



## making news ...

- 2** • The hows and whys of providing feedback
- 3** • What is the CCC Quality Working Group
- 4** • The man by the window

## Siblings Day

In July the Social Work department ran a day for siblings, a biannual event dedicated to the brothers and sisters of patients of the CCC. Siblings day is a great opportunity for children to meet other brothers and sisters, share experiences and have some fun. It was a day jam packed with activities. The children had a behind the scenes tour of the hospital, visiting the pharmacy and the research laboratories. The visitors learnt about germs and had a chance to measure each others blood pressure and temperature. The afternoon was spent in small groups completing a workbook where the children discussed their experiences and feelings about having a sibling with cancer. The feedback we received from parents and children has been positive and has shown that siblings day is a most worthwhile activity. Thanks to KOALA kids for their support in providing the food and show bags for the children. The next siblings day will be held in January 2010. For more information contact the social work

Luke and Xuan interacting with children.



## Peter Mac takes our experience internationally!

The third Biennial Paediatric Radiation Oncology Society Meeting was held in Montreal in early July. A very strong Peter Mac contingent attended the conference. Out of 30 proffered papers there were six from Peter Mac, with four in one afternoon session. Many families will know Dave Willis from Peter Mac – he was instrumental in the creation of the radiographers group meeting held the day before the main meeting.

The presentations were:

- 1.** The Paediatric Radiation Therapy Special Interest group of the Australian and New Zealand Children's Haematology/Oncology group.
- 2.** Bespoke Paediatric Radiation Therapy DVD production for Information, Integration and Celebration – Dave Willis (travel supported by Paediatric Nurse/Allied Health Scholarship from the Children's Cancer Centre Foundation).
- 3.** Customisable Paediatric Radiation Therapy Information Book – David Tongs (travel supported by a Link & Learn grant from the Victorian Cancer Agency).
- 4.** The effects of Music Therapy CD creation on initial paediatric radiation therapy treatment – Pip Barry (travel supported by Dr Mary Dwyer).

- 5.** Computerised image capture and moulding in the manufacture of a Radiation Therapy Stabilisation Device – a multidisciplinary and multi site approach – Julia McAlpine (travel supported by Dr Mary Dwyer).

- 6.** The Peter MacCallum Cancer Centre Late Effects Clinical Service – an Overview – Greg Wheeler.

The feedback from our presentations was excellent and we are now planning an assault on the next meeting in Venice in 2011.



Presenter from Peter Mac at the conference.

The **Royal Children's Hospital** Melbourne

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

**Southern Health**

**Paediatric Integrated Cancer Service**  
A paediatric cancer service for children

# The whys and hows of providing feedback

The Children's Cancer Centres at The Royal Children's Hospital and Monash Children's and the paediatric service at Peter Mac, welcomes feedback from patients and family members.

Feedback can be in the form of a positive experience, ideas for improvement or a complaint, where the experience of care or service that did not meet expectations. It is your right to express your concerns and to know that these will be taken seriously. Patients and families are not disadvantaged if they provide feedback about care or services.

When there are times that patients and families are not happy with the care or services provided, it is important that we are aware of these issues or events. The information that you provide is important to our approach to quality and safety and can help us improve care and services for patients and families.

There are a number of ways that you can provide feedback.

- Whenever possible we encourage you to resolve any concerns with the person or unit directly
  - For the CCC at RCH, you can speak to the Nurse Unit Manager, Melinda Sharpe on 9345 5649
  - For the CCC at Monash Children's, you can speak to Katy Walshe, the CNC on 9594 7660 or the Nurse Unit manager of the Ward, Siew Cheng Cheong (41N) on 9594 4160 or Gina Riewoldt (42N) on 9594 4260.
  - Suzie Taylor, the Paediatric CNC at Peter Mac can be contacted on 9656 1756.

All are available to respond to patient or family complaints or to advise you on how you can formally raise your issue or concern.

