

Children's Cancer Centre news

Issue 2 May 2010

The 2010 Murray to Moyne

The 2010 Murray to Moyne –
a report from two of the support crew

Mary Mac briefed Marguerite Wijetunge & Nadia Esposto on what to expect: "watch out for the marshalls, remember the road rules, at all times make sure the team is looked after, watch out for any tiring riders, travel slowly and at a distance to avoid hefty fines for doing the wrong thing, you will be sleeping in a sheep shed... and it smells" – with trepidation we joined the support crew and set off from Melbourne a 6pm on Friday night.

On reaching the Bolte Bridge a passing motorist flagged us down – one of the bikes was hanging off the bike rack. Rodney did a good job securing the bike with only inches between him and passing traffic. What a beginning to this fund raising event!

We arrived at Echuca at around 9 pm. Saturday morning dawned nice and bright and after breakfast, a speech from Dr Downie on behalf of Mary McGowan, last minute instructions from Leah and posing for photos, the team headed off for St Arnaud. Just a few kilometres out, Pratiti had the honour of having the first puncture!

The riders enjoyed fine weather and a tail wind reaching St Arnaud around 5.15 pm and after a hot meal set off for the night ride to Hamilton.

It was tiring driving at 30 kms/hour in the middle of the night behind the riders, watching for problems and making sure the riders had sufficient light. With no major dramas we reached Hamilton around midnight 2½ hours earlier than the previous year. On checking out the "shed" we decided the Volvo SUV was by far the best option!

Waking up at 5 am was hard, but after a hearty breakfast and a reminder from Leah to the riders to stop 5 kms before Port Fairy to "bonnet & boot" up for the team ride into the township, the riders set off on the final 92 kms. It was an amazing sight, seeing the team come over the hill in their distinctive red colours. The enthusiasm of the riders and team work made us proud. Leading the team in to Port Fairy was Matthew Bennett and his dad David.

Rodney received a nomination for the Woody's award and was very gracious in his speech ...he was also "speechless"...which was hard to believe.

The bus ride home was tiring but fun with Rodney's words ringing in our ears "what happens on the bike ride stays on the bike ride" – and we leave it at that! We really enjoyed the weekend and look forward to having Mary Mac on board next year. Thank you and congratulations to all the riders and support staff for another successful bike ride.

Preliminary figures suggest the Murray to Moyne has raised close to \$50,000 for the Children's Cancer Centre Foundation.

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Message from A/Prof David Ashley – Director CCC RCH

I wish to let you all I know that I have submitted my resignation as Director of the Children's Cancer Centre at The Royal Children's Hospital and as the Medical Director of PICS.

I have been privileged to hold the position of Director CCC for more than ten years and am very proud of the incredible achievements of our team. However, it is time for me to move on to new and exciting endeavours in cancer leadership at Barwon Health and Deakin University.

I will stand down as Director on May 14th 2010, take some much needed annual leave and then return to the RCH at a reduced sessional commitment of two sessions per week.

My ongoing clinical commitment will allow for the care of the patient population for whom I am responsible, predominantly children with brain tumours.

Once again, it has been a privilege to care for my patients, work with the staff of the Children's Cancer Centres at The Royal Children's Hospital and Monash Children's and the staff members of PICS.

I look forward to supporting the new leadership in the Children's Cancer Centre.



Monash Children's Cancer Centre news

We are delighted to announce three new positions for the Monash Children's Cancer Centre. These positions have been made possible through a formal five year funding agreement between Southern Health and the KOALA Foundation. In the first year the KOALA Foundation will fund 100% of these positions, each year reducing their contribution by 25%, with Southern Health assuming responsibility for this gap in funding, until Southern Health assumes responsibility for 100% of funding in the 5th year and beyond.

The new positions are:

Nurse Unit Manager (NUM)/Educator

This is a new full-time position in the CCC. The position will be split three ways! As a nursing leader, the NUM will coordinate and lead the nursing staff, providing day to day management. The second component of this position is that of an Educator, documenting a training program in paediatric oncology for the CCC, the inpatient wards and other areas such as the Emergency Department. The final component of this position involves nursing support for both Katy and Kate when they are on leave or away from the department.

Pharmacist (to the CCC)

This part-time 0.5 EFT position will add to current pharmacy hours providing the CCC with the equivalent of a full-time pharmacist. As part of this position, Lisa Jansen is returning from parental leave two days per week and will be based in the CCC on a Tuesday and Wednesday. Not only are we delighted to have Lisa back, we are pleased that the service will be expanded for all outpatients attending the CCC.

