

Children's Cancer Centre news

Issue 2 June 2008

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The Cytotoxic Cyclists

Dr Peter Downie and his merry band of cyclists took part in the annual Murray to Moyne Relay Bike Ride. They rode from Echuca to Port Fairy, a total of 540 km in 24 hours. This year's team consisted of parents, Bob Lyons, Cath Walters, Doug Haig, Steven McConchie, Jenny Haig and Rodney Anderson. Staff who took part this year with Peter were Rachel Conyers, Roxanne Dyas, Lisa White, Pratiti Banopadhaya and Lea Noad. Other team members included Cliff Mitchell, Craig Lawson, Denis Charles, Derek Lyons, Frank Federici, James Nowak, Kristina Cockbill, Mark Taylor, Martyn Hiley, Michael Murphy, Paul Quinton, Zane Richards, Ian and Pam Dewar, Peter Noad and Raelene Dal Santo. In the words of Peter it was a 'magical experience' for everyone. The weather was favourable and the CCCF were very pleased that the team raised \$44,000 this year. Thanks also to University Food Group, Darren Surrey, Hydralyte, Renta 2 Way, The Lawford Family, Bike Now and Fast Track Australia Fleet Services for their support. If you or any family member are interested in taking part or supporting us next year please contact mary.mcgowan@rch.org.au



The **Royal Children's Hospital** Melbourne

Murdoch Childrens Research Institute
Healthier Kids. Healthier Future.

Southern Health

CCC Psychosocial Team

When your child is first diagnosed with cancer there is often an 'information overload' in regards to the many services available to offer support during all phases of treatment. The Psychosocial Team works alongside the medical, nursing and allied health teams to provide the best possible support and care for families. The Psychosocial Team is comprised of social work, chaplaincy/ pastoral care, play therapy, music therapy, art therapy, Comfort First, mental health and the Back on Track education program. To help refresh your memory on what is available, the Psychosocial Team have addressed some frequently asked questions from families.



How can the Social Workers support my family?

Every family in the CCC sees a social worker when their child is first diagnosed and throughout treatment. Your social worker can provide some much needed emotional support and counselling during times of crisis and distress, and is a general support person on the ward and as an outpatient. They can also help with information or referrals to various financial assistance and support organisations.

Is there any pastoral care support?

Yes, pastoral care services are available to offer support and encouragement to any member of families undergoing treatment in the CCC. This includes inpatients, outpatients and day oncology patients. Families are welcome to contact Pat Leadbetter on pager 5798 for a chat or as a sounding board. This is a non-denominational service and is available to all people.

What service does the play therapist provide?

Vicki the play therapist is an early childhood professional who supervises the ward playroom from 9.00am–12.00pm every week day. Play Therapy provides a place where children can relax and enjoy 'normal', age-appropriate activities. The focus is on making hospital stays a positive experience by fostering normal growth and development through play, medical play and preparing children for medical procedures.

How can music help my child cope with hospital visits?

Music is a part of a child's healthy life. The music therapist engages that healthy part of the child to help him/her cope with frequent hospital visits. Music therapy is adaptable to any child, no matter how sick, and regardless of age. It can be used to distract before, during and/or after procedures, or can encourage the child to socialise and engage with others in hospital – and have fun!

How can art therapy help/benefit my child?

Art therapy involves using a variety of art materials and can be an excellent way for children and adults to communicate thoughts and feelings about their illness, treatment and hospitalisation. The art therapist works with children on an individual, group or family basis, either at the child's bedside or in outpatients on Mondays, Tuesdays and Thursdays. The art therapist also conducts a combined art and music therapy sessions for adolescents on the ward.

How can we help our child during procedures?

A Comfort First clinician will meet with your family shortly after diagnosis, to help you determine the most appropriate techniques you can use to help your child cope during procedures. A 'Comfort Plan' will be completed in collaboration with your family, to communicate your child's procedural preferences to nursing and medical staff.

Our child's behaviour since diagnosis has changed and has been difficult to manage. What can we do?

A referral can be made for a child, sibling or parent who may be having difficulties adjusting or coping. Allocation to a psychiatrist, psychologist or other mental health clinician will be made. They will meet with the family, conduct an assessment, provide feedback and discuss management options.