- Sometimes it is difficult to talk directly to the department. In this case all hospitals have a consumer representative.
  - The RCH has a consumer liaison officer, Judith Smith who can be contacted via telephone or email on 9345 5676 [judith.smith@rch.org.au](mailto:judith.smith@rch.org.au).
  - The Consumer Liaison Officer at Monash Children's can be reached on 9594 2702
  - The Consumer Engagement Coordinator at Peter Mac, can be contacted on 9656 1870 or email [amritpal.dhillon@petermac.org](mailto:amritpal.dhillon@petermac.org)
- If you would prefer to write down your concerns you can complete a Consumer Feedback Form and send it to the Consumer Liaison Officer at the centre you are dealing with. Please see newsletter insert for details.
- If you do not want to talk to anyone at the hospitals you can contact the Health Services Commissioner who is an independent statutory authority established to receive and resolve complaints about health service providers. This is a free and confidential service.

If you wish you can remain anonymous when providing feedback. However, whilst anonymous feedback will be taken seriously we are unable to provide a direct response or sometimes fully investigate the concern without additional information.

For further information on patient rights and providing feedback/complaints please look on the RCH Consumer Liaison webpage. [http://www.rch.org.au/qi/partnerships.cfm?doc\\_id=12257](http://www.rch.org.au/qi/partnerships.cfm?doc_id=12257) or in "Your Guide to RCH". or on the PeterMac feedback webpage <http://www.petermac.org/MacFeedback>

You're invited!

## LARCH TRIVIA NIGHT!

LARCH invites you to their Trivia Night, hosted by **Scared Weird Little Guy – Rusty**. Saturday 3rd October, 2009,

St Augustine's Parish Hall, 61 Somerville Rd, Yarraville, 7.00 pm for 7.30 pm start, \$25 per adult. Tables of 8, 10 or 12 available, all bookings and payments must be made prior to 20 September 2009. NO payments will be accepted on the night, bottles of wine available on the night, BYO soft drink.

Major raffle prizes & auction include – Sporting memorabilia, general memorabilia, silent auctions, major raffle prizes, lucky door prizes.

For more information contact - Paula Lienert 0411 106 948  
Email – [Paula.Lienert@gmail.com](mailto:Paula.Lienert@gmail.com) or Rose Stolarek 0438 938 325  
Email – [Jostolvic@ozemail.com.au](mailto:Jostolvic@ozemail.com.au).

## CIKA

CIKA is a group of parents and friends who are committed to improving outcomes for children diagnosed with a solid tumour. If you would like to help us by attending one of our events, making a donation or joining the group then please contact our Vice-President, Ellen Webb on 0423 767 136 or [ellenwebb@optusnet.com.au](mailto:ellenwebb@optusnet.com.au) or speak with Mary McGowan at the Children's Cancer Centre. You can find out more about CIKA by visiting our new website [www.cika.org.au](http://www.cika.org.au)

# What is the CCC Quality Working Group?

The CCC at The Royal Children's Hospital (RCH) has been working towards developing improved, formal strategies surrounding clinical quality and safety. In August 2008 a Quality Working Group (QWG) was formed as a sub-committee of the CCC Patient Care Committee.

Together the QWG and the RCH quality team work to improve services and experience of care, increase quality-related activities, improve systems and processes and strengthen consumer input/feedback processes. Although an RCH committee, many of the activities and initiatives undertaken can provide "lessons learnt" for the CCC at Monash Children's and for the paediatric service at Peter Mac.

