Nursing HSANZ-NG Newsletter Haematology

April 2014 *Volume 8: Issue 1*

Inside:

Plus much more…!

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The countdown is on...
7 months until HAA 2014!
19-22nd October 2014, Perth WA
REGISTRATION OPENS: April 10th 2014

ABSTRACT CLOSING DATE: 1st July 2014

www.haa2014.com

The WA team has been busy preparing the nursing program for HAA this year. We are delighted and excited to have Dr Kathryn Tierney (RN, PhD) oncology nurse specialist from the BMT program at Stanford University Medical Centre in California USA join us as our keynote speaker. Kathryn's area of interests include that of GVHD, sexuality and care of the older transplant patient and she will be presenting in the combined HSANZ session, nursing stream and hosting a nursing masterclass. Kathryn will be joined on the program by a range of excellent local speakers who will be presenting on a range of topics. Of course there will be plenty of time for 'Free Communication' where your hard work, projects, programs and research has space to shine! Please do considering sharing your good work by submitting an abstract to HAA nursing stream. Free Communication slots provide a safe and welcoming environment where you can present your work to your peers. Not presented an oral before? Why not submit your work as a poster? Previous editions of this newsletter have highlighted how to write an abstract and prepare a poster – why not review the back editions available on the nurses webpage of HSANZ website.

HAA 2014 Perth program highlights include:

- A focus on blood and bone marrow transplantation; GVHD, managing the 'older' patient; donor selection
- Back by popular demand – an interdisciplinary panel based complex case discussion focussing on a transplant patient
- Paediatric/adolescent & young adult sessions will showcase the work Perth is doing in this area of haematology nursing
- Pragmatic approach to managing myeloma – unravelling this ever complex blood cancer; updates in research & practice
- Nursing 'How To…' workshops focusing on a range of current topics

The nurses group continues to promote and encourage the good work of haematology nurses by providing grants for best abstracts submitted to conference. There will be 3 awards for best oral abstracts submitted and 1 for best poster as judged during conference. Awards are based on criteria and marked by a panel of haematology nurses. See past editions of newsletter to remind yourself of criteria used to judge best abstracts. More information also available on the conference website soon so please take the time to regularly check for program updates.

HOLD THE DATE

A Back2Basics education seminar will be offered to all nurses new and/or interested in haematology nursing. This day will be held Saturday 18th October, the day before the official program commences. The seminar will be aimed at those nurses working on the fringe of haematology, those who care for haematology patients within general areas or those new to haematology or those who just want a refresher in the basics of haematology nursing.

Perth in October is usually warm & sunny! It is because of our endless summers that many Perth activities revolve around the outdoors. So, if you enjoy sightseeing, wildflowers or lazing on clean, sandy beaches, Perth is your perfect destination for a holiday after the conference. Margaret River is only a few hours' drive away and I've heard they make a great Shiraz!

Now's the time to be thinking of your abstracts to submit, the reams of paperwork needed to attend (!) and finding those finances to support your attendance. I look forward to seeing many of you in later in the year in sunny Perth.

Cassi Lawrence
Local organising committee nurse HAA 2014.
HSANZ NG WA Chair.

A word or two from the President…

Well I survived the chills of an English Christmas, having spent it with family in the UK. I was more in danger of being swept away in the floods than suffering frostbite and am glad to return to the warmth of Australia. The year has continued with a travel theme for me with a recent invitation to visit some of the top haematology departments in China to share my experiences of the clinical management of myeloma. I welcomed the opportunity to visit other haematology nurses from around the wider region. I was most grateful for their kind hospitality shown to me by the local nurses and medical staff. They showed me around their departments and clinical areas and so keenly wanted to learn more about how we nurse in Australia. You can read more about my short trip in this edition of the newsletter. I've invited all my new friends to visit us at HAA 2014 and beyond and hope we can form an ongoing partnership to help each other improve care of people affected by haematological conditions, throughout the region.

This edition of our newsletter has an international theme. With a report on my recent visit to China alongside 2 reports from the recent Tandem BMT meeting in Texas. May I take this opportunity on behalf of the HSANZ nurses group to congratulation Prof Jeff Szer, Director of clinical haematology and BMT service Royal Melbourne hospital for receiving the prestigious Mortimer M Bortin award at this years Tandem BMT meeting. You can read Prof Szer's full report in this edition.