What happens with school?

Back on Track is an educational program that supports school aged young people who are being treated through the CCC and at Peter MacCallum Cancer Centre. The program addresses the impact that chronic illness has on a young person socially, academically and emotionally. School aged young people can be referred to Back on Track by education professionals, health professionals or families.

Nursing news

We wish to advise that Karen Egan and Sharon DeGraves have been jointly appointed to the Nurse Program Manager position covering Jacqui Williams leave for 12 months. The Nurse Unit manager position is also currently being recruited.

The CCC has recently bid farewell to three members of our nursing team and welcomed aboard two new nursing team members with more soon to join us! We are actively recruiting enthusiastic new staff members and expanding our team to meet the ongoing needs of the unit. Families will be introduced to our new team-members as they commence.

We are very pleased to announce the appointment of Matthew Stewart to the NUM position of the Children's Cancer Centre.

Matthew has many years of experience in Oncology where he has worked at the Alfred and Western hospitals. He currently is in a Nurse Unit Manager role at the Mercy Hospital for Women.

Matthew will be commencing formally at RCH on 16 June and we all look forward to welcoming him to our team.

The clinical nurse coordinator team are committed to providing optimum care and advice to families, and to streamline the journey for you. We all know how frustrating it can be for families who are trying to reach their nurse coordinator during the day and always seem to get the answering machine. (The knowledge that your CNC is meeting with or talking to another family is little comfort when you are the one getting the machine!)

The Clinical Nurse Coordinator team have implemented a new CNC parent hotline during business hours (Monday–Friday 9.00am – 5.00pm, excluding public holidays) in response to this need. This phone will be carried at these times by one of the CNC team and will be answered promptly. This phone number is 9345 5677. The CNC will either be able to answer your question or get your own nurse coordinator to respond within a set period of time.

NOTE: There is a message on this phone that you will hear ONLY if the phone is in use by another family. If this happens please leave your name and phone number as you can expect the CNC to get back to you very quickly.

The Parents Advisory Group (CCCPAG) 2008

This group continues to meet monthly with staff from the CCC. This month parent members of the CCCPAG will be attending an information session for families about the progress of the new hospital. Look forward to updates in coming weeks.

If you, as a parent, of the CCC are interested in joining or assisting the group please contact Kevin on 0408 388 007 or Asanga on 0402 262 668 or email mary.mcgowan@rch.org.au for further details.



LARCH news

LARCH (Leukaemia Auxiliary of the RCH) meeting dates:

Tuesday 19 August 2008 is LARCH's 2008 AGM to be held in the foyer of the Ella Latham theatre at The Royal Children's Hospital. Please join us at this meeting to be part of a positive future that sees LARCH continue raising funds for vital research.

LARCH Fundraising & Support. LARCH would like to sincerely thank all those individuals, community groups and businesses for their ongoing support of LARCH through the generous donation of funds, goods for the stalls, placement of collection tins at work-places, assistance at the stalls, and most of all for their precious time and commitment to our cause. Well done to all.

LARCH history. If you have any information you'd like to share or add to the history of LARCH please contact Chrissie Boulter, phone 03 9827 0072 or 0402 848 535, or email chrissie@charlyblue.com

LARCH membership. If you are interested in becoming a member of LARCH please go to www.rch.org.au/larch and select membership.

Shaker Tins. We now have LARCH shaker tins available to place in your local club, workplace or just at home to collect your spare change. Please contact Chris McRae on 9331 2373 if you would like a tin.

Contact LARCH: Email Emma Bridgeman, secretary at larch1@optusnet.com.au

CBTA news

Thanks to the Children's Brain Tumour Association (CBTA) committee members for their dedication over the two weekends prior to Mothers Day in raising funds by gift wrapping at Angus & Robertson Greensborough.

The CBTA would also like to thank Angus & Robertson Greensborough for allowing us to gift wrap in front of their store and also Wesberg Forwarding for donating the gift wrapping paper and all the volunteers that gave their time for the CBTA. Approximately \$1,100 was raised. Thank you.

