



Cancer in Kids @ RCH

curing kids' cancer through research

Newsletter, summer 2008



The Blue & Orange Ball

The Bayview Eden in Albert Park was the venue for our 2008 Blue and Orange Ball. Who will ever forget the stunning blue and orange banners which told the story of CIKA's children? We are very grateful to Fred Bergman of Accord Printing for his commitment to this project.

From the moment our guests arrived it was clear that it was going to be a great night. Welcome drink in hand, bargains were snapped up from the moment of arrival. Our sponsors had once again done us proud and our dedicated volunteers had no trouble in enticing our guests to purchase the great gift bags donated by Lowan Whole Foods, O'Hea's Bakery and the Flemington

Veterinary Hospital.

The Silent Auction ensured there was something for everyone and bidding was fierce, particularly towards the end of the night. Thank you to everyone who contributed an item for the silent auction. It raised over \$26,000 thanks to the more than two hundred and sixty items donated and the generosity of our guests. We also had no trouble selling tickets to the major raffle with a wide screen television being the major prize. Thank you to Ted Taplin and friends for raising the funds to purchase this major prize.

Our very valued regular guests at the ball have come to expect the annual game of 'Heads and

Tails' which starts the night. CIKA's patron, Peter Mitchell, and John Carter from Hocking Stuart yet again proved themselves up to the task of managing 450 people ready to have a great night. We don't envy them the job of running the Grand Auction; furniture packages, holidays, sports memorabilia and more brought forth competitive bidding from our very generous guests.

We thank our Platinum Sponsors Specto, Security Advisory, The Woodpeckers and Bev Marks Bedding for their commitment to CIKA by providing financial support and some of our Grand Auction items. The continued support of our Platinum Sponsors means CIKA can move forward with confidence

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President's Letter

Have you ever wondered how CIKA began? In this edition of our newsletter we have the story of one of the original CIKA families. We are indebted to these families for their commitment and vision and pay tribute to them. It is a privilege to continue their work. The original goals of CIKA have not changed. We fund research into solid tumours. At present, our focus is supporting the Dendritic Cell Study which was described in our last issue. Whilst there is great energy from within CIKA we know that we are unable to provide these funds without the assistance of our very diverse group of supporters many of whom have been with CIKA for many years. I would like to thank the many individuals and groups who find interesting ways to raise money and have fun at the same time. As well as our Platinum Sponsors, Bev Marks Bedding, Specto, Security Advisory and The Woodpeckers, we have several private individuals who give generously. Like us, they want to be part of the cure for childhood cancer. Thank you.

On behalf of all the CIKA team our best wishes for the festive season.

Sandra Lehrer, President.



History & 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 person who feels 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 for 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.

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Contact us at cikanews@cika.org.au

A message from our patron – Peter Mitchell

To all the friends of CIKA,

I don't know if it's just me, but the older I get the faster the clock on my wall whizzes around. It just seems like yesterday that I was leaving my youngest child, Harry, for his first day at kinder this year. That was back in February. Now he can't get Father Christmas out of his mind! It's only when you take a look through the diary that you realise, yes, another year has passed, and as always, plenty has happened.

Before we know it, 2009 will be upon us and one of the highlights for us all should be the annual CIKA ball. Next year we're back at the Sebel in Queens Road, formerly the Carlton Crest, so please put August 22nd in your 2009 diary now. We want as many people there as possible to raise much needed funds for research into childhood cancer. Thanks to CIKA's marvellous committee, around \$92,000 was raised at this year's Blue and Orange Ball, which was a magnificent effort. Surely we can aim for six figures in 2009, even with all the gloom surrounding the economic downturn.

To all the wonderful people who continue to support this auxiliary, we can't thank you enough for your help. To those who've never heard of us, please consider lending a hand, donating a prize for auction, or attending the ball.