We also welcome a short report from an overseas nurse visitor Beatrix Kirchhofer from Freiburg Germany. Beatrix's visit reminds us all of the opportunities available to nurses to apply for and receive support to study, travel and attend conferences through a variety of grants, fellowships and sponsorships. Cathy Barnett's article on *'scholarships, travel grants and bursaries'* outlines how to make the most of opportunities available to nurses and provides us with some further information and useful resources to help direct you to seek out funding opportunities. Through the efforts of our own organisation we have sought and continue to attract sponsorship opportunities for haematology nurses to attend conferences. Most recently congratulations go to the 7 nurses who will be attending the upcoming *The World Federation of Hemophilia* congress in Melbourne. We look forward to hearing more about their experiences in the next edition.

I know its not overseas but Perth is a long way from Sydney – so I for one will be treating my trip to HAA 2014 with an international approach! Cassi and her capable team are putting the final touches to the nurses program this year, which is shaping up to deliver something for everyone. Keep an eye on the website to read more about the invited speakers, the full program and don't forget to get those abstracts in; leave forms signed.

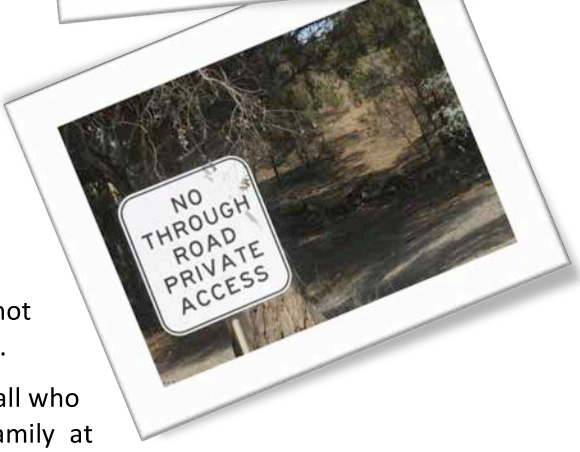
Congratulations to Natalie D'Abrew for the safe arrival of her beautiful baby boy Angus. Natalie undertakes the design and publishing of our newsletter in her spare time and has managed to give birth and manage the care of a newborn and her family whilst publishing this very edition! On behalf of the whole of HSANZ NG I want to thank her for her going above and beyond this edition

As ever, I'd love to hear from any of you with ideas and contributions for newsletter editions ahead so please do get in touch with me directly, I'd love to hear from you. See you in Perth.

Tracy King
President HSANZ NG
tracy.king@sswahs.nsw.gov.au

Stepping up to a Clinical Nurse Consultant (CNC) role for children with Haematological or Oncological diseases, who live in Rural NSW.

Tina Iacono
Acting Clinical Nurse Consultant
Sydney Children's Hospital, Randwick.



There was never any doubt that when I first started my nursing degree I wanted to do paediatrics and from my second year of nursing I found paediatric haematology and oncology to be my passion. I am currently a registered nurse at Sydney Children's Hospital (SCH), Randwick and work within the Kids Cancer Centre (KCC).

About 8 months ago I was given an opportunity to act up in a secondment position as the CNC for Paediatric Haem/Onc Rural Outreach and Palliative Care. Becoming a CNC has always been something I have wanted to achieve. So I studied hard and completed a postgraduate and a Master's degree in haematology and oncology.

When I was offered the secondment my first thoughts were:

"Yes! No More Night shift"…."What am I going to wear?" and then….
"What exactly do I do?"

I quickly learnt that being a CNC was a lot more involved than what is advertised and described in any position description. I found it a privilege to be in a role in which I am seen as a role model, leader and resource person not only to my colleagues but also the patients and their families that I look after.

The role definitely means added responsibility. I have a caseload of patients all who have either a haematological or oncological disease. I meet with the family at diagnosis and explain my role. I inform them that I am their' link' between SCH l and home. Where ever that may be. In my role 'home' includes all areas of NSW, from outside of metropolitan Sydney as well as the ACT. The areas we cover include from Helensburgh and down south to the Melbourne border, Campbelltown and further west as well as from Berowra and north to the Queensland border.

