



Cancer in Kids Auxiliary

of the Royal Children's Hospital, Melbourne

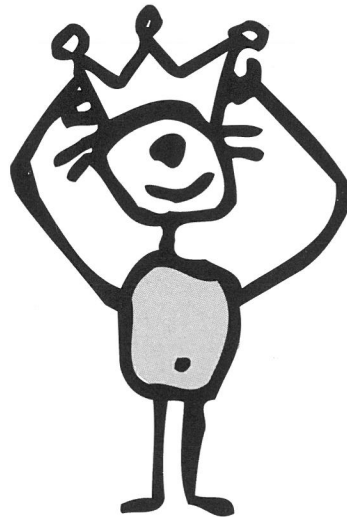
Newsletter Summer 2001



Greetings from our patron...

"It's a privilege to be involved with a group of people working so hard to help the auxiliary. Thanks to their dedication it has been a very happy and rewarding 12 months. Now we need to answer the challenge in 2002. A very happy and healthy Christmas and New Year to all our volunteers and supporters."

Peter Mitchell, Seven News



From the Editors

Dear Families and friends of CIKA,

In this issue we focus on Wilms' Tumour. Thank you to Andrew and Chris Duyvestyn for sharing their story of how Wilms' Tumour effected their son Dean.

As we draw to the close of the year of the volunteer the committee would like to say a big thanks to all the many families, friends and organisations who support CIKA. The active committee of CIKA is small and our projects are quite large. We depend on the generosity of time, skill and money from many individuals and organisations. Throughout the year we have met many wonderful people who have supported us in a number of ways.

So to all the volunteers who support us; Seasons Greetings and Best Wishes for 2002.

Ellen Webb 9326 0962

Sandra Lehrer 9696 9775

Facsimile 9372 0635

SALE, SALE, SALE!

We have casual tops for sale which are suitable for all ages; teenagers, Mums, Dads, Gran and Grandad. Designed by "Jen San", two illustrious CIKA members, they are available in various colour combinations in a choice of 3/4 Sleeve tee or Polo shirt. The tops are **Australian made** and sport the great CIKA logo. So don't miss this limited opportunity to

make a fashion statement or pick up a Christmas present for that special someone.

Support CIKA and spread the word. Ring Sandra on 9748 4944 or AH 9696 9775 to place your order now. Prices start at \$20.

Thanks to Qualitops of 466 Smith Street, Collingwood who gave us a fantastic price.

This issue of the newsletter was generously sponsored by

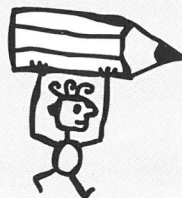


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Focus

A number of individuals and groups have been supporting CIKA for many years. One group that stands out is the **Macedon Ranges Focus Group**. The group was formed in 1997 to fill the need for friendship and social contact for people in the Macedon Ranges. The aims of Focus are to aid old friends and make new ones across all age groups, to provide assistance to those in special need and to provide financial support to one particular project each year. They have supported CIKA since January 1998 and have donated \$11,500.

Focus holds a luncheon meeting once a month at which a guest speaker provokes thought and discussion amongst members.

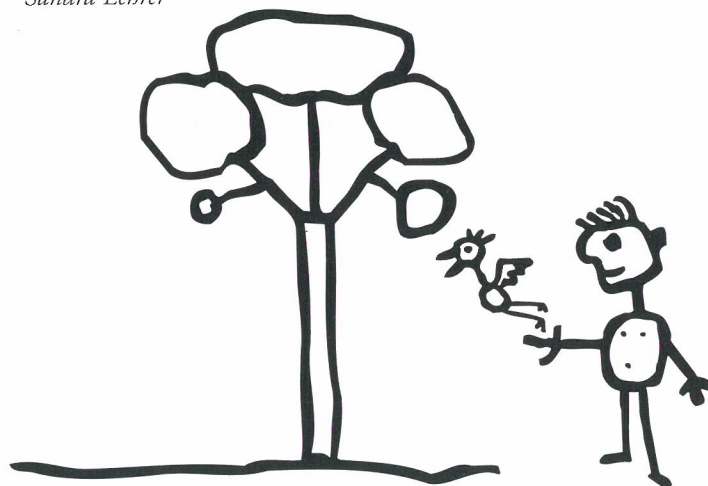
The guest speaker on June 15th was Mary McGowan, sister in charge of The Haematology and Oncology ward (6E) of the Royal Children's Hospital. Mary, equipped with studies and copious information, delivered a profile of childhood cancers. For many of the members the issue of childhood cancer was very personal and they welcomed the updated information given to them.

