



## A CARNIVAL ATMOSPHERE FOR THE 2013 CIKA BALL

For many of our supporters the CIKA Ball is the highlight of the fundraising year; a time to catch up with friends and to reaffirm an ongoing commitment to CIKA.



This event is in its fifteenth year and, this year, the CIKA Committee tickled youthful memories by putting together a wonderful night with a carnival theme.

On arrival at The Pullman in Albert Park our guests were greeted with a glass of champagne and an enticing array of over two hundred silent auction items. Thanks to **Smart Amusements** the choice of activities included spinning wheels, beat the clown, toss the coin, throw the sticky ball, hoop the wine and wobbly mirrors gazing. Madame Charlotte-Anne was telling fortunes and the balloon lady was kept busy making shapes for parents to take home to lucky children.

The evening was, once again in the very capable hands of our patron, **Peter Mitchell**. Our guest speaker for the evening was Chair of the Children's Cancer Centre, **Jeremy Smith**, whose son was diagnosed with a rare form of rhabdomyosarcoma in 2007. He talked about the gruelling experience of diagnosis, surgery, chemotherapy and follow-up care that was needed. We thank Jeremy for sharing this journey. This, and the video of children undergoing treatment was a reminder of why we continue to fund research into childhood cancer.

...continued pg 2 >

## PRESIDENT'S LETTER

CIKA has a small band of volunteers who constitute the committee but these volunteers could not, on their own, generate sufficient funds to support CIKA's research projects. In recent years CIKA has been fortunate in developing relationships with individuals and groups who devise and run events that support CIKA. With a small amount of support from CIKA these friends have raised a significant amount of money in 2013. In this issue of the newsletter we highlight some of these friends. We cannot sufficiently emphasise their importance to CIKA. We know that this is the way forward for CIKA, spreading the load (and the satisfaction) of raising around \$250,000 per year for paediatric cancer research. Also, special mention must be made of Jenny Compton in Heathmere, Carmel Loats near Stawell, Kay Rawlinson in Rosebud, Jacinta Sutton in Euston (NSW), Emily Graham in Nhill, and the many others that knit, craft, sew, collect, produce and pack goods for CIKA to sell at our stalls and use in our raffles. To you we send our gratitude; you are indeed part of the CIKA team. Finally, if you, or any of your friends or colleagues, are interested in helping us with product please contact Sandra on 0409 369 853

Sandra Lehrer,  
President

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The Grand Auction was in the very capable hands of **Will Fowles** who is not only a terrific showman but a great auctioneer. His command of this event was reflected in the financial result!

This year we had the absolute pleasure of presenting the award of CIKA CHAMPION to two longstanding CIKA supporters. This award reflects the dedication and the spirit of care and compassion shown these individuals. **Sharron Markovic** has been supporting CIKA for many, many years. She is a committed hard working supporter who has dedicated her time to the very popular CIKA stalls at the RCH. Along with Ruth Murray, many hours have been spent each week sourcing product, then wrapping and presenting it, often at considerable financial cost to themselves. **Bob Valentine** and his band have been with us since the Ball started, they never fail to please the crowd. Bob loves a good party and he always has the CIKA crowd up and dancing. We would like to acknowledge his generous support of our event. Events such as this would not be a success without the many wonderful people who support us.

A very special thanks also go to Robert and Steven of **Briamar Press**. The print work they have done for us over the last year has been extensive and the work they did for us at the Ball was fantastic. The volunteers on the night did a sterling job. It is always very busy, but each year they turn up and ensure things go so smoothly; our thanks to all of them. So many people donated to help the night, food for volunteers, table centre pieces, photography, dress ups (thanks **MLC**) and much, much more. It is only with all your help that we can run this event.

The spirit of giving was reflected in the combined amount raised by the silent auction, the raffles, the photo booth, the sale of show bags, and our new table game, 'Truth' - close to \$60,000. This is a great result in difficult times and we applaud our many supporters who continue to have faith in the work that the CIKA team has been doing since 1980.