Dietitian (to the CCC)

Similar to the Pharmacy position, this funding will be used to expand the current Dietitian position to a part-time 0.5 EFT commitment to the CCC. The Dietitian will offer an initial consultation to all newly diagnosed families and will provide education and information that is consistent between Monash Children's and the RCH. The Dietitian will also provide assistance and appointments to those requiring further dietetic advice on an ongoing basis.

We are very excited about these three positions and look forward to the new roles and services that will be created. We would like to extend our thanks to the KOALA Foundation for their vision in funding these positions over a five year period.

Paediatric Surgical Oncology Program (PSOP)

In 2008, the Paediatric Integrated Cancer Service (PICS) commissioned a project to review paediatric surgical oncology services across the RCH and Southern Health. Following on from this review, the next phase of the Paediatric Surgical Oncology Program (PSOP) has commenced. Funded by the Victorian Department of Health, a 12 month Project Officer has been appointed to work with the oncology and surgical teams across both Monash Children's and the RCH to:

- Develop and document key principles of care, agreed to between the surgical and oncology departments
- Examine the cancer journey for paediatric patients and their families from the solid tumour group in order to introduce opportunities for improved coordination of care
- Increase the number of surgical sessions thus increasing surgical access
- Decrease the number of surgeons undertaking procedures in order to increase the volume of procedures per surgeon and improve clinical outcomes

- Develop standardised and documented approaches to procedures such as standard Hickman line dressings etc
- Document all multidisciplinary meetings and introduce mechanisms to ensure all children are discussed at appropriate multidisciplinary meetings
- Roll out a standardised education session for ALL surgical disciplines across both sites that includes information regarding "right procedure, right sample, right test"
- Establish shared oncology and surgical out-patient clinics at both sites.

Thus far, both Monash Children's and the RCH have appointed full time paediatric surgeons to work alongside the oncology teams within the CCCs. This is an important step forward for paediatric surgical oncology. Prof Yves Heloury has joined Monash Children's from CHU de Nantes, France and Dr Michael Nightingale has returned to the RCH from his work at the Starship Paediatric Hospital in Auckland, New Zealand.

PICS Strategic Plan 2009–12

The Paediatric Integrated Cancer Service (PICS) has recently launched their Strategic Plan which outlines the major directions and activities for the PICS for the three year period July 2009 to June 2012.

The Plan was developed in consultation with a range of stakeholders. The PICS would like to thank all those who were involved, in particular the families from the Children's Cancer Centres at both the RCH and Monash Children's, as well as staff from the RCH, Monash Children's and Peter Mac.

Some of the key activities for the PICS in 2010 as defined by our consumers and stakeholders include:

Clinical:

- Implementing staffing and service improvements for Bone Marrow Transplant services
- Scoping, and if appropriate, implementing a regional chemotherapy program
- Implementing a Paediatric Surgical Oncology Program to ensure consistency across RCH and Monash Children's

- Supporting sustainable and accessible statewide paediatric pathology expertise

Supportive care:

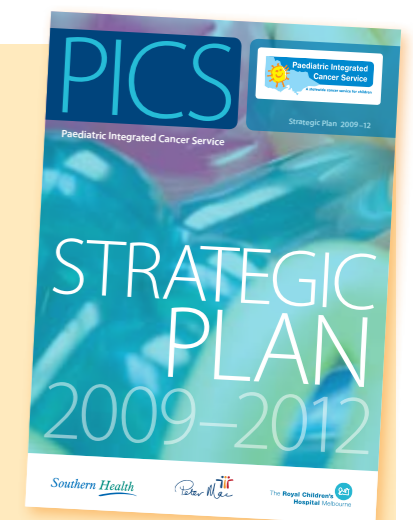
- Reviewing access to community based counselling services i.e. marriage/financial
- Documenting current psycho-oncology services to ensure consistent access and standards of care across sites and embed with sustainable funding
- Introducing a supportive care screening tool

Information:

- Developing a centralised consumer library with computer access
- Documenting and standardising a pharmacy and a nutrition education program
- Developing a database of families for information distribution
- Developing information in languages other than English as appropriate

Workforce:

- Documenting current courses/workshops/seminars for nursing and allied health staff and bringing together as a formal education program
- Working with medical staff to document a JMO orientation/training program
- Documenting a workforce plan for nursing, medical and allied health staff across sites to inform hospitals and the Department of Health of future needs
- Ensuring sustainability of philanthropic funded positions



For more information or if you would like a copy of the PICS Strategic Plan 2009–12 please contact Amy Shelly on 03 9345 5687 or amy.shelly@rch.org.au



Announcement

As we say thank you to A/Prof David Ashley who has been the Director of the CCC for over 12 years we say welcome to Professor Paul Monagle who has been appointed as the Acting Director of the CCC.

