



## The 2009 Murray to Moyne

### Madness, mayhem and magic!

**The Cytotoxic Cyclists made it...** Through the long paddocks, through towns and tiny hamlets, from one river on the border to another at the coast. In sunshine, black of night and driving rain and wind, The Cytotoxic Cyclists rode in the 2009 Murray to Moyne Cycling event to raise funds for the Children's Cancer Centre.

All of the team are connected in some way to the centre via staff, friends and relatives. In Melbourne, where it (almost) never rains, it thundered and stormed as we loaded the bus and trailer. We also learned two riders and one support crew member would be unable to participate due to family health issues.

Peter, Pratiti and Keith  
– doctors from the CCC



The Team!

Off to Echuca for a BBQ dinner and speeches. Some brief, inspiring words from Peter Downie, our oncologist, affectionately known as Dr. Doctor, who has ridden with the team for the last 11 years. A letter from Kath, Tiana's mum, was read out; so very, very sad...

On Saturday morning the team headed off just after 10.45am for St Arnaud, 228 k's away.

One of our riders, Zane, took a frightening tumble from the bike during the afternoon and was unable to ride on the Sunday.

We stopped in St Arnaud's for dinner. All of us. Something of a mistake, as we fell behind, and had some catching up to do.

We headed off into the dark for the night rides. Peter had spoken of this leg as magical-quiet on the road, stars out, cold and crisp.

2.30 am and the team arrived in Hamilton for a few hours sleep on the floor of a huge shearing shed.

We were up in the dark of pre-dawn, looking as attractive as you can imagine, and wolfing down bacon, eggs cereal, juice, coffee... it's astonishing how hungry you can get! Then we got onto the bikes to try to ride the whole last 92 km leg into Port Fairy.

It was raining, but most of us had good wet weather gear with us. It was cold, but we had a bit of a tail wind. We were tired, but the end was coming into sight. There were hills, but we were prepared to adjust our gears and speed to accommodate them.

But suddenly, with a shift in the wind, it became a different kind of event all together. Those last two despairing hours were made bitterly difficult by a freezing and gusting south-westerly wind. Our feet were frozen, shoes full of water. Death grips on the bike

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handles, we did not dare to stop, as we were frozen and exhausted. Dennis, Bob and Michael rode to the right of the ladies group, helping to shelter them from the worst of the gusts. Gentlemen, all.

Everyone rode the final ten kilometres into Port Fairy. Our support crew, bless them, cheered us on loudly when we arrived.

A hot shower, lunch, awards given... Normality slowly crept back. Kath and Paul, Tiana's parents, arrived to join us, and Kath

gave out the awards. Hugging them was heartrending. They are such very fine people.

We were quieter on the trip home. Many conversations were had, lovely people winding down for another year.

It was madness, mayhem and magic, and every minute of it was worthwhile.



The Team at the finish!

## LTF – what is it?

On December 17th 2008, the *Victoria's Cancer Action Plan 2008–2011* was announced by the Premier, John Brumby and the Minister for Health, Daniel Andrews. The *Cancer Action Plan* outlines the key priorities with regard to cancer prevention and cancer care for the state. Long Term Follow-up has been recognised as an area of high importance within the Plan. PICS has been successful in obtaining funding to develop a statewide Long Term Follow-up Program for survivors of childhood cancer.

The program will be accessible to all survivors of childhood cancer treated at the RCH or Monash Medical Centre and will provide each individual with a tailored approach to meet their ongoing needs, in the environment best suited to the level of care required. The program will be able to provide interested health and community care providers with comprehensive information about treatments, future health planning and LTF clinics at both Children's Cancer Centre sites, as well as in certain regional areas.

### What are the benefits of the LTF Program?

Everyone looks forward to the end of cancer care and life 'getting back to normal'. Sometimes this means going back to how things were before, and sometimes this means adapting to a 'new kind of normal'.

The LTF team will help children, young people and families to navigate life after cancer, and will empower survivors and families to take charge of their future health care.

Early detection and management of any 'late-effects' of cancer therapy can help to minimise the impact on quality of life and physical and emotional well-being.



Cam and Mum pop in to see Sandy 19 years after treatment

From a research perspective, any information about these late effects may be useful in modifying treatments for other children in the future.

### Who needs LTF care?

As the treatments for childhood cancer become more effective and the number of survivors increase, we are learning more about the after-effects of these therapies. Every child or young person who has lived through cancer needs to know about their experience so that they can make informed health care choices.

### When does LTF care begin?

When cancer treatment is finished, care is continued to be provided by an oncologist on a regular basis. These appointments will gradually become less frequent as the immediate effects of the cancer therapy disappear and the chance of recurrence gets smaller. The change from 'off-treatment' to 'long term follow-up' is a gradual thing and the timing depends on the type of cancer and what treatment was received.

Once treatment is over, the LTF team is available to answer questions or provide direction with regard to services and information, irrespective of whether you are in the 'off-treatment' or 'long term follow-up' phase.

In general, LTF care begins around 2 years after treatment ends. Your oncologist will discuss the timing with you.

### What can I expect from the LTF Program?

Every child or young person who has completed therapy for childhood cancer at the CCC at RCH or MMC will meet with a LTF team member soon after treatment is finished. The oncologist will notify the LTF team who will prepare an individual information pack for the next clinic appointment.