Finally, may I wish everyone a happy and healthy festive season and the same sentiments for throughout 2009



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upcoming events

Stall Dates for 2009

January Thursday 29th	July Thursday 16th
February Wednesday 18th	August No stall
March Thursday 19th	September Thursday 17th
April Wednesday 22nd	October Wednesday 21st
May Thursday 21st	November Thursday 19th
June Wednesday 24th	December No stall

Paddy's Market: March 17th
Andy's market: November 26th

CIKA Professional Development Weekend

Each year the CIKA women gather together for a weekend to plan the following year's activities. In May we had a very pleasant weekend at Daylesford. We looked at the fine tuning of forthcoming CIKA events, ongoing planning of the Blue and Orange Ball and membership and sustainability of the CIKA committee. Whilst doing so we also enjoyed a little bit of pampering and good food and wine. The PD weekend allows the committee much needed time to talk and plan and ensure that our team is able to manage the demands of CIKA with work and family.



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towards achieving our goals.

Two speakers helped our audience understand CIKA from quite different perspectives. With the help of Dr Keith Waters, Katherine Alexander told her story reminding us why the work of CIKA is so important. With your help CIKA can play its part in ensuring that there are more survivors of childhood cancer who can tell their story. Later in the night thirteen year old Joshua told us the story of his efforts to raise money for CIKA. You can read more of his story in a full article in this issue.

As always, we were treated to excellent food and great music and many of our guests danced into the small hours. We are thrilled to be able to tell you, our supporters, that this year's ball raised \$92,300 – a fabulous total. Thank you to everyone who played a part.

Wendy's Story



In January 1979 my pregnant wife Trudie was admitted to St Vincent's Private Hospital in danger of miscarrying. That left me with the pleasant job of looking after our two and a half year old daughter Wendy. We had a fine time together as Wendy was an

energetic, articulate little girl and a real challenge. She was, however, complaining of a sore tooth so I took her to the dentist. He found a lump the size of a pea in her left lower jaw. Although he felt it was most likely nothing to worry about he suggested I should consult a doctor.

Our doctor examined Wendy and also thought that there was nothing to worry about, but being very thorough, he organised an appointment with a specialist at the Royal Children's Hospital. The specialist also felt there was little to worry about, but just to be sure he organised a biopsy. The results showed that Wendy had a malignant tumour (Rhabdomyosarcoma) a tumour of the muscle of her jaw.

I was in a state of shock. Unable to confide in Trudie for fear of distressing her further, I felt all at sea, but my immediate family rallied around me. Initially, Wendy responded well to treatment and went into remission. In April she relapsed, was admitted to hospital and died there on 7th of June 1979 realising our worst nightmare.

After Wendy died we wanted to support the parents of children who were in a similar situation. We had slept on the floor beside Wendy as there were no facilities for parents at the hospital at that time. We saw country people living in nearby motels, away from their friends and families, in shock and with little help from outside. The doctors and nursing staff were wonderful but could not do everything.

Jerry Gold, a family friend, suggested that we could raise funds to support families by sponsoring a book award to be called the Australian Children's Book Award. He contacted the Australian Book Council on our behalf, but this project proved too hard and was abandoned. Mary McGowan, then in charge of the cancer ward, introduced us to Lois and John Tasker

who had lost their daughter Katie, and they, in turn, brought Karen and Nigel Hayes who had lost their son Scott, to a meeting at our home where we proposed forming an auxiliary to help fund research and support families facing a similar situation to that in which we had found ourselves.



CIKA was born at that meeting. Katie loved butterflies, Scott loved to watch seagulls and Wendy had planted nasturtiums just before she was hospitalised and continually asked if her flowers had come up yet. We decided to incorporate these three symbols into the CIKA logo in their memory.

Our first fund raiser was a stall in Heidelberg Road, Ivanhoe, outside the State Bank, and raised more than expected. CIKA's first major project was to assist in the furnishing of Ronald Mc Donald house. The rest is history as they say in the classics!

After twenty nine years I still think of Wendy often. She will always remain our gorgeous two year old. I look at our two sons and thank my lucky stars that they have grown into healthy young men.