Focus has committed to the purchase of a library bookcase, which will be installed In 6 East. The library will be used by parents to assess information about their children's diagnosis and treatment.

I attended the luncheon along with Bernie Dawson and Suzi McConville. We were made to feel most welcome and as a group Focus lives up to its aims.

To the President, committee, and members of Focus-thank you for all the support; emotional and financial that you give to CIKA.

Sandra Lehrer



New CIKA Brochure

The new CIKA brochure was unveiled for the first time at our annual dinner dance. The evolution of the new brochure has been a slow process but the end result has been an overwhelming success. The following people were instrumental in the achievement of this project:

- Committee member, Sandra Lehrer, who first suggested the need for a new brochure 18 months ago. She steered the project with great enthusiasm and kept it going no matter what.
- Lou Inness did the initial design and format. Lou has been involved with the Multiple Sclerosis Association for many years and her expertise with wording and format was a tremendous asset. Thanks Lou for seeing the project through to the end.
- Dino Cellini picked up the project when the going became very tough. Dino is a special friend of CIKA and we are very grateful for the many hours he put in to secure support for the brochure.
- John Pierrakos gave most generously of his skill and time to complete the design of the brochure.
- Brian Campisi, Managing Director of Invickim Pty Ltd, provided the link to the printer for the brochure.
- Steve Reichart, Managing Director of Blue Print Dynamic Print Services in Port Melbourne, printed the brochure.
- Gary Wilson at Paper Point, Coventry Street, South Melbourne provided the paper.
- David Rogers, CEO of Challenge, who gave CIKA permission to use photos from "The Children of Challenge". Challenge's mission is to bring fun to the lives of kids with cancer and their families.
- Our patron, Peter Mitchell, who had to juggle his hectic schedule to fit in the photo shoot.
- Jacqui Robinson, clinical nurse coordinator for solid tumours, provided the medical statistics.

Extra special thanks go to Jenny and Mario Carrafa. Their son Thomas is on the cover of the brochure. The decision to put his photo in the brochure was not easy. Thomas was diagnosed with neuroblastoma in October 1997 and completed his treatment in May 1998. He has been in remission for since then and we are hoping and praying for the doctors to one day pronounce him cured.

All of the above was given freely to CIKA. As we are a volunteer organisation we rely on the generosity of the community and this was very evident in the production of the brochure.

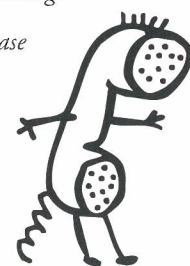
All the information in the brochure was verified at the time of printing.

If you need brochures please ring Ellen 9665 7272

AH 9326 0962 or

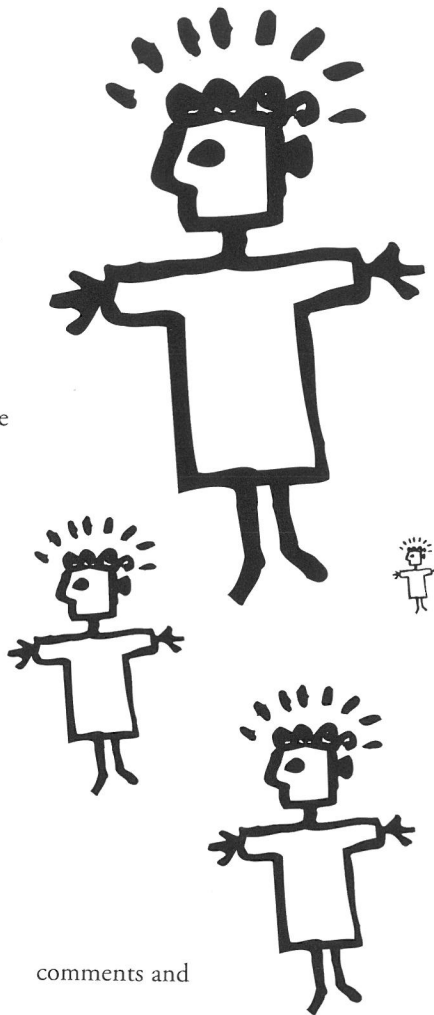
Sandra 9748 4966

AH 9696 9775.