A reminder for the CBTA's 10 year anniversary Dinner Dance that is being held at Moonee Valley on 19 July 2008. If there is anyone that wishes to help during the evening or able to donate any auction items or would like to write an article on the CBTA, please do not hesitate to contact Rosemary on 0412 216 443. It will be a great evening with lots of entertainment, so that we can continue to raise monies for our children.

Tickets are able to be purchased via the Hospital Auxiliaries Office, telephone 9345 5188.



The Back on Track team

Back on Track program

The Australian Research Council is funding a joint project between the Education Institute and the University of Melbourne that will investigate the use of a range of technologies, including notebook computers, video conferencing, chat and online learning, in maintaining academic engagement with school for a group of students who are unable to attend school for a prolonged period because of chronic illness. Students enrolled in the Back on Track Education Program are the main cohort being used for this study. The major issues being investigated are the perceptions of students and teachers about technology-based learning, and the demands made on the key participants in this new educational environment. The project will also look at what support, including professional development, is required for teachers whose students are participating in such a program, and whether similar approaches could be used to assist other student groups (marginalised, rural, remote) unable to attend school for extended periods.

While being part of this larger study, Karina Wilkie is undertaking research for her PhD that focuses on a sub-set of these students – those who are enrolled in a VCE mathematics subject.

Back on Track is an educational program funded by The Fight Cancer Foundation. The Royal Children's Hospital Education Institute is the national coordinator and Victorian state service provider of the program. The RCH Education Institute collaborates with the Back on Track team, the Children's Cancer Centre and The Fight Cancer Foundation to deliver the program.

The Back on Track program supports school aged young people who are being treated through the Children's Cancer Centre at the Royal Children's Hospital and Peter MacCallum Cancer Centre. The program addresses the impact that chronic illness has on a young person socially, academically and emotionally. The Back on Track program aims to provide young people with learning and communication strategies supported by partnerships between schools, the RCH Education Institute and families.

A key part of the program is promoting an understanding for schools about the implications of a cancer diagnosis through professional development programs. On 28 April, a seminar for teachers and health professionals was held in the Ella Latham Theatre titled 'Supporting a Student with Cancer'. Presentations were given by a variety of staff from the CCC, education professionals and the Back on Track team to 88 seminar participants. A highlight of the program was the insights given by the young people being treated by the CCC.

For further inquiries about the Back on Track program please contact Peter Samers, National Coordinator 9322 5105.



PICS update (Paediatric Integrated Cancer Services)

Fantastic news is the introduction of a mental health clinician at the MMC CCC. Dianna Russo started with the team in January this year and is working on site approximately 12 hours a week. We are most grateful to KOALA Foundation for supporting this initiative. In addition as part of the CCC budget bids at both RCH and MMC, we are requesting funding of the neuropsychologist at RCH and funding for the introduction of this service at MMC.

Thank you to all of the families who have taken the time to complete the Press Ganey patient satisfaction survey. The results will be given to PICS early in May and we hope to have a summary in the next newsletter. Over the past few months PICS has been working with DHS and the surgical teams across both the RCH and MMC to commence a project aimed at improving the coordination of surgical oncology. We are hoping to receive a grant from DHS in order to commence this project in the next few weeks. We are also awaiting news from DHS regarding our proposal to fund a formalised LTF program across the sites and with regional outreach.

Look Good ... Feel Better For Teens 2008

What is LGFB? The LGFB for Teens program is for patients with cancer who are aged 12 years plus. LGFB provides and opportunity for participants to meet other patients their own age, feel better about themselves and have FUN! The program aims to help build self worth, further develop coping strategies and to meet peers in similar situations.

The next workshop is on Monday 23 June. For bookings and more information please contact Debbie Kertesz, social worker on 93456111.

DIARY FUNDRAISING DATES FOR 2008

Saturday 19 July	CBTA dinner, Moonee Valley Racing Club
Saturday 16 August	CIKA Dinner Dance, Bayview Eden Hotel
Saturday 30 August	MY ROOM, Crown Palladium

**Contact Community Liaison Manager on 9345 4855
for details on above events**

To forward articles for the next edition, or to receive this newsletter, please contact Mary McGowan, Community Liaison Manager, Children's Cancer Centre: Email: mary.mcgowan@rch.org.au Telephone 9345 4855 or 0407 519 852.

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