

# Children's Cancer Centre news

Issue 4 **November 2010**

## making news ...

**2** Survivorship  
Information Day

**3** ANZCHOG  
Report

Siblings Day

Clinical Trials

**4** Medical  
Information  
on the Net

## Christmas message

The Children's Cancer Centre has continued to develop in 2010. There have been many highlights but equally many opportunities for us to improve. Our developing relationship with PICS and ongoing engagement with parents, families and the broader community have been important. We farewelled some staff while welcoming many new staff members.

2011 will be an exciting year for the RCH and the CCC as we spend the last months in our current environment prior to relocating to the new RCH at the end of the year. I look forward to working with everyone in 2011 for further improvements in care, research and education to continually improve the outcomes for all children with cancer in Victoria.

Wishing everyone a safe and happy festive season and a bright and prosperous new year.

**Paul Monagle** Director CCC

## The Australian study of causes of Acute Lymphoblastic Leukaemia in children (AusALL)

### Summary for participating families

#### AusALL's aim

AusALL's purpose was to find out what causes childhood leukaemia, and how it may be prevented.

#### AusALL's investigators

Researchers in WA and NSW and childhood cancer doctors from around Australia conducted AusALL.

#### Who took part in AusALL?

416 families with a child diagnosed with Acute Lymphoblastic Leukaemia between July 2003 and December 2006 took part. These children were treated at one of the 10 specialist childhood cancer centres in Australia. These families are called the 'case' families.

1,361 families with a child who did not have leukaemia were the 'control' families. To select these families, we called Australian residential telephone numbers at random and invited parents of young children to take part.

#### What did the child and parents do when they took part?

We asked parents to complete a general questionnaire, a dietary questionnaire and a telephone interview. We also collected a blood sample and a cheek cell sample from the children with leukaemia, usually when they were having a routine blood test for their medical treatment, and

their parents also gave blood samples. Most control children and their parents provided cheek cell samples. The blood and cheek cell samples gave us the DNA needed to test for changes in genes that might have an effect on leukaemia occurrence.

#### Findings so far

We are now comparing the information provided by 'case' parents and 'control' parents to see if there are any important differences that might shed light on the causes of childhood leukaemia. Here are some of the early findings.

#### Babies' growth in their mothers' womb

We found that babies who grew larger than usual when in their mother's womb have a higher risk of developing leukaemia in childhood. We think this is related to hormonal factors that are completely outside the mother's control and we hope to do more research on the reasons for higher rates of growth in the womb. If you would like to read more about these findings, our paper published in The American Journal of Epidemiology is available at [www.ichr.uwa.edu.au/files/user37/Fetal\\_Growth.pdf](http://www.ichr.uwa.edu.au/files/user37/Fetal_Growth.pdf)

#### Taking folic acid and other vitamins in pregnancy

We found that taking folic acid or other vitamins during pregnancy did not change the child's chance of getting leukaemia. There was some evidence that taking folic acid before pregnancy

Continued over page

may slightly reduce the risk of the child getting leukaemia, but this needs to be looked at in larger studies. When we combined AusALL results with those of other studies from around the world, there was evidence that taking multi-vitamins during pregnancy may reduce children's risk of getting leukaemia. We could not pin this association down to a particular vitamin and it too needs further study. If you would like to read more about these findings, our paper published in The International Journal of Cancer is available at

[www.ichr.uwa.edu.au/files/user37/Maternal\\_folate.pdf](http://www.ichr.uwa.edu.au/files/user37/Maternal_folate.pdf)

### What other results will come from AusALL?

We are now comparing other information that case and control families gave, and the results of gene tests to see if they give any clues to what other things may change a child's risk of getting leukaemia. Specifically we are examining:

- the mothers' diet during pregnancy;
- exposure to house painting;
- exposure to pest control treatments in the home or garden
- the types of jobs that parents had; and
- changes in genes that influence the way the body processes food and chemicals

### How to get more information?

If you would like to find out more about AusALL's results, please contact me on 08 9489 7756 or email [enquire@ichr.uwa.edu.au](mailto:enquire@ichr.uwa.edu.au). Our postal address is Telethon Institute for Child Health Research, PO Box 855, West Perth Western Australia 6872

As we get more results from the study, we will add them to the web pages of the Telethon Institute for Child Health Research. These should be available from early 2011 and you will find them [www.ichr.uwa.edu.au/research/divisions/pop/groups/cancer](http://www.ichr.uwa.edu.au/research/divisions/pop/groups/cancer).

# Survivorship Information Day

## Insights from a participant's point of view

### Sydney – 29th August 2010

The theme of this day was one of empowerment; empowerment of survivors and their families. The 300-plus audience included people from many walks of life and different parts of Australia. There were childhood cancer survivors of varying ages, their parents and carers, parents attending without their children and a multitude of different health professionals.

