had arrived and Nick was taking a great interest in what was going on with Scott winding the crank when it backfired and he let go of the handle and it bounced right in front of Nick before hitting him a beauty on the shin and he gave an exhibition of dancing on one leg (Kaye said she can’t believe he never yelled)!

Anyway, after having some fun with that we went out and got a few loads of wood to cut the next day and put up signs and flags on the road so that the public could find us easier. By this time more helpers had arrived and were setting up tents and caravans ready for the night and the girls had cooked up a good feed to fill our bellies. After some stories and coffee we all had an early night.

Saturday morning was bright and sunny and the Kookaburras let us know it was daylight at 5.30 am so we got up and did all those last minute jobs before the crowds started arriving.

During the day there were demonstrations of sawbenching, slab cutting, shingle splitting, dragsawing, axehandle making, log snigging, log loading, damper cooking as well as a display of photos and old tools.

The lions club had a barbeque going, we were also selling food (many varieties of damper) and drinks as well as fresh veggies (which were all donated) and tickets for a great raffle.



At about 4:30 people starting congregating around the camp area, waiting for the big shave. So Rodney got up and said that we were a bit short of the \$1000 target and managed to get a few more dollars before Geoff Inkster, a professional blade shearer proceeded to cut all my hair off. Jodie Golding (a professional hairdresser) then finished the job with clippers and took the beard off. The shave raised \$1150 and I would like to thank everyone who donated to the shave, as it caused a lot of interest as well as helping a very worthy cause. After lots of photo taking (I didn't know I was so popular) we had a fabulous dinner of soup, spit roast pork, and camp oven baked venison, silverside, chicken, sausages and beef casseroles and lots of different veggies and sweets, which about 75 people enjoyed. Once again this meal is not possible without the fabulous donations of meats and veggies.

Then the entertainment commenced which was a display of whip cracking by the Thomas and Taranto families, then more yarns and drinks. After a slightly later night we all went to bed, only to wake up to showery rain.

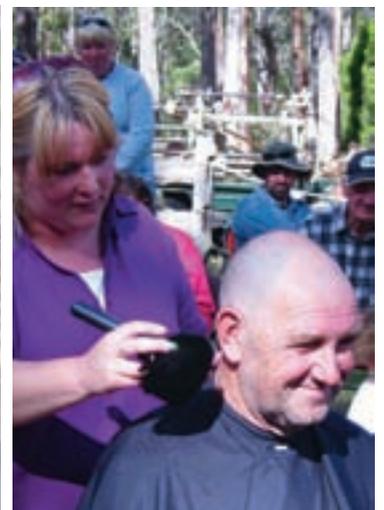
By the time breakfast was eaten the weather had brightened up a lot and the public started arriving hours before starting time so it was back to more of the same as yesterday. By mid afternoon some of the people who had distances to travel were starting to leave but the public were happy to sit around and watch and talk.

As a result of the weekend we raised over \$6000 for CIKA so it made it all worthwhile. There is a lot of work put in by lots of people and a lot of generous donations but we also have a lot of fun and as long as we can keep having fun we will keep having these days, and raising money for a worthy cause.

We would like to take this opportunity to thank everyone who has in any way helped us make our "Wood Days" weekend the great success that it was, and hope that they will ALL do it again in 2007. We would also like to invite anyone who is interested to come and see what we do "in the Bush". You are all most welcome to come for a short time, or to stay over night(s) - but just remember that we are in the bush; no power or modern conveniences, which makes it all the more fun.

Looking forward to seeing new faces (and regulars) on the weekend of November 10th and 11th 2007. Once again thanks for all the support

Andrew and Christine Duyvestyn





Ewing's sarcoma accounts for 10-15% of all primary malignant bone tumors and occurs most often in the bones of the trunk or in the mid-shaft of long bones. Ewing's sarcoma rarely occurs in children under 5 years, the peak incidence is between 10 and 15 years. It was originally thought that Ewing's sarcoma only occurred in the bone, however other tumors were found within the soft tissues and is thought to be similar microscopically.