**THE 2014 CIKA BALL** will be held at  
The Pullman Hotel on Saturday 16 August.  
Put a note in your diary now!



### BENDIGO CUP-DAY LUNCH RAISES OVER \$1500!

The inaugural Bendigo Cup Luncheon took place at the All Seasons Hotel in Strathdale on Tuesday September 24th 2013. The event was a sell-out and attracted guests from Melbourne, Sunbury, Macedon and Bendigo. The organizer of the fundraiser, local woman **Ruth Edelsten**, said that when she first put forward the idea for the lunch she had hoped for about forty guests but was overwhelmed at the response and had to close bookings at 100.

Guests heard from the mother of **Abigail Pickrill** (seen here with Ruth Edelsten) who is currently receiving treatment for cancer at the RCH. She is doing well but her mum detailed the journey and pressure that the family is trying to manage. CIKA committee member **Sala Rubinstein** hosted the hat parade which was terrific fun and CIKA is most grateful to Ali from the **Bendigo Hat Shop** and to all the volunteers who modelled the hats. We are also most grateful to all the CIKA friends who were most generous with donations for the raffle. The event raised over \$1500.00 and with that comes the promise of another lunch in Bendigo next year. A big 'Thank you' to Ruth, Sala, Linda, Fred and the many others who made the day such a great success.



## BESSIEBELLE QUILTERS

CIKA is most fortunate to have a huge groundswell of support in rural Victoria and I am always delighted to receive boxes of product that have been made with love by these volunteers. I met with Glenys Sharrock, a member of the 'Bessiebelle Quilters', at the annual Wood Days at Milltown and we were able to revisit the beginnings of this group.

The Bessiebelle Quilters were formed in 1992 by Glenys Sharrock and Carmel Jasper with the idea that it would be a social group where new quilting skills would be learned and shared within the group. The group met monthly and, as their skills progressed, a decision was made to produce goods that could be donated to charities. Some of the charities that the group support are:

- The Southern Right Quilters Exhibition
- Make A Wish
- Peters Project
- RCH- general wards
- CIKA

It is always a delight to have the goods delivered from this group and we would like to acknowledge and thank them for the wonderful support that they give, not only to CIKA but to many other charities.



*Standing L-R: Glenys Sharrock, Gail Down, Pat Bunworth (donator of the fabric), Norma Hamilton, Jan Petersen, Cheryl Hill, Heather Rowbottom*

*Seated L-R: Carmel Jasper, Diane Cowland*

## STALLS

The stalls that are held monthly at the RCH continue to be a steady source of income for CIKA. Over the last few months there have been some changes in the organisation and running of the stalls. We are working on a new look and will have some great new product for 2014.

Some familiar faces will be back on stall duty this year: Pat, Lyn, Lois, Yvonne, Sandra and, of course, our new managers, Pam Phillips and Sala Rubinstein.

We are always on the look-out for any donated product for these events. If you can help, or if you would like to join the volunteer team, please contact Pam Phillips on 0418 344 223 or Sala Rubinstein on 0411 515 119.

Pam Phillips and Friend of CIKA Lois Staunton have also been involved with several external stalls to raise money for CIKA. Pam and Lois have spent many days collecting and wrapping donated product. Lois has great dressmaking skills and her beautifully crafted children's clothes are highly sort after.



## CIKA'S VERY SPECIAL "JAM LADY"

**Margaret Greenwood** and her husband **Geoff** have supported CIKA for many years. Margaret is known as the 'Jam Lady' and has donated tens of thousands of dollars to the RCH through the sale of her homemade jams, sauces and aprons. In fact, she is now heading for the \$150,000 mark.

Margaret has shown great dedication and is a welcome sight when she sets up her stand at the RCH. Thank you, Margaret, for being part of the CIKA team. We welcome the donation of small clean jars, fruit and sugar. If you can help please contact us at [president@cika.org.au](mailto:president@cika.org.au)



## ARRESTING RECIPES

CIKA has supporters from many different walks of life who devise and run fundraising events for us. Beverley Garratt is one such person. For many years she has been a passionate advocate for the work we do.

In July 2012, the South East Metropolitan Region Community Work Team and the Jesuit Community College commenced discussions around developing an innovative unpaid educational community work program which would provide women on community-based correction orders an opportunity to learn new skills whilst working together on a project that would have meaningful benefits for the community.

The women in the Stir the Pot Program worked extremely hard to produce the Arresting Recipes book and were highly motivated to give their very best in their efforts to contribute to such a worthy cause.