The two keynote speakers were outstanding. Hamish Wallace, a Scottish pediatric oncologist, held just the right mix of wisdom, experience and humility. His wicked, but politically correct sense of humor held us captivated.

Debra Eshelman-Kent, a nurse practitioner runs an LTF clinic from Cincinnati had many insights and great suggestions for optimising LTF programs.

### Some salient insights

**LUCCA** (an acronym offered by Professor Wallace)

#### L = learn

Patients and their families seem to cope better when their knowledge and understanding of diagnosis and treatment is sound.

#### U = understand

Understanding of whether/how treatment may put the patient at risk of late effects.

#### C = contact person

Each patient and family should seek out a key person, a contact with whom they can refer to for support and advice when needed.

#### C = communication

Regular communication should be facilitated with the key person, including a clear LTF plan.

#### A = achieve

Following these suggestions may help survivors and their families achieve the life they wish to live.

### • Think treatment, not cancer type

Intensity, frequency and type of follow up organised should be assessed not on the type of cancer a patient has, but rather on which particular forms of treatment have been administered.

### • Exit interviews

A huge void in follow-up care exists between end of treatment and formal LTF programs. Individual family 'exit interviews' held with an appropriately informed nurse specialist may help alleviate anxiety levels for these patients and their carers.

### • LTF programs should continue to monitor the patient at the same medical facility if possible, even into adulthood.

The recognition of limitations to this caused by the need for specific 'adult sized' medical equipment, was made.

Psychologically, transition of a previously pediatric patient into adult based facilities for care, is extremely overwhelming and disconcerting.

### • Passport of drugs administered

Every patient should be given a discharge 'passport' which details all treatments administered, especially radiation and drugs and their cumulative doses. This passport is a valuable tool for making informed decisions about what particular long term risks a child is most susceptible to. This enables the LTF co-ordinator to schedule appointments and investigatory procedures which will provide best surveillance practices for the individual.

The information given was quite detailed and descriptive. Most people I spoke with gained much from the day, without feeling the presentations were too technical.

My thanks to PICS, and the CCC PAG for giving me the opportunity to attend this valuable meeting.

**Kim McConchie**

# Parent feedback from ANZCHOG

At the beginning of Spring Jenny Haig, Anne Kay and I were given the opportunity to attend the ANZCHOG Annual Scientific meeting as part of the first ever invitation to Consumer Representatives. This generous offer provided us with an opportunity to hear from some wonderful international speakers about the most current investigations into the causes, treatments of childhood cancers, work on late effects and long term follow up and strategies for supporting children and their families through the cancer experience.

If I am being completely honest, I didn't expect the material to be as engaging or interesting as it was. My medical knowledge is very basic, to say the least, and there were a few moments where the content was complex and even a little confronting. Without exception, however, I found I understood the ideas, the rationale, and the methods used to examine each presentation. Perhaps most clearly, I understood the universal motivation and determination of every clinician present to know more about pediatric cancers so that we continue to see cure rates increase.

I found this humbling and inspiring largely because the staff from

the RCH CCC were well represented amongst the presentations and universally well received. It reminded me again that the decisions regarding my child's treatment were essentially considered and determined by the worlds' best knowledge.

We were also able to participate in a National Consumers Workshop with other parents and young survivors from around Australia. It was truly wonderful to meet the other representatives and enjoy a rare opportunity to exchange information and ideas and make connections. We also began forming a collective agenda for future participation in ANZCHOG meetings in the hope that the vast-lived experience of our families can be routinely included in the continual improvement of outcomes.

Oh, and my favourite presentation? Undoubtedly Nancy Cincotta, a social worker from the United States, who presented the idea that the notion of 'hope' is one of the most useful and necessary tools for families with a child diagnosed with cancer. But then as parents we already know all about that, don't we?

Many thanks to PICS and ANZCHOG for their generous support.

**Brigitte Walker**

## Siblings Day

Twenty-two bright and bubbly siblings ranging from 5–15 years old attended Siblings Day on September 28th.

The children were given a behind the scenes tour of the pharmacy and Dr Keith Waters answered some very thoughtful and insightful questions following his talk with the group.

This was followed by lunch where the children enjoyed a variety of foods.

Nurse co-ordinator Jayne Harrison and Raelee Wheelan provided some information about central lines. They also demonstrated how blood pressure is checked, with each child eagerly lining up to participate.

Art Therapist Michelle Dixon worked with the children giving them an opportunity to explore some feelings around the impact of having a sibling with cancer.