The RCH CCC Quality and Safety initiative was developed to improve systems and processes in the following areas:

## Reactive measures

- Clinical risk management
- Incident report review
- Complaint/feedback letters

## Pro-active measures

- Clinical improvement activities
- Mandated ongoing organisational projects
- Proactive and locally responsive activities
- Supporting and evaluating changes in practice

## Current Quality Improvement Projects

The RCH CCC is currently involved in a number of quality improvement projects. Some of these are long term initiatives while others are smaller projects. Many have a statewide perspective and have included liaison with the other Paediatric Integrated Cancer sites and as appropriate, the Parent Advisory Group. A summary of some of the projects are listed below:

### BMT model of care and FACT accreditation

The Haemopoietic Stem Cell Transplant (HSCT) programme encompasses all aspects of bone marrow transplantation for children with both malignant and non malignant disease in Victoria and Tasmania, with some referrals also from South Australia. In accordance with best practice and international standards, the HSCT programme now wishes to obtain FACT-JACIE Accreditation inclusive of all aspects of transplantation. In addition, PICS has funded and is coordinating a project to document a model of care for BMT. The FACT accreditation process together with the PICS BMT model of care will establish a rigorous quality management system with documented procedures, improved staff training and efficiency and a clear vision and budget for an improved BMT service. We are aiming to have obtained FACT accreditation by the end of 2010. Nancy Messino is the FACT quality project officer: 9345 6628.

### • Development of the Family Education Program

The family education program (FEP) is a structured program for the parents/family of children newly diagnosed with cancer. It is applicable for children being cared for at both the RCH and Monash Children's. The program consists of three sessions that parents are encouraged to attend before their child is discharged following their initial diagnosis. Families are currently given a DVD of the sessions to take home irrespective of where they are treated. We are working with the Educational Resource Centre at the RCH to develop a professional DVD which has a voice over and is chapterised. It will be possible in the future to have the voice over available in various languages. Upon completion the FEP will undergo formal evaluation to demonstrate the impact and effectiveness of the program. Sharon De Graves is the contact for this project: 9345 4039

### • Auditing patient related calls to the CCC

When parents ring the CCC with patient related concerns and inquiries, the calls are answered by a variety of different nursing, medical and administrative staff. This project will audit the number and type of calls received with the aim of developing a profile of the calls. The information gathered will be used to develop guidelines to help nurses respond to patient calls in a consistent manner based on best practice advice.

### • Bedside information folders

Bedside information folders have been developed to provide information about the CCC and RCH during in-patient admissions. The folders will remain in each in-patient room and contain useful information about the ward and hospital resources. These folders will be available in the coming months. Once completed, PICS will review if these folders are applicable for use at Monash Children's.

### • Long Term Follow Up and Coming Off Treatment Surveys

The Long Term Follow Up Program is in the development stages and is soon to be rolled out. Any questions can be directed to the Long Term Follow-up (LTF) team by calling 9322 5181 or by emailing us at [ltf.program@rch.org.au](mailto:ltf.program@rch.org.au)

### • Nutrition model of care work

The role of adequate nutrition is an important aspect of the treatment of children and adolescents with cancer. The 'Nutrition service model implementation project' will improve access to outpatient dietetic support within the Children's Cancer Centres and will enable the dietitian to test the proposed service model developed by PICS in 2008. Funding has been received from LARCH to roll this project out at The Royal Children's Hospital and PICS is seeking a funding source to fund the service at the MMC CCC. You may be asked to complete a brief survey to evaluate this program.

### • Experience of care survey for young people

It is well recognised that adolescents with cancer have different needs than younger children or adults. To explore this further, the CCC is developing a survey that aims to provide a better understanding of the experience of young people with cancer and their preferences for service delivery. The project outcomes will help inform the development of services and interventions for the adolescents we care for, as well as identify areas that need further research. Dr Lisa Orme and Sharon De Graves are the contacts for this project on behalf of the Adolescent Subcommittee.

## The man by the window...

I was weaving my way through people. There were so many of them. Children, parents, staff and visitors scurried along the corridors while some moved at a slower pace. Everyone was heading for something, something important. I saw familiar faces but many of them were unfamiliar to me. Strangely, I felt a connection with everyone. Amongst unfamiliar faces I saw familiar impressions. We shared something very personal, something that changed the course of our lives forever. We came from different places and we were heading to different destinations. But we were together on the journey. I found myself at the entrance to the parents' retreat. I was on the 6<sup>th</sup> floor of Children's Cancer Centre at the Royal Children's Hospital. A place people dared not enter but an oasis if your fate has uttered the word 'Cancer' in the same sentence with your child's name. I was one of those who found this place to be an oasis. This was the connection I felt with others who were around me and this was the familiarity I saw in their faces.

