



Newsletter Winter 2005

Cancer in Kids Auxilliary

www.cika.org.au

for the Royal Children's Hospital, Melbourne

President's Letter

CIKA is 25 years old, and we celebrate this year, by announcing that we have raised over \$1,000,000 since our inception. Our aim since we were founded, was to increase awareness of cancer in children and to encourage financial support to aid research in to childhood cancer.

Many individuals and organizations have helped contribute to this fantastic amount, and thanks must go firstly to the CIKA committee, and their families, past and present. Many of those involved have felt the terrible loss that cancer can have and others have celebrated the joy of a cure. Our auxiliary comes together with a common goal – that one day, **all cancer in children**, will be prevented and or cured.

In this issue, Vice President Ellen Webb, has provided a brief of the research programs that CIKA is committed to, and we will continue to support the quest for a cure for cancer. We are very fortunate to have many skilled researchers working at the RCH. To continue supporting research, CIKA needs your support – translated, we need your dollars. If you or your business would like to participate, in any of our fundraising activities, please contact us on the following numbers:

Pres. Sandra Lehrer: 9696 9775

V Pres. Ellen Webb: 9326 0962

HAWAIIAN DINNER DANCE

Proudly sponsored by

Cosmetries of Richmond

&

The Woodpeckers' Association

(representing the furniture industry in Victoria)

hawaiian paradise

Curing Cancer through Research

Date: Saturday 13th August 2005

2005

Venue: Grand Ballroom, Hilton on the Park

Time: 6.15 for 7.00pm Dinner

Theme: Hawaiian

Dress Code: After 5

Cost: \$100 per head including: 3 Course Meal, Live Band, Beer, Wine & Soft Drink

Hosted by our patron Mr Peter Mitchell

Evening includes Grand Auction, Silent Auction, Raffles and Surprises

To book phone: WK: 9353 1350

AH: 9326 0962

Fax: 9353 1375

ALL PROCEEDS FROM THIS EVENT WILL BE DIRECTED TOWARDS CHILDRENS CANCER RESEARCH AT THE ROYAL CHILDREN'S HOSPITAL

"Hillview"

AT BRIDGE CREEK

Bed and Breakfast

Heather Dixon & Kevin Dixon

0407 368 663 04 19 368 663

1527 Mansfield-Whitfield Rd,

Bridge Creek via Mansfield 3723 (RMB 3126)

P: 03 5776 9695 | F: 03 5776 9552

hillviewstation@bigpond.com

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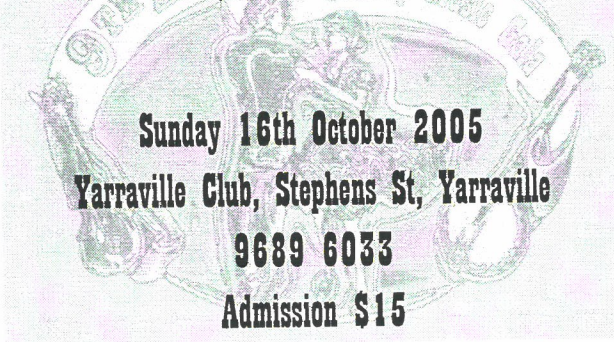
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Upcoming Events

9TH ANNUAL COUNTRY MUSIC GALA

Memorial Benefit for Kids with Cancer



It's on again folks! After a break of two years, the 9th Annual Memorial Benefit for Kids with Cancer is to be held at the Yarraville Club in Stephens St, Yarraville. The driving force behind this event is the very energetic Brian, who along with his lovely wife, raise funds for cancer research in children after the passing of their good friend, Country and Western singer, Merv Lowry from lung cancer. The Country Music Gala starts at 12 midday on Sunday 16th October for an entry fee of only \$15. Food and drinks are available at competitive prices throughout the day.

The music begins at midday with the live acts (including Donna Fisk & Michael Cristian, Billy Bridge & Rebecca Lee Nye, Shane Conners & Blackhill Ramblers, Phil Younger & The Brew, Steve Lowry & Band, Andy Dee & Chizam, The Edge Brothers, Rene Diaz) playing through until 7pm, and various raffles and other fundraising activities will take place over the day.