Symptoms

The most common symptoms are increasing, persistent pain and swelling of the affected area with impairment of function. The patient usually presents with a palpable, painful, and tender swelling, rapidly increasing but quite variable in size. Depending on the location of the tumor a variety of symptoms may be reported and occasionally a fever develops.

Tests

If a child has pain in a bone an x-ray will probably be taken. If this suggests there is a tumor, a biopsy will be carried out to determine exactly what sort of tumor it is. Further x-rays and an MRI scan of the limb may give an idea of the extent of the tumor and may be done prior to the biopsy. Blood tests will be done and a chest x-ray, bone scan and bone marrow aspiration may also be carried out to investigate whether the cancer has spread to other parts of the body.

Treatment

Usually involves all three modalities (chemotherapy/surgery/radiotherapy). Intense chemotherapy is used initially to reduce the size of the tumor and enable subsequent surgery. Surgery is carried out if the tumor is in a bone, which can be removed without causing cosmetic or functional damage. Limb preservation or bone grafts are often possible. Radiotherapy may be used when tumors are not fully respectable, Since the introduction of using these 3 modalities for Ewing's sarcoma the long term survival rate has improved. Prognosis is dependant on the extent of the disease at initial presentation, size of the tumor and response to therapy, however for localised disease the disease free survival rate would be approx 50-70%

ewings sarcoma

..... fiona's story



My name is Fiona and in May of 1989, at the age of 15, I was diagnosed with a Ewings Sarcoma in my right hip. I soon began a 13-month course of chemotherapy at the Royal Children's Hospital.

The chemo treatment required that I stay in hospital for 5 nights one cycle alternating with a 3-day cycle the next and this happened every 3 weeks.

In between these treatments I tried to live as any other teenager would (minus the hair) and attended school but often ended up back in hospital for blood transfusions due to low blood counts.

The tumor responded well to the chemo, and in the December had shrunk enough to be removed surgically. Following the surgery the chemo continued and I also underwent a course of Radiotherapy at Peter MacCallum.

Finally in the June of 1990 the doctors said the treatment was complete and I was in remission. I still remember this time vividly and was so happy and relieved it was finally all over. I was most excited to have my hair grow back and despite being warned it may grow back differently it came back the same.



Well 17 years on, I am a healthy 33 year old. I am still required to attend check ups annually as there are numerous potential long-term complications from the chemo drugs I had. I don't mind going in for an hour once a year for monitoring to ensure all is okay.



As a result of spending so much time in hospital I was inspired to become a nurse and gained my bachelor of nursing. I currently work in community nursing and enjoy this.

I have been married to Jamie for nearly 8 years and we have two sons. As a consequence of the Radiotherapy I was left infertile, a fact I knew from the time of treatment. In order to have a family we chose the road of Intercountry adoption and both our sons are adopted from South Korea.

Our eldest son Mitchell Min Soo is 3½ and our youngest son Lachlan Joo Hyeok is 4 months old and has only been home with us 3 weeks. They bring us so much joy and we are so happy we were still able to have a family.

Having cancer has also had an impact on those around me. My parents Faye and Michael Love have been involved with CIKA for years and they gain satisfaction from being able to fundraise for research into cancers such as the one I had. My sister Sarah was involved in the various support groups for teenagers and siblings with cancer, and is now in the health profession too.

I don't dwell on the fact that I had cancer all those years ago but it certainly influenced the person I am today and I will never take my health for granted again.





dr. denise caruso

Dr. Denise Caruso received her Bachelor of Science degree with Distinction in Biology from Simmons College, Boston. During her university studies she worked in a research lab at the Children's Hospital Boston at Harvard Medical School and at Beth Israel Deaconess Hospital. Dr Caruso received a Research Assistantship from the National Science Foundation (USA) to perform basic research while at Simmons College. After graduation Dr Caruso moved back to her home town of Seattle, Washington and was a research assistant in the Dept of Molecular Cytogenetics at The Fred Hutchinson Cancer Research Center for two years. Dr Caruso then began her doctorate work at the University of Texas-Houston, Graduate School Biomedical Sciences at MD Anderson Cancer Center in the Dept of Immunology. She received a Pre-Doctoral Fellowship from the National Institutes of Health (USA) for studies on cancer immunology and tumor immunology. She joined the Children's Cancer Center as a Post-doctoral scientist in 2001 and has been working in the Tumor Immunology Lab on both clinical trials for patients and on basic research projects to help identify immunological defects in children with cancer, since that time. Currently Dr Caruso is preparing for the next generation of immunotherapy trials to open at the CCC, while furthering the basic and translational research projects underway. Our research interests are to understand both how to harness the power of the immune system to attack cancer cells and also to determine immune function status in children with cancer.