There was also a section in the book where the participants wrote their stories and talked about what they gained from attending this program. Arresting Recipes could not have been created without the dedication and commitment of the women involved in this special unpaid community work project and their 'we can do this' attitude was commendable. Not only did the women learn new skills, they also took on the challenge of planning, organizing and providing the MC coverage for the official launch of the book, which involved presenting to an audience of sixty people. This was something that they had not done before and highlighted the increased confidence and self-esteem gained by the women.

Ms Gabrielle Levine, Regional Director -South East Metropolitan Region Department of Justice, officially launched the book at the Drum Theatre in Dandenong on 4th October 2013. The Drum Theatre kindly donated this fantastic venue for the launch, which was also attended by

Councillor Angela Long, Mayor of the City of Greater Dandenong and Magistrate Fleming, Coordinating Magistrate, Dandenong Magistrates Court.

This was a fantastic experience and achievement for everyone involved. Five hundred copies of the Arresting Recipes cookbook will be sold through the Jesuit Community College with all proceeds being donated to CIKA.

The 'Arresting Recipes' cook book is now available for purchase at \$10 plus postage and handling from CIKA President, Sandra Lehrer, so call her on 0409 369 853 or send an email to [president@cika.org.au](mailto:president@cika.org.au). All proceeds will go to CIKA.

*Footnote: The project was runner up in the Educational Institution Program. The certificate was presented at the annual Corrections Victoria Community Work Partnership Awards ceremony at the Melbourne Cricket Ground on November 20.*



### METHODIST LADIES' COLLEGE: YEAR 7 'BUILD A BASKET'

The year seven 'Build a Basket' program has continued to grow since its inception in 2005. It has provided many hundreds of items for the silent auction at the annual CIKA Ball over the past few years, raising well over fifteen thousand dollars as a result. The students enjoy this program a great deal, learning about CIKA and then putting their creative talents to the test. The knowledge that their giving continues once the baskets are finished is immensely satisfying for all involved. The staff at MLC are very committed to the 'Build a Basket' program and much of its success is due to their ongoing support.

### METHODIST LADIES' COLLEGE: COOKING UP A STORM!

'Cooking for Cash' is an annual initiative of a group of year nine students at **Methodist Ladies' College** in Kew. For the past eight years a small group of students has elected to raise money for CIKA by creating a small catering business. Meals that they cook in the Home Economics Department are available for purchase by staff during term four. With the \$1500 raised by just sixteen students in 2013 the total has now reached well over ten thousand dollars.



### THE NATURALLY COOL BIG BAND

The Naturally Cool Big Band joined forces with the **Gisborne Peak Winery** in the Macedon Ranges for an afternoon of food, wine, music and fellowship on Sunday January 19. Special thanks must go to the band for donating their services and choosing CIKA to be the recipient of monies raised on the day. Our hosts Bob and Barb Nixon were most kind in providing an idyllic setting for this sell-out event which attracted more than two hundred guests. We appreciate their support.



The raffle of wine donated by Gisborne Peak was very popular and, whilst the total for the day, is not yet known, we believe it will be around the \$2,500. A great day out in a beautiful setting with a fantastic band which includes CIKA member Jim Dawson. A well-run fund raiser. Thank you to the CIKA members who attended and all those involved.

*The Naturally Cool Big Band will again be supporting CIKA in April at the Hedge Farm at Carlsruhe. Watch the cika website for more information.*



### FOCUS CROWN LUNCHEONS

Undeterred by Melbourne's unseasonably cold weather, a very determined group of women gathered at the Crown Casino to enjoy a lovely lunch and to raise money for CIKA.

This was the second of the twice-yearly Crown luncheons organised by **Lesley McKibbin**, an avid cyclist, member of Focus and a terrific supporter of CIKA.

As with most of their previous events, this was a sell-out, with seventy guests coming by train and bus from country Victoria. Lesley was thrilled that the event raised \$1143.00 for CIKA and our special thanks go to her for all the work that she does for us.

We are also grateful to everyone who braved the weather in order to attend.