I walked in and started to settle in for the morning tea that the parent's group had organised. I was keen to talk to parents over a coffee. I wanted to hear their story and their experiences. This is one story that I have heard in many different ways. There was always something new, something different and something that drew my attention. I often felt as if I was watching an artist paint an elaborate picture on a canvas. Every time a parent offered their experiences it added shades of colour at times with deep and other times subtle brush strokes. All experiences enriched the painting. I noticed a man by the window. He had his eyes fixed on something far away from the hospital. I stood next to him and looked out the window. A crisp morning and the landscape bathed in bright sunlight. People in the distance went about their business in a hurry. They all appeared to be running late for some urgent meeting. The glass panel on the window seemed to divide the world into two. I learned that the man I was standing next to had his daughter diagnosed with Cancer only a few hours earlier. He was new to the world that I was so familiar with. A few paces from him was a father with his daughter who had come back to the hospital for routine checkups. The daughter had completed her treatment and getting on with life. There are many shades of colour between the two images with instances of triumphs and tribulations. One thing tied the two ends, a father's love for his daughter.

I will leave the rest of the story for a later day. I'm a member of the Parent Advisory Group where we hear stories, experiences and opinions from parents and children. We attempt to improve the way parents experience their own journey through the complex and complicated world while caring for their children. We learn from the parents and work with our dedicated doctors, nurses and other clinical and administrative staff to bring about real improvements. We encourage you to talk to us at every opportunity. We invite you to join our team of parents so you can directly influence how we make a positive impact. As once I have, there will be many others looking out the windows of the Children's Cancer Centre caught between worlds. Stand by the window with me and help others be guided by the vibrant colours of your canvas.