Our Special Volunteers

The CIKA committee did a great job planning their Annual Dinner Dance at the Carlton Crest in July of this year. The event went very well and was profitable for our group. We had a great time enjoying ourselves and mingling with the attendees and left the running of the silent auction, raffle etc in the capable hands of Suzy, Naida, Deb, Laurence, Jason, Bryan and Bronwyn our kind volunteers. Suzy Jones and Naida Gordon, the auction Queens, did the book side of things and I believe did a great job. Thank Goodness Suzy was not drinking because she had to drive to Maldon at 1.00 am. Deb and Laurence Cornish and Jason Alexander had offered to assist with other tasks on the night along with some more volunteers. Lo and behold when three volunteers pulled out Deb said "no worries - I will ask my neighbours Bryan and Bronwyn". Bryan's skills as an ex-security officer came in handy. To the volunteers, CIKA would like to say a big THANK YOU. You made our job a lot easier and your



comments and suggestions will assist us greatly in the planning of next year's event. Hopefully you guys will come back and help us once again and we will have a few more volunteers to relieve the burden somewhat for you. Have a nice Christmas and all the best for next year and look forward to having you join us again at the Carlton Crest for another fun fundraising night.

Mary McGowan

And many happy returns

Well what a night!!!! On 21 July CIKA conducted their 4th annual dinner dance at the Carlton Crest. After many months in the planning, we celebrated our 21st birthday. Founded in 1970, it certainly was appropriate that we celebrate and party we did.

Once again the evenings proceedings were well led by our Patron Peter Mitchell. With major auction items up for grabs and spirited bidding encouraged by our auctioneer Tim Fletcher, the fundraising efforts got off to a great start. The silent auction display of over 100 items gave everyone the chance to go home with that 'special something'. And then the raffle with in excess of 50 items gave even more chance to win a prize.

The entertainment by Bob Valentine and band had everyone on the dance floor and perhaps singing a few lines from music of 21 years ago.

The evening profited approximately \$33,000 and for that, CIKA are very grateful.

Of course these occasions do not occur overnight and without a great deal of effort. To my committee, thank you does not say it all. To our very generous sponsors Cosmetics - (Heather and Kevin) THANKYOU. The take-home bags were overflowing and very much appreciated by all. To all people who assisted in any way to make the night so successful - please accept our heartfelt thanks.

A big thank you to Peter Mitchell for keeping the evening moving, to Tim Fletcher for his enthusiastic encouragement to bidders, Bob Valentine for the 'memories' and to Carlton Crest for fine food and drinks.

Keep the 10 August 2002 free and come back to the Carlton Crest and help us celebrate again.

Kaye Murphy
President

Wilms' Tumour



Wilms' tumour is also known as nephroblastoma, as it arises in the kidney. Almost 90% of all kidney cancers are rare forms of childhood kidney cancers: clear cell sarcoma of the kidney, malignant rhabdoid tumour of the kidney, and occasionally renal cell carcinoma. Wilms tumour is the second most common type of all childhood solid tumours, not including brain tumours. It can occur in children of all ages, but most are under five years of age. The tumour usually develops in only one kidney. Rarely it occurs in both kidneys.

Wilms tumour is believed to result from mutations or changes in certain genes. The involved genes and other genes located nearby are not only associated with Wilms tumour, but several other rare conditions. Wilms tumour is strongly associated with several congenital abnormalities, notably anaridia (a rare condition, in which there is incomplete formation of the iris of the eye, can lead to blindness) and with some specific syndromes such as Beckwith-Wiedemann syndrome.

Symptoms

Many children with Wilms' tumour have no symptoms at all and may be diagnosed when the child is evaluated for other

reasons. Often a parent will notice a lump or mass in the child's abdomen, or the child may complain of abdominal pain. Sometimes the child may pass some blood in his/her urine.

Tests

An ultrasound examination and a CT scan of the abdomen will be done to show the position of the tumour in the abdomen. A CT scan of the chest will also be done to find out if the cancer has spread to other parts of the body. This is known as staging, for example, Stage I refers to a tumour which is limited to the kidney and is able to be completely removed surgically. Other tests may be necessary, including blood tests to check liver and kidney function.

Treatment

Treatment may be with immediate surgery to remove the kidney and the tumour. It is perfectly possible to live with only one kidney. Alternatively, chemotherapy may be given first to shrink the tumour so that the operation is easier.

At the operation the surgeon will examine the whole abdomen and will take specimens of lymph glands, to determine if they are

affected. The best treatment for each child with Wilms tumour is dependent on told by a pathologist. Depending on the type of cells seen the tumour is said to be either of favourable or unfavourable histology. The vast majority, approximately 95% of children diagnosed with Wilms have cells with a favourable histology.

Treatment is dependent on the extent of the tumour. Chemotherapy may be given for up to one year at regular intervals. Radiotherapy may also be needed.