I take great pleasure in reading of the accomplishments made by the researchers funded by CIKA, and am proud that I was one of the founders of this group.

Stan Gore





Joshua raises funds for CIKA

We are proud to print this excerpt from Joshua's inspirational speech made at this year's Blue and Orange Ball. We predict he will go far!

My name is Joshua Brooks-Duncan and I am thirteen years of age. In the Jewish religion this is my Bar Mitzvah year. I completed the formalities of my Bar Mitzvah just under a month ago but the preparation for this began over a year ago. It is the transformation a child into a young adult and has its roots and customs in traditions that are 40 centuries old. The learning and training during my Bar Mitzvah year prepared me to lead the service on the 26th July and to read from the Torah, which is the scroll containing the five books of Moses.

The move into adult life involves the acceptance of responsibility for one's own actions and one of the lessons I have learned is to have consideration for other people. My reading from the Torah was all about vows and promises and I thought that it was very fitting that my Parsha, which is the portion that I was allocated to read from the Torah, was all about vows. When I sat down and actually looked through it I thought that it was a really good fit with my promise to attempt to raise five thousand dollars for CIKA.

Why CIKA? I have, over my thirteen years, known three people who have died from cancer. One of these friends was a five year old boy by the name of Edward, who spent most of his life in hospital. He was a very good friend of mine, and my family. To date, I have managed to raise more than my target of five thousand dollars.

I have actually raised six thousand and sixty-five dollars and eighty-five cents. I made this promise, I have achieved this promise and I am very proud of it.



I am deeply honoured to be able to present a check of \$6065.85 + \$2,800 to CIKA in fulfilment of my Bar Mitzvah promise.

This journey that this challenge has taken me on has been amazing and extremely frustrating. It was so hard to raise the money! I started by selling fundraising chocolates and snakes but quickly found that the fundraising company got half of every dollar that I made. I soon realised that this way was going to take too long, so I just started to ask people for donations, and this seemed to work a lot better! I was encouraged by my parents to go into houses and offices, where the people were total strangers. I learned, however, that those strangers were kind enough to help me reach my goal, and that every donation, however small, helps. Collecting this money was hard but by doing it I am now able to stand here tonight and give this speech to you.

Now, as it turns out, I still have two boxes of snakes! I would like to auction these snakes tonight. I have sold OVER one hundred eighty boxes so the two that remain are extremely special. I am selling them as a set. The money that I raise from this auction will contribute to my grand total, which as I mentioned earlier is sitting on six thousand and sixty five dollars and eighty five cents. I want, from someone sitting here tonight, two thousand dollars for these boxes, who will give it to me?



Joshua's Story – a mother's perspective

Joshua chose to raise the money for CIKA because of his connection with Edward Taplin and the Taplin family, who have been close friends of ours for many years. Since Edward passed away we have had a strong interest in CIKA and tried to support the organization along with the Taplin family. Since Joshua was a small boy, CIKA has always been spoken about at home and so it was almost a natural choice for him when he was considering raising the money. Another reason why Joshua chose CIKA was because another very close family friend, Brian Giddons, who used to take Joshua fishing and with whom he built and flew model aeroplanes, died of cancer in January 2008. Brian lived in the country and would stay with us when he was receiving his treatment at Peter Mac or Monash so Joshua was really affected when Brian passed away.

Once Joshua made the commitment to raise the money he decided that selling chocolate bars and jelly snakes would be effective. He searched the internet to find out the most appropriate organisation for the purchase of the confectionery and used his own savings of thirteen years to make the purchase. He realised at this point that he had to sell them once he had bought them as he was paying for them himself and definitely did not want to be out of pocket! The lollies he sold were \$2.00 per packet and



he had to pay \$1.00 back to the company. Once he received the 1st delivery of lollies, Joshua loaded up the shopping trolley and went door knocking around the neighbourhood. Most of the time he achieved a sale, but he discovered that not all people responded in a "giving" manner and he was quite surprised by this! Robert or I would go with him and would wait by the front gate and sometimes some of his school friends would walk with him.