### MORE FROM FOCUS

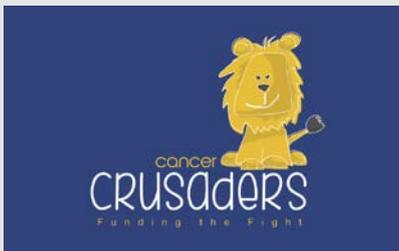
The Focus Christmas Lunch is held the second week of each December. It ends the year for the group, giving members the opportunity to reminisce and, with great pride, to present the result of their year's fundraising.

The Macedon Ranges Focus Group was initially formed as a social group with the support of charities being a secondary purpose of their meetings. It was felt that, after personal involvement with two families whose children had battled cancer, their energies could be directed towards cancer research and so began their support of CIKA in the late 1990's. Raffles are conducted at each monthly get together, a huge trading table heralds the advance of spring, and Focus member Lesley McKibbin with her boundless energy organises her 'Crown Lunches'. The result of all this work is a wonderful Christmas cheque for CIKA. This year we were overwhelmed by the amount: \$9,000.00! This was such a surprise and reflects the kindness and generosity of this wonderful group of supporters.

Once again former Focus president **Gwen Kakafikas** and her husband **Andy** presented a cheque for \$1000.00 on behalf of their company **TBS Australia**. Gwen and Andy have been long time supporters of our work and we appreciate the continued recognition they give to CIKA. Bronwyn Judge who was formerly a member of Focus has made her home in Bermagui but loves to get back to Victoria to celebrate Christmas with her Focus friends and on behalf of her family presented a personal cheque to CIKA.

All these women reflect the spirit of community kindness and care. As CIKA president Sandra Lehrer said in her speech, it is much more than the money that they donate to CIKA; it's the passion they have for the research we fund and for the constant support that they give us.

On behalf of all the CIKA committee and all of the CIKA families, our thanks and best wishes to all our Focus friends.



## CANCER CRUSADERS @ RCH

**Ruth and Peter Murray (Ausinc)** have been generous supporters of CIKA for many years. They have both had a high level of involvement with the annual CIKA ball and supported many of our fundraisers. In November each year they have hosted the annual Christmas Market at their home. Ruth and Sharron Markovic have been shakers and movers at the monthly stalls that are held in main street at the RCH and have raised the bar in the standard of goods sold to the many parents, children and staff that support these events.

An opportunity has arisen for Ruth, Peter and Sharron to establish their own auxiliary that will encompass their friends and the business associates that live in their area. The aptly named "Cancer Crusaders" started late 2013.

The goal of "Cancer Crusaders" is to raise funds for Children's Cancer Research at the Royal Children's Hospital. They have not announced their first project yet but some serious money has been raised to support this.

We would like to acknowledge the support of Ruth, Peter, their family and friends, including Sharron, for their kindness and generosity towards CIKA and its members and we wish them every success as we walk alongside one another in the quest to assist in the cure of childhood cancer and to improve the outcomes of children diagnosed now.



## CIKA SUPPORTER - ELAINE GREGORY

At this year's annual Focus Spring Luncheon a surprised Elaine Gregory was presented with a certificate of appreciation from the Royal Children's Hospital by CIKA members Bernie Dawson and Sandra Lehrer. Elaine was a founding member of FOCUS and was instrumental in the establishment of CIKA as the recipient of all fundraising by the Macedon Ranges Focus Group. Elaine has served on the executive for many years including a stint as treasurer. She has decided to reduce her Focus work load but still remains a very active member. We acknowledge the great support that Elaine has given to CIKA and wish her well for the future



## CIKA SUPPORTER - DR KEITH WATERS

Dr Keith Waters retires from the RCH.

CIKA was proud to be represented at a retirement function for Dr Keith Waters on Monday 28 October. Nine members of the CIKA team joined with a large crowd of well-wishers to celebrate Keith's outstanding contribution to the treatment of childhood cancer sufferers.

During his working life, Keith has seen the cure rate rise from virtually zero to over eighty percent. He has touched the lives of thousands and we all wish him well for a long and happy retirement.





### WOOD DAYS 2013

From the moment you drive off the highway to enter the Old Time Wood Days, you feel like you are stepping into another era, it is like walking into an old time market village, leaving behind the hustle and bustle of modern life to escape for just a few hours or if you are lucky, a few days.

Every November **Christine and Andrew Duyvestyn** generously open their private “bush block” at Milltown to over five hundred visitors with the sole aim of raising as much money as possible for CIKA, an organisation that they are passionate about.