Treatment of Wilms tumour in children is one of medicines success stories. Due to improvements in surgical techniques, chemotherapy drugs and radiation, 90% of children with Wilms tumours will be cured.

Follow up care

Most children recover very quickly from the operation. Follow up care involves regular clinical examinations, abdominal ultrasound's and chest x-rays.

After the first few years the focus of follow up changes to monitoring growth and development and other possible later side effects of treatment.

(Jacqui Robinson)

Wilms' Tumour and our family - Dean's story

Dean was born on 8 February 1974. He was a normal healthy two year old when one day our lives changed forever. Dean was having trouble doing his trousers up so he asked his grandmother to do it for him, when she did them up she noticed a lump in his stomach. We took him to the doctors; our local GP took one look at his tummy and after a bit of poking and prodding told us that he thought he had a growth on either his kidney or his spleen.

He sent us to a paediatrician in Hamilton and after numerous people checking him out and having an X-ray, we were told to head straight to the Children's Hospital as he had a very large growth on his kidney.

We were at the Children's Hospital very early the next morning, after more tests and x-rays he was operated on for what seemed like hours. The surgeon removed one of his kidneys and eighteen inches of his bowel, the kidney had a growth on it the size of a cantaloupe, which had burst before they could get it out, so they had to flush his lungs just in case some of the cancer cells had managed to find their way there.

We spoke to the surgeons straight after the operation, and they told us that Dean had a Wilms' tumour of the kidney and hopefully they had got all of the cancer. Dean had weeks of chemotherapy and four

weeks of radiotherapy; he went from a very robust little boy to a frail child in a very short time. Fortunately Dean was one of the lucky ones-he has made a complete recovery and is now 27 years old, married, and has a four year old daughter. He still has the same size waist he had as a two year old, has a few problems with his back and has high blood pressure, but considering what he went through as a 2yr old we are very fortunate to have him still with us, which is due to the great work of the oncology department of the Royal Children's Hospital.

Christine Duyvestyn
(Dean's Mum)

First timers raise \$\$\$\$s's

In July this year I was contacted by Wendy at the Auxiliaries office and advised that a lady *Corina Molinaro* wanted to run a fund-raiser for CIKA.

I agreed to meet with Corina at the hospital the next week and discuss her plans.

Corina, a friend of hers and I met the following week and Corina explained that she was doing a course which required that she organise an event. She had chosen the RCH and after speaking with Wendy settled on CIKA as the recipient of any funds raised.

We discussed a dinner dance with an auction and when Corina left I thought that it was possible that she felt she had taken on something more than she could manage. I didn't hear anything for a few weeks and then out 'of the blue' *Elda Conte* called and said that she was now organising the evening. Elda explained that Corina was required to hand the

arrangements on to a friend to continue.

On Saturday 27 October in company with Ellen and David Webb we attended at Diana Receptions in Sydenham.

Approximately 150 adults and children were present and what a great night everyone had. The food, drinks and music were good but the highlight of the evening was the auction. A number of items, both small and large in value had been donated and were ably sold to willing bidders by *Claude Pannunzio*. Claude is a qualified electrician cum maintenance man (Quick Smart Maintenance ph 9442 9699) but did a fantastic job as an auctioneer (and it was his first time). He prised just over \$4000 from people's pockets and the end result for the night was a little over \$6000.

We at CIKA are very grateful for this effort from Corina, Elda, Claude and a number of extended family and friends. Our efforts to continue to fund research can



only be buoyed by the likes of these community minded people. Importantly, they have gained confidence to take into their professional and personal lives and also have a good sense of community participation.

Kaye F. Murphy

President

Editors note: *Elda, Corina and Claude have formed the organising committee for next years dance!!*

Update to MAGNETIC FIELDS IN MELBOURNE SUBURBS "RELAX: THERE IS NO DANGER" First printed in autumn 2001

We have been advised of some points of clarification to the above named article that was printed in the autumn 2001 newsletter.

The following statement "this finally demonstrated that the risk of acute lymphoblastic leukaemia does not increase with increasing electromagnetic fields energy levels" should be read as the opinion of the author, David Ashley. David has the following points to add:

"This finding has been challenged but the whole story of electromagnetic fields and cancer remains tenuous at best.

It is my opinion that the most likely explanation for these observations are pure chance or some type of confounding environmental factor linked to but not electromagnetic fields.

A fact that is never overt in all the media hyperbole is that even if this small effect was a "real" thing it would

account as a cause of leukaemia in only one child in the whole of Australia about every two years. Put the other way it is certain that more than 99% of childhood leukaemia is not caused by electromagnetic fields. There is no evidence that any other form of childhood cancer is linked to electromagnetic fields."