Robert and I also gave Joshua a contact list of business people that we know. By this time Joshua had decided that it was going to take too long to raise the money by selling his wares door to door so he went all out with our business contacts! We left it to Joshua to make the contact and explain what he was doing and ask for their support. They were all very receptive to the idea of Joshua's quest and took some of the boxes of chocolates and snakes and placed them in their staff canteens. Every fortnight or so Joshua would either

telephone or email to see how sales were progressing and if there was money to be collected. On many occasions you would see Joshua pushing his trolley up the city streets to either deliver boxes, top up boxes or collect money. We took Joshua with us to a business function Robert and I attended around this time and he was invited to come up on stage and speak about what he was doing and for whom. From this he also raised a considerable amount of money. Joshua also just started to ask people to donate money as time was marching on and August was getting closer! Whilst he was fundraising Joshua set up an excel spreadsheet and continuously tracked all the money and goods that went out and came in and from whom.

I believe Joshua learned two important things from his experience – how generous and receptive some people can be, even perfect strangers, but also how others can be dismissive of your best efforts. Prior

to the night of the ball Joshua had decided that he would auction his last 2 boxes of snakes to try and top up his donation and it was decided that he was going to ask \$2,000 for the snakes. When Edward's mother, Tina, heard about this she and her husband Bill decided to attend the ball, which was very special for Joshua. Joshua was somewhat nervous about giving the speech, but once he got started he became very comfortable. Who would have thought that the response to his snake auction would be so overwhelming? Together Joshua and John Carter from Hocking Stuart managed to sell the boxes of snakes for \$2,800! Joshua walked off stage donating a total sum of \$8,865.85. Once Joshua had sat down and the all the items for the auction had been sold people who were attending the ball were coming over to Joshua and giving him extra donations. Ultimately the total was over \$9,000. The response from everyone in the room to Joshua's efforts was just so special and the number of people who approached Robert and me to say what a great job Joshua had done was overwhelming. Both Robert and I were so proud.

Lorraine Brook

Research Update



I am pleased to provide the latest update of the project that CIKA is currently funding. We have now commenced the second year of our three year minimum commitment, with an annual commitment of over \$100,000. This project was chosen as our main focus as it builds on previous work we have done, it has the potential to benefit all types of solid tumours and it has potential to be of benefit to current patients.

From a personal perspective I am pleased to see us being able to offer this as a treatment option to current patients at RCH. Although it was over 11 years ago, I can vividly remember desperately looking for clinical trials for my son Brian, as we had been told there were no viable treatment options for him here in Australia. At that time we were spending most of our time at RCH, and I would ring overseas specialists from hospital payphones, dropping countless coins into the phone as I agonized over leaving Brian in his bed in the ward, and trying to settle my infant son Andrew in the pram. As Brian was too ill to meet any of the eligibility criteria for any of the trials, participating in a trial was not an option for us.

CIKA is committed to curing kids' cancer through research, and we hope that this project will directly help current patients, and be part of the research that eventually leads to the cure. Please join me in supporting Dr Caruso in the vital work that she does.

Ellen Webb, CIKA Vice President

Active immunotherapy for children with advanced malignancies

BRIEF DESCRIPTION OF PROJECT

Building on our previous results, and those of others around the world, we are employing advanced technologies and methods to produce and administer dendritic cell based anti-tumour vaccines. Children with recurrent solid or brain tumours and newly diagnosed neuroblastoma stage 4 are eligible for this study. Patient's tumour lysates are mixed with their dendritic cells to produce cellular immunotherapy products that are then able to produce specific immune responses against their own tumours. We will monitor their responses to vaccines at the end of study to determine in vitro markers of response correlated with clinical responses. This is a phase I study of safety and feasibility as primary objectives, with secondary aims to investigate efficacy. Our goal is to recruit 54 patients in total, with 18 patients for each cohort of patients; newly diagnosed neuroblastoma stage 4, recurrent solid tumours, and recurrent brain tumours.