It is a great credit to Brian's energy and perseverance that he has managed to organise some amazing acts for this event, and all of the performers have donated their time to CIKA. This day is great fun for country music lovers and is always supported well by the local community. So put the date in your diary, have fun and support CIKA.

Sincere thanks to the following sponsors

Pantheon Confectionery 283 Hyde St, Yarraville

Kwik Kopy Footscray 65 Charles St, Seddon

Children's Palace 246 Hyde St, Yarraville

Retravision Barkly St, Footscray

Ash Novelties 34 Evans St, Braybrook

Melbourne Chef 33 Barrett St, Kensington

History and Aims

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 tumours, the 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 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.

Newsletter News

We are very grateful to member Lyle Warwick for offering to take over production of our newsletter. Lyle has been a very active member for some time, and is very busy with his monthly book stalls at RCH – all profits from which are directed to CIKA. Lyle works in conjunction with new member Damien Finn (who is recuperating after spinal surgery) to produce this newsletter. These two wonderful young men have taken on the job with great enthusiasm. Please email: cikanews@iprimus.com.au

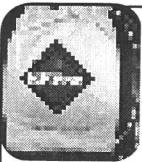
Fundraising Feats

Shaker Tins

CIKA has been distributing Shaker Tins for over a year now, and what started as a small fundraising effort, has snow-balled into a great income stream for our auxiliary. The tins have been distributed into many varied places and following are some stories about our supporters.



Ted is a very active CIKA member, doing a great job shaking the tin at the Heathmont Bowling Club – so well in fact, that the tin needs changing over every 2 months! Great work Ted!!!



Arena Brothers

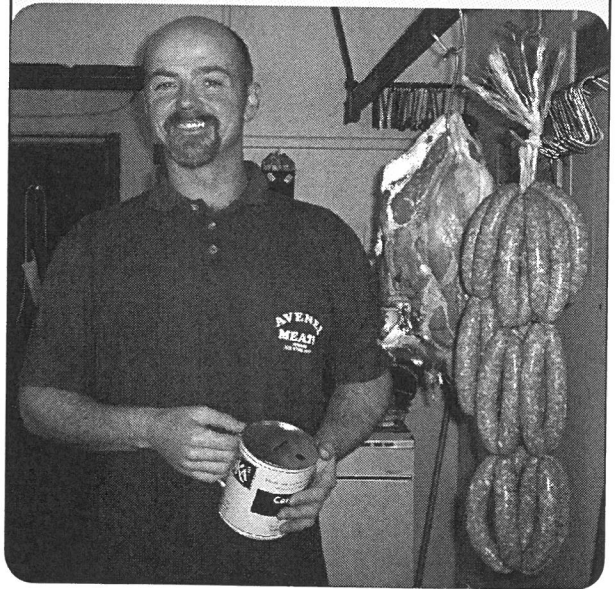
203-205 O'Hea St, Coburg 3058
(03) 9354 8070

A boutique delicatessen started 50 years ago by their father, Arena Brothers is run, 7 days a week by the four brothers: Dom, Nick, Joe and Jim. Offering a huge range of delectable foods including continental breads baked daily on-site, cakes for all occasions and local and imported deli produce such as cheeses, cured meats, pastries and more – people have been coming from all over Melbourne to buy their produce.

The family have designed and printed up Calico bags, which were on sold to customers, raising over \$600 for CIKA. The brothers are continuing their support again this year, so let's all race down, buy a calico bag or two and stuff it full with fresh deli foods from the Arena Brothers – and support those who support us.

Avenel Meats Best Butcher Shop

10 Bank St, Avenel 3664, (03) 5796 2491
Run by Scott and Neisha Reed and Scott's Dad, John, Avenel Meats supply a great range of fresh meat to Melbourne. John's old fashioned, homemade sausages are famous and the family always have collection tins on their counter. The Reeds rotate tins between different charities including CIKA, Lost Dog's Home, and the local hospital, raising further funds through donations from dog bones and scraps and customers' good will. Support Avenel and be rewarded with the freshest, old-fashioned meats in Melbourne.



Some families have used the Shaker Tins at Grown-Up birthday parties, to have them filled instead of receiving presents!