new children's cancer centre

The new Children's Cancer Centre at the Royal Childrens Hospital was officially opened by The Hon Mr. Tony Abbott, Federal Minister for Health, The Hon Mr. Steve Bracks, The Premier of Victoria, The Hon Mrs. Bronwyn Pyke, State Minister for Health and Mr. Doug Rathbone, Chair Children's Cancer Centre Foundation on Tuesday October 10th 2006. Charlotte Pope, a patient of the CCC, who was the face of the capital appeal, was present to join both Mr. Abbott and Mr. Bracks in cutting the cord on the opening plaque.

The new Children's Cancer Centre of excellence is situated on the 6th floor of the main hospital building. The clinical arm of the centre opens out in continuous space onto the research arm of the centre. The new Children's Cancer Centre is the only single entity in the Southern Hemisphere offering world-class care in all facets of children's cancer management including treatment, clinical research, laboratory research and public health research.



The vision of the CCCF now is to sustain and develop the Centre's world-class service delivery and ensure its ongoing position as the Australasian leader in the holistic care of children's cancer.

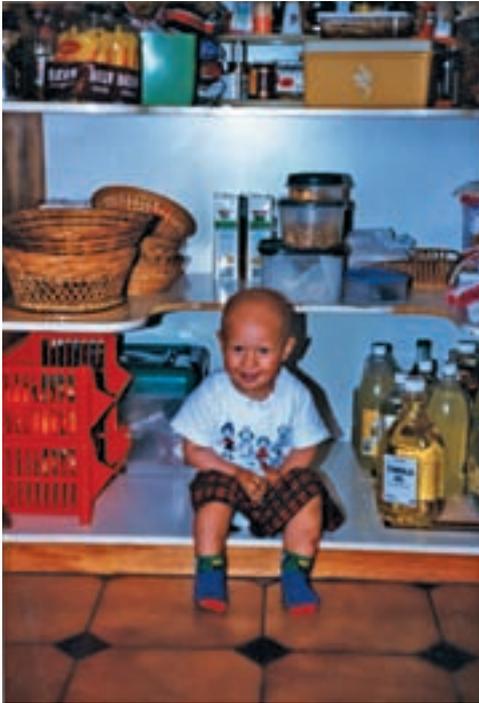
The new Cancer Centre has improved air filtration throughout the entire ward. The centre now has 27 in patient beds allowing for all patients and their families to be cared for in this dedicated cancer ward at all times. There is an increase in space for parents to stay with their child overnight. The Day Treatment area is within the ward area and is just sensational compared to the previous area. It is bright and much larger and much more comfortable. Improved psychosocial care for parents and families, including interview and counselling rooms, kitchens, laundries, bathrooms, education services and bereavement services. The co-location of research and treatment facilities of the new centre is in line with best practice.





lab open day

Thomas had cancer and now he is well, although he will continue to be monitored closely for the rest of his life by his doctors at the Royal Children's Hospital. Thomas' great outcome, is not only a reflection of the excellent care given to him by the medical and nursing team at RCH, but by the dedication of research scientists, here and worldwide.



It has been several years since CIKA has held an open day in the laboratories at the RCH, in fact we have not had one in the new facilities. It is only timely that with the opening of the new research department that we invite you, our supporters and friends, to be a part of this day.

The open day is on Sunday July 1, between the hours of 2pm and 4pm. On hand will be the CIKA executive and committee members. Research scientists, doctors and staff will be available to show you around the new facilities, explain the equipment and to give an overview of the progress they are making.