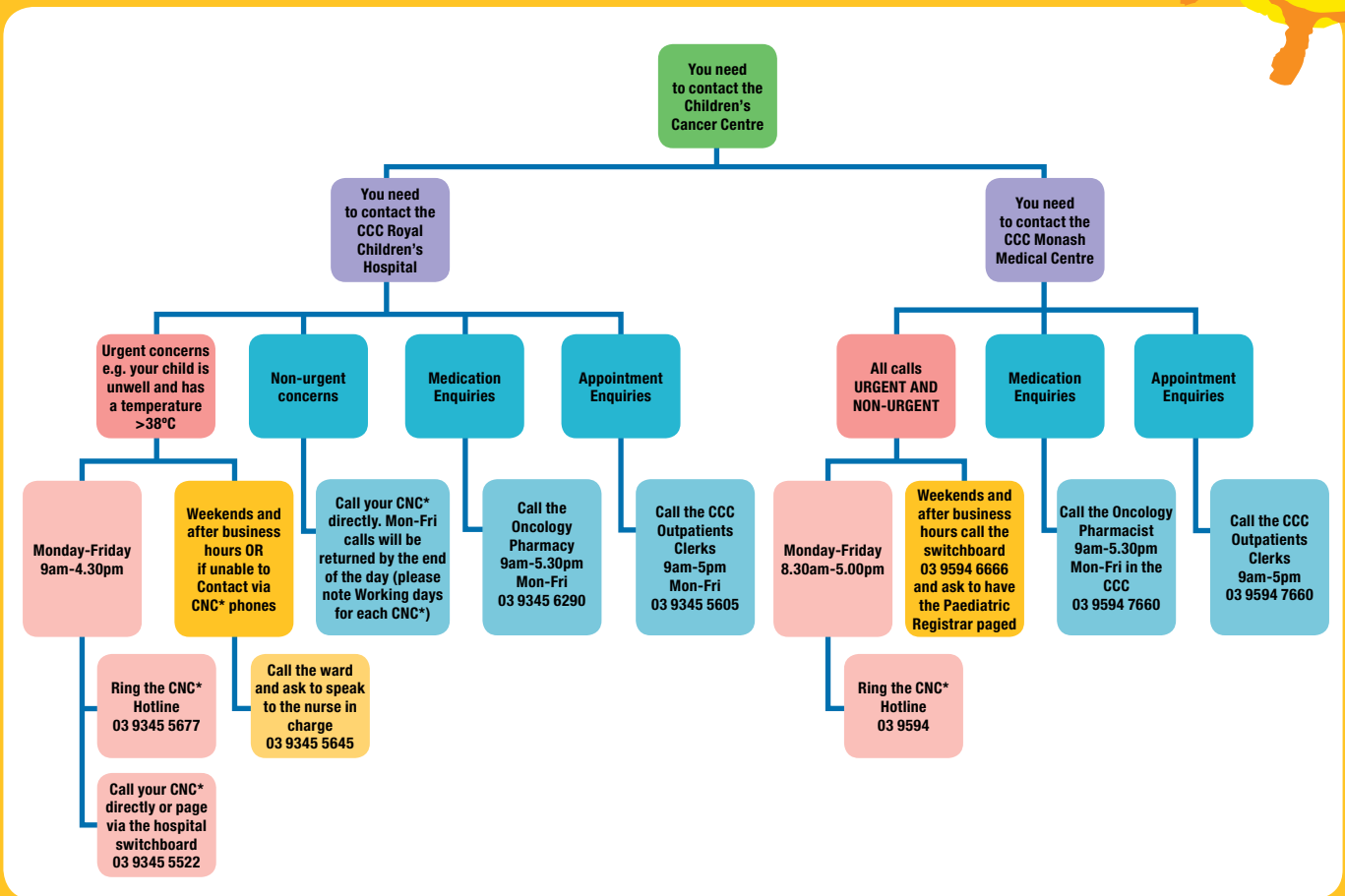
**Asanga (Parent) 0402 262 668**

**Jenny (Parent) 0438 110 989**

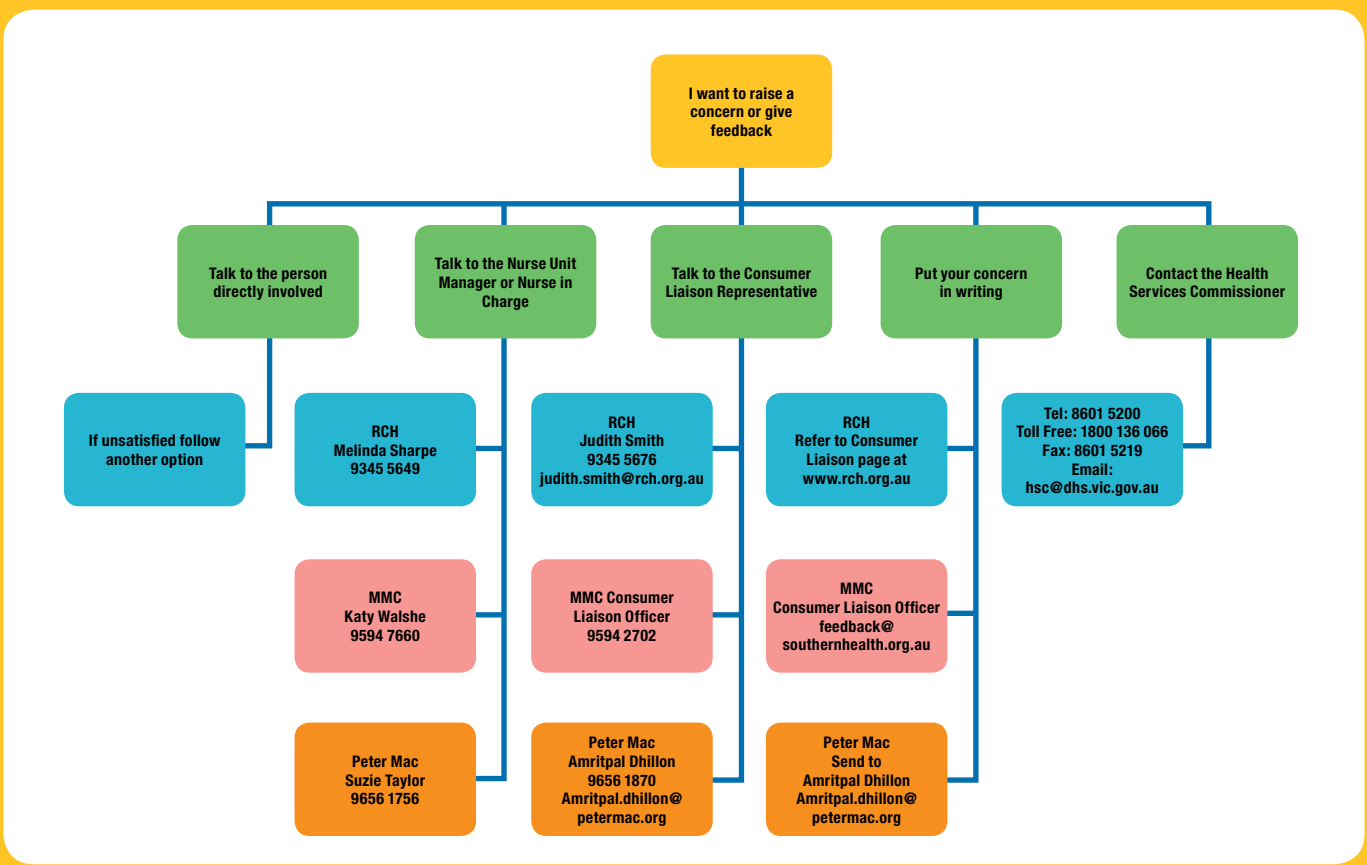
**Mary (RCH) 9345 4855**



# How to contact the CCC



# Options for providing feedback



# Clinical Nurse Coordinator Update

Over the last few months the Clinical Nurse Coordinator (CNC) team at RCH has experienced a staffing shortage. We are very pleased to announce that we now have our full quota of CNCs. The new CNCs have worked within the CCC and will be familiar to families.

The RCH CNC's along with their counterparts at Monash Medical Centre and Peter Mac form the CCC CNC team. Their clinic contact details are as follows:

Site	Clinical Nurse Coordinator	Coordinating the care for patients of	Contact details	Available
RCH	Raelee Whelan	A/Prof Ashley and Dr Orme	9345 4868 or Pager 4868 via hospital switch board 9345 5522	Tuesday – Friday
RCH	Sally Anderson and Jayne Harrison	Dr Downie and Dr Heath	9345 6975 or Pager 6975 via hospital on 9345 5522	Monday – Friday
RCH	Jeni Moodie	Dr Waters and Dr Super	9345 4867 or Pager 4867 via hospital on 9345 5522	Monday – Thursday
RCH	Luke Mc Eldrew (replacing Aimee Stewart's parental leave)	Bone Marrow Transplant families and Dr Tiedemann	9345 5613 or Pager 5613 via hospital on 9345 5522	Monday, Wednesday, Thursday
Regional Outreach and Shared Care	Shanelle Scriven	Regional Nurse Coordinator	9345 5393 or Pager 5393 via hospital on 9345 5522	Tuesday – Friday
Monash Children's	Katy Walshe	Monash Children's	9594 7657 or pager 5777 via hospital switchboard, 9594 6666	Monday – Thursday
Peter MacCallum Cancer Centre	Suzie Taylor	Children requiring radiotherapy	9656 1756 or pager 7405 via switch 9656 1111	Monday – Thursday