Fundraising Feats

Cooking for Cash



Each year all classes at Methodist Ladies' College choose to support a non profit organisation through social service. This program has been a feature of the College for many years and seeks to encourage girls to care for other people and to be aware that the community functions because people help each other.

Recently a group of fifteen girls chose to support CIKA and embarked upon an initiative known as 'Cooking for Cash'. The students worked as part of a team to produce and sell food products to College staff. It was a hectic time for all as the students grappled with planning and costing, preparation, packaging and delivery of food products to our customers. There were three 'Cooking for Cash' days. Chocolate Chip Cookies proved to be very popular as did Banana and Pecan Muffins but our Creamy Tomato and Bacon Pasta Sauce was the real winner - staff were very



happy to give their money to CIKA and not have to cook dinner that night.

Thanks to the efforts of the students and the generosity of staff \$600.00 has been raised for CIKA and the students have a greater understanding of solid tumours and the importance of research in this area.

Colleen Clift

Rotary Club

With sincere thanks to the Rotary Club of Grovedale for their generous donation of \$1000 in June, 2005.

We were flattered to receive this amount, which shows great community support and spirit towards the children and families affected by cancer.

Past President, Mr Joe Cordone has attended our Annual Fundraising Dinner Dances for the last several years as a guest and has obviously found the Cancer in Kids Auxiliary of the RCH to be a reputable and worthy fundraising organisation.

From all of the Children and their committed Families, we thank you very much for your kind donation.

With thanks, Jenny Carafa.

Fay's Mum

On behalf of the CIKA Committee and the R.C.H. Auxiliary Staff, we would like to extend to Fay Love and her family, our sympathies on the recent passing of her mother.

Fay's mother, Mrs Doris Lang, was a long time supporter of CIKA – for many years, she contributed her hand-made crocheted rugs and stuffed toys to our various fundraisers.

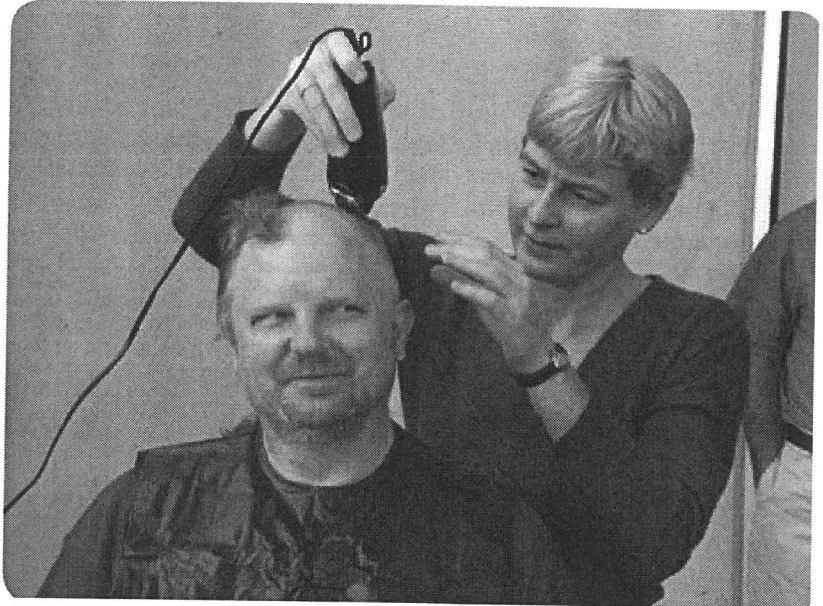
Mrs Lang had an amazing sense of humour and strength of character, which shone through and touched the people around her. At 93 years old, she was a true inspiration – our sincere condolences.

Fundraising Feats

Jim's Head Shave

On April 8th, employees of Airservices College took part in the Shave for a Cure Day in which a number of Air Traffic Control Staff shaved their head to raise money for their charities. Our own Jim Dawson took part with the motive of much thicker regrowth. He raised almost \$340, which is a fabulous effort. However after a month, he is becoming pessimistic about the regrowth.

Alexa remembering her days as a Vet, preparing canines for surgery.