PROJECT DURATION

June 2007-June 2010

DESCRIPTION OF PROGRESS IN CURRENT PERIOD

To date we have 10 patients enrolled to the neuroblastoma cohort which is well above our predicted recruitment at this stage in the trial. Of those, we have treated to completion, two patients, each receiving 6 vaccine doses. We have had two patients enrolled on the recurrent solid tumour study, with one patient completing her immunotherapy receiving 4 vaccine doses. Finally we have three patients enrolled to the recurrent brain tumour study, with none of them well enough to receive vaccine. The vaccines have been very well tolerated by the patients and have had no side effects of note.

Dr Ashley has been away much of this year on sabbatical, but has recently returned, we expect that recruitment to the brain tumour and the solid tumour cohorts will increase dramatically with his input.

FUTURE PLAN FOR NEXT TERM

The future of the trial includes making vaccines for newly enrolled patients and administering vaccine doses as patients achieve stable disease and are well enough to receive them. We expect that the next year will be very busy with increased numbers of new patients. We will continue to follow all patients clinically and scientifically to further improve the therapy.

Dr Denise Caruso

CIKA Annual General Meeting

The annual general meeting of Cancer In Kids @ The Royal Children's Hospital was held on the sixth of October in the Historical room.

Sue Manson, Auxiliary Co-ordinator, who presided over the meeting, expressed her thanks for the great work that the CIKA team performs throughout the year. In a year of economic downturn CIKA has again, through its dedication, maintained a consistent level of funding for research projects.

The results of the election of office bearers were:

President: Sandra Lehrer
Vice President: Ellen Webb
Secretary: Louise Learmonth
Treasurer: Jill Tremonti

The CIKA executive would like to express their thanks to the outgoing secretary Ms Judy Benholz. Judy has made herself available for many CIKA projects this year and has helped to streamline the position of secretary. We also thank Silvia Vargu who has managed the position of treasurer with two small children and her work with the RCH. Both Judy and Silvia will remain as committee members.

We would also like to thank Mr Harry Benholz who has donated many hours to film the varied activities with which CIKA is involved. We appreciate the time

that Harry has given and will have more about this in the next newsletter.

Leo Vargu (CPA) from Vargu and Associates donates his time to the annual auditing of the CIKA books. Despite the demands of a busy practice and a young family Leo is always happy provide this assistance.

The 2009 CIKA Team

Fred & Leah Bergman
Judy Benholz
Jenny & Mario Carafa
Julie & Sam Casilli
Colleen and David Clift
Bernie & Jim Dawson
Dr Anne Dynon
Andrew & Christine Duyvestyn
Dean Duyvestyn
Damien Finn
Sandra & Steve Lehrer
Louise Learmonth
Faye & Michael Love
Mary McGowan
Ruth Murray
Ted Taplin
Wendy Taylor
Jill Tremonti
Silvia Vargu
David & Ellen Webb

CIKA People



You might remember reading in our last newsletter about Nicole's work for CIKA in her role at Allure Designer Stationery. As well as doing fabulous design work for us she has created something even more wonderful. Nicole, Simon and Taya welcome with love the arrival of Mikayla Bella Dawson on September 22. CIKA wishes them all the best at this special time.

Should you need any design work undertaken we can recommend Nicole. She can be contacted by email at Nicole@allurestationery.com.au



CIKA Supporters



Methodist Ladies' College - Kew

Students at MLC have actively supported CIKA for the past four years. Junior Secondary School students enjoy working on the Build a Basket project which involves small groups of students in creating a gift basket for the Silent Auction at the ball. Over the years more than seventy baskets have been produced. The students really enjoy this opportunity to be involved. They know that their donation to CIKA enables our guests at the ball to also donate – a double opportunity for giving and a lot of pleasure when the baskets are taken home!