This is a wonderful opportunity to show your support to the dedicated staff of this marvelous new facility as well as seeing where the CIKA fundraising efforts are put to use.

BOOKINGS ARE ESSENTIAL for this limited experience, please contact Sandra Lehrer on 9696 9775 (ah) or Silvia on 9345 5188.

TRAIL trial project

CIKA has funded, both fully and partially, many research projects. One of these was the TRAIL trial project.

CIKA vice-president, Ellen Webb, recently contacted Christine Hawkins from the TRAIL project and this is what Christine had to say.

“Largely as a consequence of the CIKA funded TRAIL project, the Childrens Cancer Centre has comprehensively re-vamped the way tumor samples are processed, for both research and diagnostic purposes.

This new process will enable us to further pursue in vitro sensitivity testing for solid tumors - analysing sensitivity to TRAIL as well as other new agents.

As you'll understand, development of the new operating procedures was very time-consuming and involved. We had to get surgeons, pathologists, oncologists, researchers, ethics committee etc all on board, trained and organised.

While doing that, we've been researching TRAIL sensitivity and signalling in both adult gliomas and paediatric leukaemias. I know this isn't an area CIKA is directly concerned with, but I mention it because we're hoping to be able to re-start the paediatric solid tumor TRAIL line of enquiry soon.

When we do, we'll be able to take advantage of some new techniques we've developed while examining those other tumor types.”



2007 Bookstalls

- Wed 20th June
- Wed 4th July
- Wed 26th Sept
- Tues 2nd October

Young Set

14th June - 10am
Ella Latham Theatre

Lab Open Day

1st July

Auxiliaries AGM

4th Aug

Dinner Dance

18th Aug

Combined Auxiliary Meeting

5th Sept - 10am

Living Treasures Lunch

21nd Oct - 12 Noon

... did you know that....

- Each year the Children's Cancer Centre at the RCH treats around 160 newly diagnosed cancer patients under the age of 18.
- A further 1,000 children receive ongoing treatment and/or active patient follow up.
- 40-50 children in our community continue to die each year of incurable cancers.
- The Children's Cancer Centre at the RCH treats the largest number of children with cancer in Australia per year.

What is not mentioned in these facts are the mothers, fathers, brothers, sisters, grandparents, aunts, uncles, cousins and friends of these children who are all affected by the diagnosis of this terrible disease in a loved one.

CIKA has funded research for over 25 years and whilst great advances have been made in the diagnosis and delivery of treatment for our children, aggressive funding of research must continue to be a high priority. Not all cancer research projects presented, are able to obtain funding. They are expensive, an average cost is \$100,000 a year and included in this cost are salaries, equipment and very sophisticated testing procedures.

The information that is gleaned from all these research projects, is so important for the future, for all children. CIKA is very committed to continue funding cancer research but we need your support. Translated we need to fund more of these projects. So how can you help? There are several options:

- **Donate money. All donations are tax deductible and 100% of funds raised goes to research.**
- **Donate goods, for either our monthly stalls or for our annual dinner dance.**
- **Organise a function, we can help with the planning and provide volunteers for your activity.**
- **Become a CIKA volunteer, we need extra hands at many functions and we do have fun.**

Interested? Please contact:

Sandra Lehrer President ah 03 9696 9775
Ellen Webb Vice President ah 03 9326 0962



birth news

Mia Levy

30-09-06

7.2 pounds

saturday 6pm

(just after the AFL grand final had finished)

5th Grandchild for Leah & Fred

"lucky us - she is an amazing sleeper, averaging 9 hours a night... what a dream"



announcements

passing

Our condolences to CIKA committee members Bernie Dawson and Michael Love, who are mourning the passing of their mothers.

Michael's mother, Edna Love, was 89 and Bernie's mother, Mary Halloran, was 90.

Our thoughts are with you and your families.

next issue



- Research Funding '06 & '07
- Dog Parade
- CIKA Young Set
- O'Hea's Bakery Fundraiser
- Corporate Brochure
- Lab Open Day
- Dinner Dance
- CIKA Personal Development Weekend
- ... and much more!

if you would like to contribute to the next newsletter, please contact us at cikanews@cika.org.au