Clarenavale Retirement Village

A mass of residents at the Clarenavale Retirement Village in Chelsea banded together for craft days, making all sorts of goodies. They then held a stall, selling on their amazing works to other residents and visitors as well as donating craft work to the auxiliary office at the Royal Childrens' Hospital. This phenomenal effort raised \$1110. A huge thankyou to all involved.

Macedon Ranges Focus Group

The Macedon Ranges Focus Group was formed in 1997 to fill the need for friendship and social contact for people in the Macedon Ranges area. At present there are over 60 members who regularly participate in luncheon meetings, morning coffees, excursions, trips and theatre nights. The Cancer in Kids Auxiliary has been Focus' nominated project for many years, during which time the members have donated over \$28,000 to CIKA. On Tuesday 17th May, CIKA President Sandra, Auxiliaries Co-ordinator Sue Manson, and Manager of the



Children's Cancer Centre Mary McGowan, welcomed five members of Focus to the Royal Children's Hospital. The visit was to inspect the new Centrifuge Machine that was purchased with Focus' funds. This machine is used to separate cells for cancer research, and Dr Elizabeth Algar was able to provide more information about the research being done at the Centre's laboratories. Our sincere thanks must go out to the Macedon Ranges Focus Group for their continuing support of our auxiliary.

Phoebe's Journey

I thought I'd had the worst day of my life when I was told my son had been killed, but 18 months later, after my daughter had had X-rays to investigate a chronic shoulder problem, I rang her doctor to hear the results. She gave me the 'worst case' scenario and recommended visiting an orthopaedic surgeon for follow-up tests! I heard the news on Thursday: had to wait until Monday to see the surgeon. Tuesday and Wednesday, it was tests, X-rays and biopsies; Friday was 'Chemo' in the Royal Children's Hospital for a tumour the size of a mandarine in the top of her right humerus.

Phoebe was 15 at the time. She had been at her new city school for 6 months and had just begun to settle in, make new friends and establish herself as an elite athlete. She was into everything; running, jumping, diving, gymnastics, hockey, tennis and horse-riding.

She had said that she had had trouble sleeping but I put it down to the new environment – city noises are quite different from those in the country. Her high-jump coach came to speak to me as he was concerned about the fact that every time Phoebe landed she would grimace but then get up and go for another jump!

It was not until holidays when I noticed that her posture was not as it should be and she re-iterated that her shoulder was a problem. Because she was so active and often landed on her shoulder I thought it must have been injured at some time. Things really came to a head when she began gymnastics; something she had always wanted to try. The pain was more apparent but we thought she may have strained something. When she came to try hockey, she found the pain shot down her arm! After numerous visits to doctors, physios and chiropractors, she was eventually sent for X-rays and the 'worst case' scenario became a known reality.

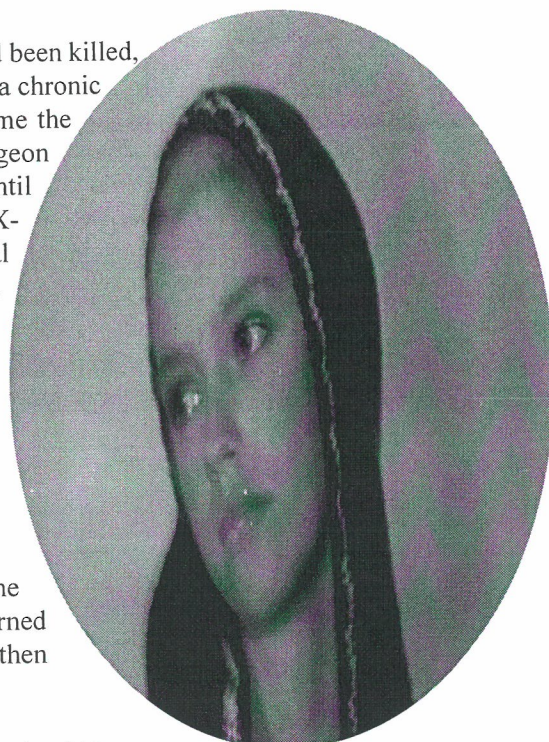
Phoebe did not know what a 'tumour' was so on one level, she was spared some of the anxiety, but she was soon to find out the full meaning. Everything happened so quickly to begin with and during that time I operated on autopilot, enveloped in a protective cocoon; doing what had to be done and forever thankful that there are people who have the skills and knowledge to be able to give us the second chance; even though we were almost destroyed in the process!

