In December 2004 Prof van Dongen was the guest speaker of the Adelaide Blood Club meeting at WCH. He is both a paediatrician and a brilliant laboratory scientist from the Netherlands.

Prof van Dongen gave an excellent talk on Minimal Residual Disease. His expression describes the situation when after chemotherapy a small amount of leukemia or tumour cells are still present in the patient's body. At an early phase of the disease, the presence of even very small numbers of leukemia cells can have an influence on survival. This important observation is now incorporated in the current Acute Lymphoblastic Leukaemia Study VIII and enables us to plan the intensity of treatment even more accurately than before.

As an invited speaker at the ANZCHOG Conference in Melbourne, Dr Peters extended her stay in Australia to share her experience and knowledge on Stem Cell Transplantation here in Adelaide. Dr Peters also holds one of the busiest transplant units in the world at the St Anna Children’s Hospital in Vienna, Austria.

Dr Peters gave an informative talk on the supportive care of children undergoing stem cell transplantation. This was a timely topic for us with plans for an extended transplant program.

She also talked in great detail about the transplant indications & modes of transplant in children with ALL.

Adelaide also hosted a leading Haemophilia treator, Prof Victor Blanchette. He gave an evening seminar on new strategies and his experience in prophylaxis, offering children once a week factor VIII infusions and increasing to 3 times a week depending upon adequacy of biochemical. New insights into genetic reasons for bleeding and why some children with severe Haemophilia B (less than others are starting to emerge. These findings may soon become applicable in the clinic and help with treatment plans.

**SUPPORTERS LIST**

We thank the following organizations, groups and individuals for their generous support of our work:

- **Buey Day**
- **Camp Quality**
- **CanTeen**
- **Childhood Cancer Association**
- **G N Wicker**
- **Hudson Meher Foundation**
- **Kids with Cancer**
- **Landmark**
- **Leukaemia Foundation**
- **McGuiness McDermott Foundation**
- **Paul Williams**
- **Red Kite**
- **Ronald McDonald House, Adelaide**
- **South East Children’s Cancer Association**

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**PAEDIATRIC HAEmatology - Ongiology**

**NEWSLETTER**

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- "Musings of a Master"

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Welcome to the first edition of the Haematology – Oncology Newsletter. The aim of the newsletter is to inform our patients and families of our research and service improvement activities. We also want to thank our wonderful donors and fundraisers who make these activities possible.

We plan to publish a newsletter once a year and are really keen to have your feedback. So please write in with your ideas and contributions for future issues. Please forward your comments to the Haematology – Oncology Newsletter Editor, Broomei West, Children, Youth and Women’s Health Services.

The team are presenting “Little Aussie Red Riding Hood”, a Pantomime this Christmas which is a perfect opportunity to launch our newsletter. The pantomime is a fun family activity and our way of welcoming our families, supporters and friends a VERY HAPPY CHRISTMAS AND HEALTHY 2005.

Warm and festive wishes to all.

Tom and Meave

And the combined Brookman, Ronald McDonald Clinic and Haematology Laboratory Team

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Why do we need research in children?

Improving patient care through clinical and laboratory research

When we talk of scientific research, people often connect it with obscure laboratories, animal experiments and wearing of a lab coat. Yet some of the greatest discoveries in paediatric haematology-oncology were the result of such research. This can take the form of careful observation, for example the discovery that certain developmental abnormalities are linked with an increased risk of cancer. If these children are followed up closely, cancer can be detected early and dealt with more easily. Clinical trials are conducted in groups of patients (including children) to explore the role of a new drug or treatment methods. The results may not change the treatment for those participating in the trial but help to form the basis of new treatment methods for future patients. All current treatment protocols are based on the experience and results in hundreds or thousands of patients before. Many trials have also shown that treatment results are improved in children who are treated in line with scientifically run clinical trials than in those who are treated in the basis of ‘personal experience’.

Laboratory research in paediatric haematology-oncology mostly entails using cells or tissues removed for diagnostic purposes to research an unknown biological aspect of the disease or actual cells that are left over from diagnostic tests in children with leukaemias are subjected to detailed ‘interrogation’ with very sensitive molecular genetic methods. In the last decade this allowed us to detect very small numbers of leukaemic cells (one leukaemic cell among 100,000 normal cells) that may still be “hiding out” among the normal blood or marrow cells. ‘Timely detection of these cells (the so-called minimal residual disease study)’ is a major treatment development and this approach is now a vital part of the current Australia-New Zealand Childhood Haematology-OncoLOGY Group (ANZCHOG) Study 8 protocol.