Each year a small group of year nine students take part in Cooking for Cash where they run a small business catering to staff at the College. Treats prepared by the students include Raspberry and White Chocolate Muffins, Chocolate Chip Biscuits and a great pasta sauce ready to heat and eat. Marketing, packaging, cooking and delivery is managed by the students and to date over \$3000 has been raised in this way.

Emily Graham – Nhill College

Emily Graham, niece of Sandra and Steve Lehrer, used this year's annual fundraising day at Nhill College to put together a stall for CIKA. Emily baked cookies, made scoobies (creative plastic key chains) and also presented RCH auxiliary products for sale to the Nhill community. As well as having a fun day, Emily raised over \$160.00 for CIKA. Thanks, Emily!



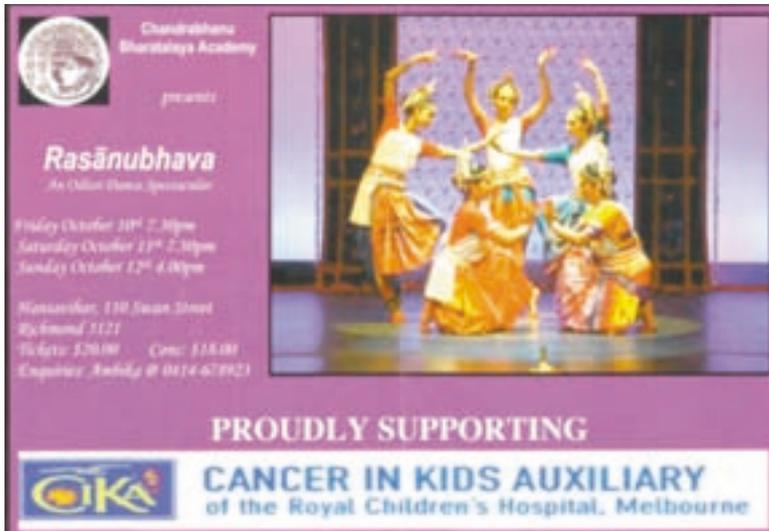
Kangan Batman TAFE - Broadmeadows

Alan Bolton is a staff member at Kangan Batman TAFE in Pearcedale Parade, Broadmeadows. This year he offered dancing classes to staff members. Basic ballroom dancing is a great recreational activity and gives confidence when at social dances or other events.

The classes are held every Wednesday evening and many staff members take part. Dance styles include Modern, Latin American and New Vogue styles. The classes are free but the participants donate a gold coin for the one and half hour lesson. Staff decided to donate the proceeds and when asked where the money should go, it was immediately suggested that CIKA be the organisation supported. I was introduced to CIKA last year when I attended the CIKA ball in August 2007 with my very good friend Kostas Kyrifidis of Security Advisory who is also a sponsor. This year we have been able to donate over \$500 to CIKA and hope that it helps the important work being undertaken.



CIKA Supporters



Chandralaya Bharatalaya Academy – Richmond

The weekend beginning Friday October 10th saw the first of three outstanding performances of Rasānubhava – An Odissi Dance Spectacular. For those of us not familiar with this art form it was a revelation. The performance contained many stories told through dance and the energy, precision and beauty contained within was amazing. CIKA members were invited to explain CIKA to the audience and sold raffle tickets on the night. We thank the Academy for their commitment to help CIKA's work.

John Carter, Hocking Stuart - St Kilda 0416 056 705

John has been a supporter of CIKA for over four years. An experienced real estate agent with Hocking Stuart in St Kilda, John believes that knowing the area and meeting people are what makes his work so enjoyable. As a long term resident of St Kilda John knows what attracts buyers to the area and how vendors can best market their property. John never gets tired of the thrill that comes with auctioning a property and achieving the best possible price for the vendor. At the annual CIKA Blue and Orange Ball John generously donates his time to run our Grand Auction and achieves excellent results for us too.



Platinum Sponsors