One of the hardest things during the 'chemo' sessions (before and after surgery to remove her humerus) was the fact that whenever Phoebe began to feel better after treatment, it was time to return to hospital; once again the vomiting, diarrhoea and ulcers. Her long, thick brown hair and eyelashes dropped out, grew then dropped out again (she still has times when her eyelashes fall out).

The time all her mucus membranes ulcerated was one of the most heart wrenching times. Her lips, eyes and nostrils were swollen and bloodied and her fingers and toes developed huge blisters. There is much to be said for 'Resource Plus' fed through the PEG. Without it she'd have starved.

Phoebe's greatest fear was that of losing her arm or the use of her hand and I remember so well her first words after surgery, "Look!" and she wiggled her fingers, ever so slightly, although she can no longer raise or rotate her arm. After surgery to remove the tumour and replace the humerus with a prosthesis, she had to undergo another round of 'chemo'; having to cope with it without the use of her right hand. Throughout all of this most horrific time, never once did I hear my daughter complain.

continued...



...into Wellness!



Wendy Taylor

Phoebe is one of the 'lucky' ones. She came through treatment without too many setbacks. She had no health problems before this; many of which add complications to an already extremely complex process of treatment. She has taken up tennis using her left hand; has continued to do her athletics, but has replaced high-jump with left-handed discus. She is a natural right hander! Her piano playing is restricted although she plays what she can. Diving is not an option and she no longer does ballet. She will be undergoing more surgery at the end of this year.

Along our journey to recovery there have been many children we have met who have not been given a second chance and these are why we must continue on with research into ways of catching this devastating disease before it can wreak too much havoc. It is wonderful how much doctors now know about the many forms of cancer. The different tests and imaging processes all help them to pin-point the subtle differences to enable each cancer to be given specific treatment. Continuing on with research to improve these processes is the reason why CIKA exists and by being part of this auxiliary, I and many other families who have loved ones affected by the disease, can contribute to this wonderful and valuable cause.

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 ratio 1.6:1). The aetiology (origin) 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 penetration 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, 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, 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 include Chest X-Ray, CT Scan, MRI, bone scan, etc. Collectively, the information gained provides greater understanding of the nature of Osteogenic sarcoma, therefore determining the most appropriate course of treatment.

Treatment

Treatment of Osteogenic sarcoma depends on the age of the patient, the size 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. 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.

Jacqui Robinson

Research News

CIKA Research Update

CIKA is currently funding three research programmes at RCH. The total funding committed to is \$120,000 for 2004/05 and the forecast for 2005/06 is \$160,000; with planned expenditure of \$280,000 it is vital that we find ways to raise more money! The details of the programmes are outlined below:

Research projects	Dendritic Studies	Diagnostic Testing	TRAIL Trial
Laboratory	Tumour Immunology Lab	Molecular Oncology Lab	Apoptosis Lab
Summary	Leveraging results found in earlier vaccine studies, aim is to isolate why cancer patients become immunodeficient.	Development of diagnostic testing, using molecular genetics, that will be applied to facilitate the diagnosis and monitoring of childhood solid tumours.	Develop new technique to predict responses of solid tumour patients to conventional and novel anti-cancer drugs. Novel agents to be tested include "TRAIL" (TNF-related apoptosis inducing ligand).
Outcomes expected	Reduction of immunodeficiency will enable treatment protocols to be completed on schedule. Patients comfort will be increased due to better health, costs will be reduced through less hospital admissions.	Establishment of accredited tests to enable tailored treatment protocols which should help reduce later life side effects from cancer treatment.	Establish whether TRAIL will be effective in treating solid tumours by developing new technique and analysing 50 tumours during 2005. New technique will enable tailored treatment protocols which should reduce later life side effects from cancer treatment.
CIKA Funding Commencement	2003 (earlier funding of vaccine studies commenced in 1997)	2004	2005
Expected Completion	2006	June 2005	2006
Milestones	NHMRC Funding in 2007. Developemnt of mouse models.	NATA accreditation completed Nov 2004. Automation of PCR based assays for molecular tests during 2005.	NHMRC funding in 2006.
Cancers Targetted	Neuroblastoma, recurrent solid and brain tumours.	Hepatoblastoma, desmoplastic small round cell tumour, rhabdomyosarcoma, neuroblastoma, Wilms tumour, brain tumours, Ewings sarcoma, and cancer related syndromes.	Neuroblastoma, Wilms tumour, Ewings sarcoma, osteosarcoma.
Achievements to date	Identified co-stimulation molecules. Research accepted and published in scientific journals.	13 tests for solid tumours and tumour syndromes have been established and accredited.	NA-new project.