The day ended with certificates, lots of smiles, friendly chatting and great artwork.

The feedback we have received from the siblings and their parents has been tremendously positive.

The social workers in the CCC would like to thank everyone who was involved and helped to create this very special and memorable day.

Please speak with your Social Worker to find about sibling days in the future.



## Clinical Trials Office update

There was much activity in the Clinical Trials Office earlier this year as we began preparation for our three year audit by the Children's Oncology Group – (COG). COG as many of you know is the world's largest childhood cancer research organisation and the primary supporter of our clinical trials. Their mission statement – “to cure and prevent childhood and adolescent cancer through scientific discovery and compassionate care” – is reflected and supported in the ongoing research and effort to open and maintain new clinical trials at the CCC.

The audit is a major event for us and a mandatory requirement for RCH if it is to continue its standing as an accredited COG institution. The audit is just one of a number of elements used to grade our overall performance by COG. We are also graded on the number of “delinquent” or late data reports for patients enrolled on study, the number of studies we open and the number of patient enrolments we accrue each year. At the end of each year, our report card is released showing our overall performance score in each of these areas. Although the Data managers are largely responsible for preparation of the audit, a successful outcome can only be achieved with combined support from the entire multidisciplinary team. I am very pleased to be able to announce that we have successfully obtained re-accreditation with COG for the next three years.

The next few months will be a busy time as we open a range of clinical trials, including those studies using therapeutic agents not used in paediatric trials before. In doing so, we look forward to increasing the number and types of trials offered to ensure all patients continue to have access to the most up to date therapies available.

**Gayle Cantsilieris**

Clinical Research Associate  
Clinical Trials Office



# Finding reliable medicine information on the Internet

**There is a vast amount of information on the Internet about medicines. Some of it is reliable and relevant to medicines in Australia, but some of it is not. This information gives you a few hints and tips on finding reliable medicine information.**

## Points to consider

**It is vital to remember three things when you're looking for health information on the Internet:**

**1** No one is responsible for the Internet – anyone can post information and although some sites are careful about checking information posted, this may not be true for every website.

**2** There are some people who use the Internet to make money, either by selling medicines illegally, selling medicines that do not contain what they say or selling products that do not work.

**3** Remember that healthcare in other countries is organised in different ways to Australia. Some treatments might not be available in Australia or be offered to different people. In addition, some conditions or medicines have different names in different countries.

There are other points to consider as well when you are looking for information about medicines on the Internet:

**Medicines have two names: a generic name and a brand name.**

For instance, paracetamol is a generic name and Panadol® is a brand name. You may also hear medicines referred to as 'proprietary'. This is the same as a brand name medicine.

**Medicines sometimes have different names outside Australia**

– they may be known by their generic name or the manufacturer may use a different brand name. For instance, paracetamol is known as acetaminophen in the USA.

Some medicines were originally developed to treat one condition but were found to help a completely separate condition so any information you find might seem misleading.

When you read any information, you might also read that the medicine is not licensed for children and young people, but is licensed for adult use. We will only use medicines that have been proven to be safe and effective in children by extensive research. You can be assured that an unlicensed medicine has only been prescribed because no licensed alternative is available.

The majority of side effects are identified when the medicine is being tested, and they are all included in the patient information leaflet. This can make for worrying reading, but remember that some of the reported side effects are extremely rare.

## People you can ask

Your hospital pharmacist or doctor should be your first port of call if you have any questions about medicines.

Ward nursing staff and community pharmacies can also be helpful resources, especially after hours if required.

## Search engines

It is the easiest thing in the world. Just type in a few words into a search engine and get lots of web pages back in seconds. However, using a search engine is not always the most reliable way of finding medicines information on the Internet.

When you find a website covering your area of interest, you need to ask yourself a series of questions before accepting what the website says.

**Remember to be cautious when reading any information on the Internet.** A website that appears to be credible might not be all it seems. Learning to think critically about information is a vital skill in using information well.

**The sorts of questions you should be asking include:**

**Who has produced the information and posted it on the internet?**

Follow any links on the site that say 'home' or 'about us' to find out more. Visit websites produced by organisations you trust first, those from academic, professional or government organisations will be the most reliable ones.

**Look at the date when the information was produced and/or posted.**

As a general rule, be wary of any information produced more than four years ago. Information about specific medicines should be updated more frequently than this, often once or twice a year.

**Ask yourself why the website is there.**

Is it trying to recommend a particular product to you or a specific company? If the website is selling something, the information it provides may be biased.

## Using the information you find

Talk to your doctor or pharmacist about the information you have found. It might be a good idea if you use the information you find to put together a list of questions to ask.

**Oncology pharmacy staff RCH**