Professor Monagle is also the Head of Clinical Haematology and the Head of the Department of Paediatrics. We take this opportunity to welcome Paul as the Head of the CCC and look forward to working with him in the future.

CCC Parent/Carer/Patient Network

An important way to ensure that our services meet the needs of children and families is to seek your advice on future service development and gain your feedback on our current services. The Parent Advisory Group together with the Paediatric Integrated Cancer Service are developing a Network database of parents, carers and patients in order to provide you with information and seek your feedback. To do this, we are collecting email and/or postal contact details of patients, parents and carers of children who have attended the Children's Cancer Centre at The Royal Children's Hospital, Children's Cancer Centre at Monash Medical Centre or have been treated at Peter MacCallum Cancer Centre.

If you would like to be on our contact list please complete and return the form provided with this newsletter. You will be able to unsubscribe from this email contact list at any time by indicating your wish to do so by return email.

Anyone who has been an inpatient at The Royal Children's Hospital will know Merridy, the Family Resource Coordinator. Congratulations to Merridy and Gerry who were married on Friday 23rd April, 2010 at the Elwood Sailing Club.

Cancer in Kids @ RCH (CIKA)

CIKA is a group of parents and friends who are committed to improving outcomes for children diagnosed with a solid tumour. The CIKA committee is now hard at work planning the annual Blue and Orange Ball to be held on August 21. In this, our 30th year, we are aiming to make the ball a very special event. If you would like to attend then please contact our President, Sandra Lehrer, via email president@cika.org.au or phone 9696 9775. Donations to CIKA can also be made at any time via our website (see below). Goods and services are particularly welcome in the lead up to the ball and either Sandra or our Vice-President, Ellen Webb, would be pleased to speak with you should you be able to help. Ellen can be contacted on 0423 767 136 or ellenwebb@optusnet.com.au CIKA friends can also speak with Mary McGowan at the Children's Cancer Centre.

You can find out more about CIKA by visiting our website www.cika.org.au

"Say Something..."

As a parent at the CCC, I'm sure that you have come across situations where you think "I need to say something". We face adversity in our own ways. We see things differently. At times we feel that we are at the lowest point and other times in awe at someone's kindness and selflessness.

I felt the need to "say something" when my son Dylan was being treated at the CCC. There were many occasions that I felt sheer gratitude towards the kind people who put their all into caring for our kids. There were also occasions that I felt that some aspects of Dylan's care could be better handled. I later realized how what I wanted to say could help improve the way CCC cares for our children. I found a group of likeminded parents. I joined the CCC Parents' Advisory Group (PAG).

Having being on the group for a number of years and chairing it, today I say farewell to the CCC. Over the years we have successfully worked with the CCC, its medical, administrative as well as government bodies in representing your views and suggestions to improve many aspects of the care provided to our children. There is much to learn from all our experiences and I encourage you to say something... I invite you to join the PAG. As I depart, it is with pleasure that I introduce two parents who recently joined the PAG.

Brigitte Walker: Brigitte was five months pregnant with her second child when her son Leo was diagnosed with Acute Lymphoblastic Leukaemia in early 2008. Leo continues in treatment and Brigitte believes that well supported families are best placed to care for their children. Brigitte is interested in continually finding the 'best way we know so far' to sustain families and to celebrate all the beautiful moments that are witnessed in our CCC's. Brigitte is a social worker and has worked in a range of community settings.

Tanya Anderson: Tanya's son Jai was diagnosis with Acute Lymphoblastic Leukaemia on Christmas Eve of 2006. Tanya feels privileged to be able to provide support and assist other parents and families throughout their journey of treatments within the Children's Cancer Centre. With her many years experience in International logistic in the Lifesciences and healthcare sector, Tanya expects to contribute her expertise to best position the parents' advisory group in supporting the families.

Brigitte and Tanya's contributions will no doubt help, as will yours, to give our kids the best they deserve, a healthier future.

Thank you!

Asanga Lokusooriya

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

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