Report

RCH Annual Report - CIKA

Founded 1980

President: Sandra Lehrer

Vice-President: Ellen Webb

Secretary: Bernie Dawson

Treasurer: David Webb

CIKA has raised \$1,000,000 since our inception in 1980. Yes, CIKA supporters need to be congratulated for such fund raising success.

In the last 12 months, CIKA has been supported by many people. Those who donated product and attended the Dinner Dance in August 2004 helped raise \$55,000, which included a generous donation of \$5,000 from the Australian Wheat Board presented on the night by CEO, Mr Andrew Lindberg. A very sincere thank you also goes to Heather and Kevin Dixon from Cosmetries of Richmond who are one of our major supporters for the annual Dinner Dance along with Loreal who have also contributed so generously with supplying product.

Other major donations to CIKA during the year included \$1000 from ACI, \$3,000 from the South Melbourne Recording Company, \$1,000 from Inner Wheel, \$1000 from Austrade, \$1,100 from the Clarendale Retirement Village, \$600 from Ladies Methodist College and \$5000 from Lifestyle Fitness of Williamstown.

One thousand dollars was received from Powercor as a result of Mr Gerrard Nolan who nominated CIKA after winning Powercor's Spirit of Excellence Award.

The Macedon Ranges Focus Group has been a long time supporter of CIKA. They have purchased 2 pieces of equipment for the laboratory at RCH.

CIKA has had success also with the shaker tins, distributed in shops and businesses. The second-hand bookstalls in the foyer of RCH have been popular raising approximately \$1050.

Over the next few years CIKA will be funding two projects. Dendritic Studies headed by Dr David Ashley in the Tumour Immunology Lab will isolate why cancer patients become immunodeficient. Secondly the TRAIL trial headed by Christine Hawkins in the Apoptosis Lab will predict responses of tumour patients to conventional anti-cancer drugs.

There have been many donations received over the past twelve months and only a few mentioned here but CIKA members are extremely grateful for each and every one. Special thanks goes to the ladies in the Auxiliaries Office for their generosity and support throughout the year.

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 or the RCH.

Permission to reprint articles from this newsletter is required from the author or the newsletter's editors.

Friends of CIKA

Report from the Children's Cancer Centre

Mr. Doug Rathbone, Chairman of the Children's Cancer Centre Foundation (CCCF) and Prof. David Ashley, Director of the Children's Cancer Centre, on behalf of the CCCF thanked those present at a recent gathering for their support in assisting the Foundation reach its goal of \$19.2 M for the new cancer centre. The CCC Development Council and major sponsors including representatives from the State and Federal Governments, The ACRF, Camp Quality, MY ROOM, AMCOR and Goldman Sachs JBWere and others were present at the Thank You gathering. The amount of \$19.2 M is for the building of the new centre. This amount allows for the bricks and mortar of the new centre with the goal now for the CCCF to raise funds for new services within the centre and for various pieces of equipment.

The Bone Marrow and Cord Blood Bank and Research Laboratories have relocated to their new facilities in the new Murdoch Children's Research Building at the West End of the hospital. The Research Laboratories of the CCC are hoping to move to their new facilities on Oct/Nov of this year.

Staff of the CCC had a strategic planning day recently to update clinical and administrative development plans for the next 5 years.

The Parents Advisory Group have produced brochures informing all families associated with the unit or their existence and what they can do to assist.