Everything for the weekend is donated, which is such the country people’s way – from the food for the Saturday night feast, to the raffle prizes and auction items, to the time and effort of the exhibitors. This year’s Wood Days raised over \$25,000 but as all Wood Days participants know, so much more is achieved. It is generosity that encapsulates the whole vibe of the weekend, a true sense of community and working together towards a common goal.



We had the extremely good fortune of meeting Christine and Andrew through our Finn’s love of horses. Every day during our summer holidays at Port Fairy he would be there going for a ride on the coach and it was from these early beginnings that we have forged a very special friendship. Andrew and Christine are such wonderful friends and role models for our boys and we are forever grateful that they invited us in to their world.

There are many things that we love about the Wood Days weekend. The family atmosphere and chance to slow down, watching all of the kids exploring and playing in the bush environment, sitting down and chatting to the person next to you over a cup of coffee and homemade cake or biscuit or hot fresh damper that has just come out of the coals. Everyone is happy and sociable, interesting and interested. It’s getting back to basics, a “no-tech” weekend where you rediscover that the simple things in life really are what make you happy. It’s the opportunity for our “city kids” to live the life of “country kids” for just one weekend. Getting dirty, climbing trees, the freedom of roaming through the bush, hunting and gathering, learning and exploring, making new friendships and rekindling old ones.

The atmosphere is relaxed, with visitors watching the exhibitors work their craft, and where the kids can discover how things were done back in the old days. There is nothing more satisfying than watching a tree stump being manually chopped down and turned into a tangible post and rail fence to keep the horses in. The noise of the tractors, engines and saws are incessant but in a productive way, coupled with the voices of the workers and visitors sharing tales.



The star attraction for us is seeing Tiny and Lofty working in their natural environment, pulling massive tree logs up from the bush or giving the kids a ride on the sled. The clanging of their chains, the thunder of their big hoofs and their strong powerful bodies working is a sight to see. And let's not forget Andrew being the Pied Piper with children following him down the bush track to see what things they may discover!

The three course meal cooked on the enormous fire pit for over 150 people on the Saturday night is truly a unique experience; all orchestrated by Christine and her many helpers. Once the guests have enjoyed their meal, the old time band starts up and people gather round the tree stump candles that Andrew has set blazing earlier in the day. Enjoying a camp fire under the stars in a peaceful bush setting is truly a magical experience, an ahhhhh moment.

But the thing that we love the most is spending time with the inspirational Duyvestyn family and their extended CIKA family and friends. Andrew and Christine and the CIKA crew are to be commended for the mammoth operation involved in the setting up of this wonderful weekend for all of us to enjoy and I'm sure everyone who visited on the weekend would join with me in thanking them for their efforts. If you do ever get the opportunity to pull in off the highway to discover the wonders of the Wood Days weekend, you will not be disappointed. We are already looking forward to Wood Days 2014!

Thank you to the Grant Family, long-time Wood Days participants, for this report of the event.

*The 2014 Wood Days weekend will be held on November 8-9. For more information ring Andrew 0427 090 356.*

### WOOD DAYS CALENDAR

The CIKA Committee is indebted to the entrepreneurial energy of **Daniel Burke (Graphic Impressions)**, the driving force behind the production of Wood Days calendar each year.

After the event, **Sam Taranto** delivers photos from the weekend and Daniel, along with members of **Spicers** (paper) and **Marvel** (book binding and print publishing) set about the design, print and publishing of 2000 calendars. All the design work, paper, printing, production and binding is donated. Although we do not know many of those involved, we thank you for your contribution that adds so much to the Wood Days weekend. Each calendar sells for \$5, so the 2000 copies contribute another \$10,000 to childhood cancer research.

*Please note that the 2013 Wood Days calendars are almost sold out.*

*If you have not yet obtained one, ring Christine on 0427 101 559 to secure your copy.*



## CIKA FUNDED RESEARCH - TRANSLATIONAL RESEARCH CENTRE

When considering projects to fund, CIKA looks for projects that:

- Conduct research into multiple types of solid tumours;
- Have the potential to provide benefit to current patients;
- Build on research we have previously funded.