The Editors

Solid Tumour Parent Group

After discussions with CIKA and individual parents of children diagnosed with a solid tumour, the Royal Children's Hospital Haematology/Oncology Unit invited a group of parents to form a committee to look at the support needs of parents and families. Associate Professor David Ashley, Jacqui Robinson (Solid Tumour Nurse Coordinator) and Nicole Tokatlian (Social Worker) have meet with the group twice in the last three months, with a further meeting planned for October. The main aim of the Committee is to look at ways to support parents of children with a solid tumour. To this end, the goals that have been set are (1) the establishment of a parent support group and parent support network (2) the establishment of a parent advisory committee that will give feedback to hospital staff

about the experience of parents (3) the coordination of educational sessions for parents and families (4) dissemination of information about the above by way of contribution to the CIKA newsletter.

The committee plans to have a close working relationship with CIKA and acknowledge the valuable work that they are doing.

At the last meeting, a President (Julie Sweeney), Secretary (Brendan Case) and Treasurer (Ana Verlander) were elected.

We will keep you updated of further developments. Please contact me or Jacqui (9345-5522) if you would like to discuss the above or have any suggestions. We are still looking for a name for this group and would certainly appreciate any ideas.



Nicole Tokatlian

Social Worker

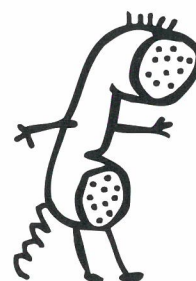
Team Leader –

Haematology/Oncology

Social Work Team

Royal Children's Hospital

Ph 9345-6111



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Cosmetries has been a great supporter of CIKA/ Please consider using them for all your hair and beauty needs

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32A Clayton Rd, Clayton 9545 5400

Shop3/441 Sydney Rd, Coburg 9354 8975

Shop 44, Keilor Downs Plaza, Taylors Road, Keilor Downs 9364 1555



Disco nights!



On Friday the 9th of November, Mill Park Heights Primary held a disco to raise money for CIKA. Ten Year 6 students gave up their lunchtimes to organise it. We got two students from each grade 6 class to make the committee. Those students were Krysten Donaldson, Ryan Ackland, Alex Bitzilis, Sarah Blake, Nadia Elshaar, Gulrez Kaur, Adam Houlihan, Daniel Tasevski, Tracy Puc, and Nathan Karas.

We played all kinds of songs for the threes, fours, fives and sixes and for the prep ones and two's we played Bob the Builder and Hi Five. Everyone enjoyed it. All of the students were invited to attend, for 50 cents, with around 650 students arriving.

We got the idea to raise money for CIKA from Jenny Carafa, a teacher at our school. She is part of CIKA and her son had cancer.

It was a big success, with \$330.35 raised. All of the money will go to CIKA to help them find a treatment for solid tumours. A special thanks to all of the people who donated money to CIKA.

Ryan Ackland and Krysten Donaldson, *Mill Park Heights Primary School*



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.

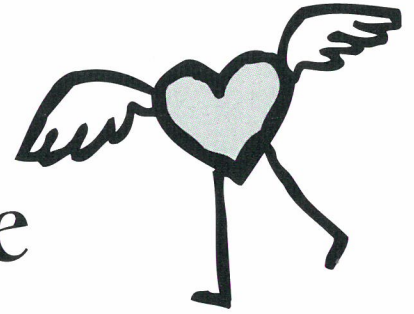
The hopes and dreams of CIKA are to stop children from ever contracting these types of cancer, but if they do, to ensure that the treatment they receive will be successful. At present the only way to move positively towards these ideals is through Research.

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!

A gift of Love



CIKA would like to offer you the opportunity to recognise your friends and loved ones and help CIKA at the same time. We have honorarium and memorial cards available to send out on your behalf.

Contributions may be given in memory of a loved one or in honour of special occasions such as Christmas, birthdays, anniversaries, etc.

Contact Ellen Webb (9326 0962) for more information.

MERV LOWRY MEMORIAL BENEFIT

Congratulations to Brian Allen on the success of the 7th Merv Lowry Memorial Benefit which raised over \$3,000.

Brian founded the event in memory of his friend Merv who lost his battle with cancer and has raised in excess of

\$21, 000 over the last 7 years. CIKA member Julie

Cassili said "an enjoyable day as always. The Yarraville Club is a great venue and you could tell that everyone was having a great time."

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.