A 'Passport for Care' document has been developed, which will include a vinyl wallet and a booklet which fits inside. The booklet will contain personal information and medical contacts and has space for notes and appointments etc. The wallet will contain a detailed treatment summary, a plan (roadmap) of care for their next 2 years 'off-treatment' and any specific medication-related information that might be required. The passport is a portable record of cancer treatment, and the plan for the future. This can be shared with your local doctor and other health care providers as required.

A folder of information about life after treatment, resources for information and contact details for the LTF team will be provided. At the end of this 'surveillance period' the LTF team makes contact to invite help transition to the LTF clinics.

Some children and young people will need to continue to come to the CCC at regular intervals, others will be able to have care provided in the community or in specific regional centres.

The health professionals at each clinic will vary according to the individual needs of those attending. There are many faces in



Ngairé working in the CCC research laboratories 25 years after her time as a patient in the CCC

the LTF team. At each clinic appointment, a comprehensive physical, psychosocial and emotional assessment, will be undertaken, discussion held regarding investigations and interventions, an updated treatment summary and specific treatment-related health links or information about actual or potential health issues arising from previous treatment.

- The focus of the LTF clinic will be on health promotion and awareness, early detection and intervention of cancer-related or other health and well-being issues. The emphasis is about empowering individuals and families to take control of their survivorship and on improving the child's future health possibilities and on preparing the family for transition into a suitable adult health care setting at the appropriate time.

- The local doctor (GP) will be kept informed about the child's medical management and may be actively involved in ongoing care.

**How can you find out more?**

- The LTF Program is currently in development and there will be new information and resources coming out very shortly.

- Keep an eye on the CCC website for the upcoming Long Term Follow-up section to find out what's new in survivorship, clinical guidelines, support forums and more. Look out for regular updates in future CCC newsletters.

- Any member of the wider oncology team will be able to put you in touch with the LTF team so feel free to ask!

- If you have any questions about the LTF program, please contact the team on 9322 5181 or by emailing on [ltf.program@rch.org.au](mailto:ltf.program@rch.org.au)

- **Karen Egan**  
• LTF Program Manager  
• April 2009

## Note from Oncology Pharmacy

Chemotherapy, radiotherapy and surgery are important methods for treating a variety of childhood cancers, and many children's lives are saved as a result.

Most chemotherapy side effects are temporary and disappear once treatment is over. However, there is a chance that some of the treatments your child receives might cause problems in the future. These side effects may happen months or years after the chemotherapy has finished.

After treatment, your child is likely to have a lower resistance to infection for quite a long time after chemotherapy has finished. This will gradually get back to normal, but can take several months.

Some chemotherapy medications can cause long term problems with specific body organs. There are medications, for example, that can cause heart damage, lung damage or infertility. Your doctors are aware of this and if your child is having one of these medications, tests may need to be performed beforehand and throughout treatment so that your doctor can monitor your child.

With some medications there is a risk of getting another cancer in the future. It is a very small risk and is not associated with all chemotherapy medications. The cancer you child is being treated for poses a greater risk to your child's health and your doctor will talk to you about the specific risk with the medications your child is having. There may be no risk to your child at all.

There are many different chemotherapy medications and they all have different side effects. If you are worried about long term side effects from your treatment, ask your doctor or pharmacist about the medications your child is receiving.





## LARCH Meeting Dates

Our next meeting for 2009 is our AGM on August 18th @ 6.00 pm. This meeting will be held in the hospital Board Room on the 5th floor of the front entry building. Everyone welcome to attend and hear a presentation on the benefits of the Comfort First Program for the patients, families and staff of the CCC. The first meeting of the new committee to plan for the new year ahead will be held on September 15th at Ronald McDonald House, 22 Gatehouse Street, Parkville. Parking is available on Gatehouse Street, Flemington Road and the two side streets either side of Ronald McDonald House.

Please join us at our next meeting to be part of a positive future that sees LARCH continue raising funds for vital research.

## LARCH Puffing Billy Day

The LARCH Puffing Billy Family Day on 17th May was another great success. Everyone enjoyed their ride on the famous Puffing Billy to Emerald Lake Park and a scrumptious BBQ at Lakeside. Details of the day will be posted on our website [www.rch.org.au/larch](http://www.rch.org.au/larch)

## Contact LARCH

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## Donate to LARCH

LARCH is committed to raising funds specifically for the Childrens 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 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 [www.rch.org.au/larch](http://www.rch.org.au/larch) and sent by mail, to:

LARCH  
c/o Auxiliaries Office  
Royal Children's Hospital  
Flemington Road  
Parkville Vic 3052



## CIKA – Cancer in Kids

CIKA – Cancer in Kids @ RCH has, as always, been busy raising funds for research into solid tumours. Active Immunotherapy for Children with Brain and Solid Tumours is a project to which we have committed \$300,000 over three years so we have to work hard. We recently held a family dog show in Flemington which raised nearly \$3,000 and also raised community awareness of solid tumours in children. We are now hard at work planning the annual Blue and Orange Ball to be held on August 22 – always a great night out.

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 the Ball, making a donation or joining the group then please contact our Vice-President, Ellen Webb on 0423767136 or [ellenwebb@optusnet.com.au](mailto:ellenwebb@optusnet.com.au) or speak with Mary McGowan at the Children's Cancer Centre.

## DIARY FUNDRAISING DATES FOR 2009

<b>Saturday 25 July</b>	Sri Lankan Dinner at Flemington
<b>Saturday 8 August</b>	Night of Sparkle
<b>Saturday 22 August</b>	CIKA Blue & Orange Ball
<b>Saturday 29 August</b>	MY ROOM Ball

Contact Community Liaison Manager on 9345 4855 for details

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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