

# Children's Cancer Centre news

Issue 3 October 2008

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## ROSCP – What is it?

The Regional Outreach and Shared Care Program (ROSCP) has been developed by the Paediatric Integrated Cancer Service (PICS) in conjunction with the Children's Cancer Centres (CCC) at the Royal Children's Hospital (RCH) and Monash Medical Centre (MMC). Until recently, children and adolescents with cancer have had most of their treatment managed by the CCC at the RCH or MMC.

The aim of the regional program is to allow part of the care for children and adolescents with cancer to be provided in their local regional community when it is appropriate and safe to do so. We are achieving this by providing education and ensuring there are agreed levels and standards of care for medical, nursing and allied health staff, and that supportive services are available.



Jane Templeton (with patient) Regional Clinical Nurse Coordinator at the Shepparton Regional Clinic with three Regional Link Nurses from Goulburn Valley Health.

### What are the benefits of the regional program to the CCC patients and families?

- Improved coordination and streamlined care between the RCH or MMC and the Regional Centre
- Reassurance for parents that the regional centre providing care to their child is working together with the RCH or MMC, using agreed policies and procedures.
- Opportunity to attend outpatient clinics at the regional centre
- Reduced travel and reduced costs associated with traveling to Melbourne e.g. time off work and time away from family

- Clearer clinical guidelines regional centre and families in making decisions regarding emergency care
- Identified regional staff have access to the RCH CCC data base so they have up to date information regarding treatment plans, admissions and overall communication.

### What regional centres have been set up as a part of the program?

As a first step, regions across Victoria which have had a number of childhood cancer diagnoses were identified and then secondly, hospitals in these regions which had the facilities to support and safely care for a child with cancer were selected.

The **Royal Children's Hospital** Melbourne

**Murdoch Childrens Research Institute**  
Healthier Kids. Healthier Future.

**Southern Health**

In the twelve months to April 2008 formalised arrangements for shared care have been agreed at the following centres:

- Goulburn Valley Health (Shepparton)
- Albury Base Hospital
- Ballarat Health Service
- Barwon Health (Geelong)
- South West Health Care (Warrnambool)
- Bendigo

Discussions have commenced with Peninsula Health (Frankston) and the Gippsland region.

### What education has been provided to the staff in the regional centres so far?

#### Nursing Education

The PICS has developed a nursing education program that includes supportive care, Hickman line and port a cath care and side effects of treatment. The program aims to reduce variations in care and increase consistency of practice. Seminars have been held at the regional centre and to date 107 nurses have attended. The RCH CCC now uses videoconference facilities to hold fortnightly education sessions for regional paediatric nurses and to communicate with staff in the regional centres.

#### Medical Education

The PICS has also introduced a regional doctor program where paediatricians can attend the RCH CCC for two days to meet the CCC team and review RCH policies and procedures. To date, 18 paediatricians have attended with 15 more to visit later in the year. Ten medical seminars for doctors have been held in the regional centres. These seminars will be ongoing.

#### Comfort First Education

The Comfort First training program has been delivered to over 240 regional nursing, medical and allied health staff.

- Paediatric Oncology study day in Geelong, attended by Regional Nurses from Geelong and Warrnambool.



Jane Templeton, Regional Clinical Nurse Coordinator and colleague videoconference to nurses in Shepparton, Albury, Ballarat, Geelong and Warrnambool.

#### Other Education

Due to its success in 2007, a full day seminar on nutrition in paediatric oncology was repeated in 2008. The seminar attracted dietitians from throughout Victoria and interstate. Plans for future seminars are underway. In the second half of 2008 we are delivering 3 full day workshops across Victoria on paediatric palliative care.

#### What is the regional link nurse program?

Each of the regional centres children's ward's have nominated up to four nurses to participate in a 5 – 7 day education program at the CCC at RCH. 21 nurses across Victoria have now completed the training to be recognised as a CCC regional link nurse.

#### What are the regional clinics?

Previously, regional clinics have been held only in Albury and Geelong. The ROSCP has now established clinics in Goulburn Valley and Ballarat with clinics planned in Bendigo and Warrnambool in 2009. These clinics are attended by one of the CCC oncologist's. If you are a regional family please speak to your oncologist at your next clinic appointment to see if it is suitable for you to attend a clinic locally in the future.

#### Exciting times...

These are exciting times for the regional program. If you are a family who live in regional Victoria it may be possible to have part of your care delivered closer to home. Please speak with your consultant or nurse coordinator to discuss this further.

## Laboratory update from Denise Caruso

The Tumour Immunology Lab has been very busy over the last few months. The team has recently had a paper accepted for publication in the international journal *Experimental Hematology*.

The study was performed at the RCH CCC Research Laboratories with all participants being RCH patients. This work, titled 'Co-stimulation molecule expression and subset distribution of blood dendritic cells in normal children, and newly diagnosed pediatric Leukemia and Lymphoma patients' examined the immune systems of healthy children

compared to children with untreated cancers.