We, as a group would like to foster an open and joint approach with parents and fund-raising groups to promote research in children with cancer and blood disorders. Only with such an approach can we ensure that we do our best in improving the outcome for children and young adults with these serious illnesses.

A/Professor Tom Revesz
Haematology Information for Parents and Families

Listening to and meeting the needs of families is a vital part of the service the unit provides. Families have highlighted the need to improve access and provide information about their child’s disease. In recognising these areas for improvement the unit has committed resources to the development of information specific to families of children with rare blood disorders. Generous financial support from the Hudson Waterer Foundation has made this possible with the funding of nursing hours to manage the service improvement project.

The process of writing specific quality health information involves both the Haematology Onology Team and consumers. A number of nursing staff have written health information sheets, with further topics being developed. The clinical practice committee will then review and endorse these topics to ensure they are based on the best available evidence and are of a high quality.

Parent help is crucial to the success of this project and there are a number of ways they are involved including giving feedback on the new health information sheets.

One of the aims of the project is to improve access to information for families. Finding different ways of providing this information is being explored. A favoured option is to have computer access to useful Internet sites for families as well as unit developed printable information. Future projects includes the possibility of touch screen computers for families to access health information relevant to their child’s disorder, whilst in FMDC.

Providing health information is crucial to ensure families understand their child’s disease and care as well as being involved in the decision making process and helping them cope with the stress of diagnosis.

Anne Jacon CN
Heather Palmer CNS

Clinical Trials Program

Multidisciplinary team in therapeutic research in childhood cancer has been responsible for enormous improvement outcomes. Clinical trials in large tertiary care centres or co-operative group member institutions are the best way to improve outcomes for Australians of all ages with cancer.

Clinical trials are needed to assess the success of treatment programs and to find the least toxic treatment while maintaining excellent survival. In addition, rigorous trial discipline improves the quality of patient care as shown in better overall outcomes from treatment in trial centres.

The data office is the centre of research information in the Haematology and Oncology Unit. At this present time we have 23 trials open or temporarily closed to accrual. 5 studies in the process of being opened and 10 studies closed but active to follow up.

Clinical trials which are being run in the data office are coordinated through the Australian and New Zealand Children’s Haematology and Oncology Group (ANZCHOG), the Children’s Oncology Group (COG), the International Society of Pediatric Oncology (SIOP), and the International Society of Thrombosis and Haemostasis (ISTH).

The Oncology, Blood Disorder and Central Access Devices databases are kept up to date and are presently being reviewed to improve the quality of data available.

The aim for the future is to improve clinical trial recruitment. To do this we need to continue educating all members of the Haematology and Oncology discipline and the wider community as a whole to the benefits and the availability of studies. At the same time there is also the need to open more studies as they become available, so we can offer trial enrolment to all patients in our care and to the wider community of South Australia.

Carina Boehm, Late Effects Clinical Nurse

Colin Story, Scientist in Charge
Haematology Laboratory

Left to Right: Margaret Roberts (Pharmacist); Dr Maria Kirby (Principal Investigator); Barbara Chamberlain (Clinical Research Associate); Mary Dovens (Nursing Unit Head) and Nina Green (Clinical Research Associate).

STEM CELL TRANSPLANTATION SERVICES

As many are aware, the Bone Marrow Transplantation program at the previously named Adelaide Children’s Hospital was established in the early 1980s. Chris Jumper, Ian Togood and Michael Rose were the pioneers in those early days with help and support at Karl time from the adult haematologists at the Royal Adelaide Hospital. Whilst at first we performed simple bone marrow infusions, patients’ own bone marrow cells, cells in the fighting from performing transplantations.

In total we have performed 247 transplants at the Women’s and Children’s Hospital – with 164 using a patient’s own cells and 63 coming from related donors. Over this period of time we have built up extensive experience in the management of these transplant.

As of 2015, we have performed both allogeneic and related transplants in patients.

Over the next 18 months to two years we will be working towards giving more experience in unrelated and cord blood transplantation and hope to perform these in Adelaide in the future.

We are aware of the benefits to our patients and families if these transplants can be done here rather than interstate. Adelaide has a history of being a world leader in the use of peripheral blood stem cells for transplantation and we are aiming to build on this.

Dr Heather Tapp

New Research into Prostate Cancer’s (Alimentary Thrombocytopenia FMATC): A new collaboration between the Dept of Haematology, Australian Red Cross Blood Service and the Dept of Obstetrics has started examining FMATC. This is a serious and poorly defined (the licenced agent) in newborns and adults. It is usually due to a specific antibody against a platelet glycoprotein called HPA-1a. Our lab will be investigating a new method for measuring this antibody along with the screening. For its development and following the antibody through pregnancy. We hope to progress a clinical intervention in the future.