Thus, in 2013, CIKA committed to a three year project for the establishment of a Translational Research Centre in Paediatric Solid Tumours, to be conducted through a partnership between The Royal Children's Cancer Centre and Murdoch Children's Research Institute. By working together we hope to realize our common vision, that through research we can not only improve treatment, but also discover a way to prevent childhood tumours.



When CIKA was formed in 1980, patients diagnosed with a solid tumour were given a standard treatment protocol. However, no two childhood tumours are ever identical, and we now know that differences in these tumours require different treatment. Current approaches to treatment offer only crude 'tweaking' of a few generalized treatment protocols. We know that placing children on standard treatment when they will not respond decreases their chances of overall survival – but alternatives simply do not exist today.

Recent advances in mapping human DNA, has brought us to the cusp of a technological revolution. This revolution will enable us to see the 'real time' generation of such a map for all patients, and will allow unprecedented insights into the tumour type, aggressiveness and response to different treatment protocols, all of which will inform an individual's treatment to maximize chances of a favourable outcome. The challenge is to discover predictive biomarkers that identify which children are unlikely to respond to conventional treatment to assist in timely direction to more aggressive regimens or clinical trials.

This projects key goals are:

1. To establish a state-of-the-art solid tumour biobank and parallel cell line facility
  - to provide valuable resources for the identification of molecular markers associated with tumour development, or predictive of outcome,
  - the pre-clinical testing of novel therapies directed at specific cellular pathways disrupted in cancer;
2. To use the molecular information to prospectively assist in timely clinical trial enrolment of patients unlikely to respond to current treatments and to attract novel studies.

Banking of tumour tissue is essential for research into childhood tumours, as researchers need access to sufficient numbers of samples of these rare disorders. The RCH CCC tumour bank is one of only a few in the country that routinely collects such tissues for these purposes, and currently houses over one hundred samples. CIKA was involved in the initial creation of this tumour bank; a 2007 report from the research head stated "Largely as a consequence of the CIKA funded TRAIL project, the Children's Cancer Centre has comprehensively re-vamped the way tumour samples are processed, for both research and diagnostic purposes. To realize our research goals the existing tumour bank needs to be transitioned and brought to a standard that will facilitate sample and knowledge sharing with other centres nationally with equivalent tumour banks, to coordinate research projects between teams. This project is helping to build solid foundations on which to implement this 'personalized' model of care within the RCH Melbourne in the very near future.

*Tumour bank coordinator: Louise Ludlow*

## CIKA FUNDED RESEARCH - LEICA MICROSCOPE

The CIKA coach drive provided funding for the purchase of a Leica microscope and accessories in May. It was very quickly put into action and in November we received this report on its use in examining the morphology of cells derived from tumour biopsies.



*The Leica microscope provides the best resolution we have yet had for the visualisation and characterisation of tumour biopsies and derived cell lines. Already since acquiring this system we have been able to explore the phenotype (physical characteristics) of twenty tumour-derived cell lines obtained from culturing of primary CNS tumour biopsies at the Royal Children's Hospital, Brisbane. Previous studies carried out in our lab had revealed a tremendous level of molecular difference between these cell lines and the primary tumour from which they were derived. This has profound implications for their future utility, given that the primary purpose of deriving such cell lines is to explore the potential of novel therapeutic agents to kill cancer cells.*

*Using the Leica microscope we have been able to demonstrate that 19/20 cell lines examined had cellular characteristics reminiscent of connective tissue (fibroblast) cells rather than neural type cell morphology. This would suggest that the cells grown in culture were actually derived from the supporting brain tissue (stromal cells) surrounding the tumour mass, rather than the tumour itself. This important piece of equipment has therefore helped us to understand why the majority of tumour-derived cell lines do not 'look like' primary tumour when examined at the molecular level. Importantly, it provides an additional screening step to ensure that we only test novel treatment approaches on those cell lines that really are tumour derived.*

*Our findings have been communicated to our colleagues in Queensland who are modifying their protocols for cell line generation accordingly to try to prevent stromal cells from taking over the tumour culturing in future. The significant benefits to date arising from the use of the new Leica microscope for children at the RCH (Melbourne) is that we have been able to develop novel protocols for cell line generation from RCH tumour samples which will result in better quality pre-clinical model cell lines for testing novel drug therapies on local samples.*

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