This work was a world first to establish normal ranges for a type of immune cell, the dendritic cell, in normal children and therefore the first to be able to determine how this is altered in children with cancer prior to receiving therapy for their disease.

The team would like to thank all of the patients and staff that were involved for their participation, time and effort. We studied nearly 200 blood samples so a

great effort and outcome. Additionally the Tumour Immunology Lab is developing new therapies using the immune system to fight tumours.

The Phase I Safety and Feasibility Clinical Trial is now open and we are treating patients with advanced malignancies. The trial will run over three years to reach patient recruitment goals. We are in the early stages of this trial and the dendritic cell anti-tumour vaccine has been well tolerated by our patients. We look forward to completing this work in the years to come.

# CCC Monash Medical Centre – Psychosocial Team

Hello from the team at the Children's Cancer Centre – Monash Medical Centre. The Allied Health team here includes:

**A Family Resource Coordinator** who is here to have a friendly conversation, to play and to offer practical support on the day of attendance, or during an inpatient stay. Melanie Povey is here to make the environment of the CCC safe and enjoyable to visit.

**A Mental Health Clinician** who is a specialist in providing therapeutic support to children and their families when cancer or its treatment presents challenges with an impact on the child's social/emotional development and/or the way in which they cope. Diana Russo is here to offer one-on-one therapy to children and at times siblings, as well as providing information and support to parents and families.

**A Dietitian**, Kris Gay, helps patients and families to manage changes in diet, weight

loss and other major feeding challenges that cause great concern to patients, parents and families.

**A Social Worker** assists patients and families to cope with the changed circumstances that can arise from having a cancer diagnosis. Lynette Ozols will commence with the team in October. She will provide support at times of crisis, and counselling to patients and families, connecting families to practical advice, to the many cancer support groups, and to other resources and sources of information that can enhance coping. Lynette will work with the CCC team to coordinate the services provided to children and families including information re diagnosis and treatment as well as information about groups they can attend.

**A Music Therapist** offers individual and group music therapy sessions in the Children's Cancer Centre and in the inpatient units. Annette Baron provides opportunities for creative expression

through the medium of music. Some of the techniques used in sessions include; playing instruments, singing familiar songs, learning an instrument, relaxation sessions, song writing and much more such as distraction and therapeutic exploration of patients' experiences of hospital and treatment.

**A Procedural Pain Play Therapist** who is responsible for implementing the Comfort First program. Karen Jolly supports patients and families with managing pain, discomfort and anxiety related to medical tests and cancer treatment. She also provides play opportunities at other times.

**The School Teacher** can be called upon to help with the schooling and education of the children as well as liaise with schools to get school work and promote the school connection. Patricia Chaves can also provide tutoring; refer the children to the Visiting Teacher Service; and Ronald McDonald House learning program if required.

## Nursing news



### Introducing Matt Stewart

Matt has commenced as the Nurse Unit Manager at the RCH CCC and we are thrilled to have him on board.

"I wish to thank all involved in making my welcome to the CCC warm and very friendly. I am very excited and privileged to have the opportunity to be in the position of the Nurse Unit Manger of the CCC. I look forward to meeting all the children and families that attend the CCC over the coming weeks and months."



### Introducing Suzie Quick

Suzie has recently been appointed as the Paediatric Clinical Nurse Coordinator (CNC) at the Peter MacCallum Cancer Centre whilst Carmela Rooney is on secondment. Prior to taking the role as Paediatric CNC Suzie worked in the Apheresis Department at Peter Mac and as the Project Officer for the Regional Outreach and Shared Care Program (ROSCP) for the Paediatric Integrated Cancer Service. Suzie still works in the Apheresis Department.

Suzie can be contacted via the Peter Mac switch board on 96561111 (pager 7405) or direct line 96561756. She is available on these numbers on Monday, Wednesday and Thursday.

### Farewells

The CCC also recognises the valuable contribution of two long-serving nurses, Paula Johnson and Linda Burnett. Paula began her nursing career at the RCH in 1966 and worked here as an RN until 1974. She broadened her professional and life experiences with roles at Frances Perry House, Prince Henry Hospital and some time in Canberra, as well as having a family of her own. Paula returned to RCH in 1984 and has been with the Paediatric Oncology Service for the past 25 years including being AUM in the CCC, driving many quality improvement projects and having a profound impact on the way we nurse children with cancer. Paula is retiring in November this year. We will remember her fondly and wish her many happy years of retirement-bliss!

Linda began her career at the RCH over 16 years ago when she worked as a ward clerk in the oncology ward whilst studying for her nursing degree. After graduation Linda began working as an RN in the oncology unit and has taken on a variety of senior nursing roles in the CCC over the years. Some of you will know her as a bed-side nurse on the ward, others as an AUM or Bone Marrow Transplant Nurse Coordinator.