Changes in Social Worker: We are pleased to announce that Kathryn Le Maistre, Social Worker has been appointed to replace Heidi Jurisch during Heidi's one year leave. Kathryn has worked for over three years in the RCH Cardiac Unit and the Neonatal Unit and was selected from a competitive field of applicants. Kathryn will be the designated haematology social worker (the social work team covers the Clinical Haematology Unit) as well as working with liquids/BMT families.

Changes in Nursing: In May we farewelled Sonya Camerilli (Solid Tumor Nurse Coordinator) and Karen Egan (Brain Tumor Nurse Coordinator) on maternity leave and wished them well. From Monday 9th May we welcomed Anthea Neunohoffer (Solid Tumor Nurse Coordinator ext/pager 4868) and Trisha Crankshaw (Brain Tumor Nurse Coordinator, ext/pager 6975, working Monday, Wednesday and Thursdays) into these positions. Linda Burnett will be working in the role of Bone Marrow Transplant Coordinator on Tuesdays (Ext 4867).

Following the Premier's announcement earlier this month of funds for a new children's hospital there are currently many different focus group meeting be held for staff and families of the hospital to make sure that the new hospital is the best possible and meets the needs of the staff and consumers.

Paediatric Intergrated Cancer Service (PICS), as informed at the last network meeting by Jane Williamson, Program Manager, has commenced to make inroads to meet their goals and achieve the outcomes set by the DHS and the PICS management group.

For more information regarding PICS or CCCF please contact Mary McGowan:
Children's Cancer Centre,
Royal Children's Hospital
Parkville VIC. 3052 Ph: 9345 4855

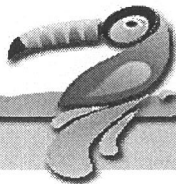
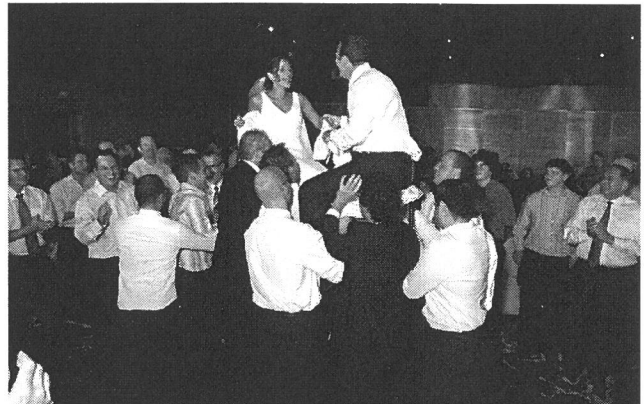
Accord Wedding



The committee members of CIKA would like to congratulate Judith and Marcel Levy on their recent marriage. Fred and Leah Bergman along with their youngest daughter Judith, are enthusiastic and most generous supporters of CIKA, and have been for many years.

Our auxiliary continues to flourish with the help of many. The Bergman family, particularly Judith, donate many hours of their company time and product to CIKA. Without their valuable assistance, the newsletter, dinner dance brochure and other printed material would not be produced.

Our best wishes to Judith and Marcel for their new life together.



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Leah & Fred Bergman, Judith & Marcel Levy, Naomi & Ben Landau, Ruth & Andrew Bendel are proud to sponsor this latest edition of the CIKA newsletter in memory of their son & brother Simon.

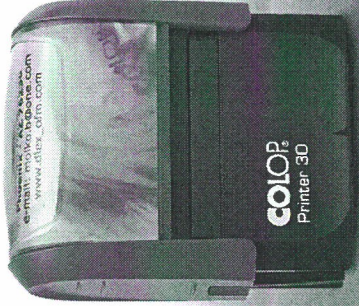
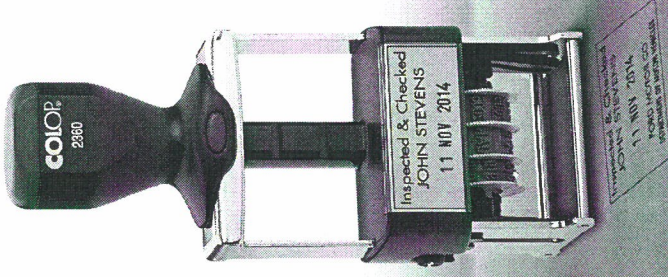
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