Linda is taking up a challenging new position establishing a hearing screening program. We wish Linda well in her new endeavour and will miss her greatly.



## LARCH news

The Leukaemia Auxilliary of RCH (LARCH) final meeting for 2008 will be held on Tuesday 18th November at 6.00pm, in the meeting room at Ronald McDonald House, 22 Gatehouse Street, Parkville (opposite the hospital). Parking is available on Gatehouse Street, Flemington Road and the two side streets either side of Ronald McDonald House. Please join us at this next meeting to be part of a positive future that sees LARCH continue raising funds for vital research.

**LARCH history** Chrissie Boulter is compiling a history of LARCH and is trying to source copies of old LARCH minutes and RCH annual reports. If you have any of these filed away and would be happy for us to either archive those or copy and return them, please get in touch with Chrissie on phone – 03 9827 0072 or 0402 848 535, or email [chrissie@charlyblue.com](mailto:chrissie@charlyblue.com).

**The Lotus Dinner** The inaugural Lotus Dinner and Auction, held on April 18th at the Brighton Savoy raised over \$55,000 for LARCH to fund research into Childhood Cancer. This extraordinary effort was the result of many months of hard work by the Lotus Dinner Committee of Lynne Marchesani (CCC parent) Bronte Sutcliffe, Kate O'Donnell, Robyn Creed and Kate Wilson. Our sincere thanks and appreciation go



Prof David Ashley and Claudia McCarthy (LARCH) receiving cheque from Lynne Marchesani with Dr Keith Waters and Adrian Marchesani.

to the Marchesani family and their many friends and supporters for this magnificent result.

**Yering Station Gallery** continue to support LARCH through their ongoing art and photographic exhibitions.

Admission to all exhibitions is free and a percentage of sales is donated to LARCH.

For further information call on Wednesday or Thursday  
T – Amanda Ruck 03 9730 0100  
M – 0418 389 964  
E – [artgallery@yering.com](mailto:artgallery@yering.com)

Yering Station, 38 Melba Highway  
Yarra Glen, Victoria  
Telephone 03) 9730 0100.

Opening hours: 10.00 am – 5.00 pm  
weekdays and 10.00 am – 6.00 pm  
weekends and public holidays.

LARCH again wishes to acknowledge the generous support of Yering Station through their donation of all commissions on artworks sold during their exhibitions.

### Contact or donate to LARCH

President: Claudia McCarthy  
Treasurer: Christine McRae  
Vice President: Mario Lopreiato  
Secretary: Emma Bridgeman  
Stalls Coordinator: Chrissie Boulter  
M – 0402 848 535,  
E – [chrissie@charlyblue.com](mailto:chrissie@charlyblue.com)  
W – [www.rch.org.au/larch](http://www.rch.org.au/larch)  
E – [larch@iprimus.com.au](mailto:larch@iprimus.com.au)

LARCH is committed to raising funds specifically for the Children's Cancer Centre. 100% of donations are directed toward research and care of children with cancer and their families at the Royal Children's Hospital in Melbourne. All donations over \$2.00 are tax deductible.

Donations to LARCH can be made by sending a cheque, money order or credit card details using our form downloaded from the LARCH website and sent by mail to the address on the form.

## CBTA news



The Childrens Brain Tumour Association (CBTA) celebrated their 10th birthday with a very successful dinner dance at Moonee Valley on July 19th. It was great to have so many of the founding members present on the night. Space prohibits me from thanking everyone individually but on behalf of the CBTA committee we could not have had such a successful night without the support of those who donated items for the auctions and raffle, those who purchased tickets and the volunteers on the night.

CBTA's main objective is to provide information and support to all families of children diagnosed with a brain or spinal tumour.

Having a child with a brain or spinal tumour is such an intense experience that often the only folk that can relate to your experience are those who have trodden the same path. If you want to contact the group please either e-mail to [mary.mcgowan@rch.org.au](mailto:mary.mcgowan@rch.org.au) or phone Rosemary, CBTA President on 0412216443.

The group would like to see all families of newly diagnosed brain or spinal tumours get involved. You can then find out first hand about the family fun days and also our family education nights. The next family fun day is planned for Sunday, December 14th. Keep the date free and contact either of the above to find out more about this event. The CBTA are also looking for ideas and suggestions from the families of today as to how we can help you better. Please let us know what it is you need from us to assist you on your journey.

## CCCPAG news

The Children's Cancer Centre Parent Advisory Group (CCCPAG) meet monthly with staff of the CCC to discuss comments, suggestions and feedback from parents and families. The CCCPAG identifies priorities and suggests solutions to issues and have been recently involved in the progress of the new hospital.

If you, as a parent of the CCC are interested in joining or assisting the group, or have ideas or feedback, please contact Kevin on 0408 388 007 or Asanga on 0402 262 668.

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](mailto:mary.mcgowan@rch.org.au) Telephone 9345 4855 or 0407 519 852.

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