I sit down with the families and provide them with information about the child's disease, educate them about the treatments, side effects associated with treatments and provide a listening ear for them to talk about their fears about diagnosis and what it means for the child and their family. Developing a trusting relationship with the families is essential, as I want them to feel that they can contact me at any time to either ask me questions or inform me if the child is unwell. I offer reassurance and provide them with a plan that we put together with all of their admissions, clinic visit times, when they require blood investigations. We set up links between the local hospitals and SCH and devise action plans in the local hospital to ensure that a child who is being treated for a haematological or oncological disease and who presents febrile or acutely unwell is reviewed and treatment is commenced within an hour of their presentation to hospital.

This involves education to the local hospital, educating them about the dangers of oncological emergencies and other side effects related to cancer treatment, providing them with education on how to access port-a-caths and hickmans catheters l in children as well as delivery of chemotherapy. Empowering those nurses to have the confidence to look after children who present to hospital in a safe manner as well as providing excellent quality care. When I know a child is going to be heading home then contact is made with the local hospitals informing them what treatment the child has received here at SCH and what side effects they may present with. We encourage our rural hospitals to set up folders on each child that is newly diagnosed so that they will have up to date information in a readily accessible place that can easily be presented to medical staff if the child was to present.

As a part of my role, I also undertake school visits to the school at which that child attends. Attending school is a very important aspect of a child's normal development of social, learning and developmental skills and attendance during treatment despite being erratic, is something we encourage. We want the children to feel welcomed when they go back to school as well as ensuring that the teachers have some education on what to do and who to contact if the child becomes unwell whilst at school. Our visits also involve speaking, in an age appropriate manner to the class of the ill child. We attempt to allay fears around the child's illness by answering questions honestly and discussions are done around why and how the child might look different on their return to class but they are still the same person as well as demystifying the diagnosis and its treatment.   The KCC also runs a number of outreach clinics. The clinics are located in Coffs Harbour, Armidale, Canberra, Campbelltown and Wagga Wagga. These clinics run 4 times year at each place. We organise the clinics and book patients in who have been or are currently being treated for haematologic or oncologic diseases. We then travel with medical staff to these locations and review patients there. These clinics were put into place so the families do not have to travel to Sydney as often to be reviewed by their Oncologist/Haematologist.

Palliative care is also an area that we are involved in. There are very few solely focused paediatric palliative care services available for children. Especially when the child is from the rural area's we co ordinate palliative care for a child by arranging visits or cares by either their paediatrician or adult palliative care services and link them in with SCH palliative care team. We educate families on how to look after the child at home should they choose to die at home and remain in close contact to ensure the child's end of life is made as comfortable as possible.   Overall, I have found this experience as a CNC to be extremely rewarding. Being in this position has really highlighted how physically, emotionally and financially tough it can be for the rural families when they have a child who is being treated for cancer. I have learnt a lot over these last 8 months and am enjoying my new role as a CNC. I am sure I will continue to grow in developing my professional capacity in this role.

Germany to Australia: Beatrix Kirchofer, CNC visits abroad with an EONS travel grant award

My name is Beatrix Kirchhofer and I work at the Centre of Tumour biology in Freiburg, which is in the southwest of Germany, as a Clinical Nurse Consultant. The Centre of Tumour biology is a comprehensive cancer centre with around 200 beds for cancer medicine and care, comprising medical oncology department and the department of oncologic rehabilitation. The department for medical oncology mainly treats patients with solid tumours, however the focus in rehabilitation wards includes patients after bone marrow transplantation.

The position of Clinical Nurse Consultant is still not very common in Germany. In our hospital I am the first and the only one. This is a significant opportunity and a challenge to develop this position to ensure it provides improvements of the care for patients. Therefore, for me it is particularly valuable to see how other countries with more experience with CNCs, have developed the roles.

The European Oncologic Nursing Society (EONS) supports every year, two nurses who are working in oncology with a travels grant of 2500 € to obtain clinical experience by visiting another cancer centre. With the support of my nursing director I applied for this grant and decided to visit the cancer centre at the Royal Prince Alfred Hospital in Sydney, based at the Cancer Nursing Research Unit with Professor Kate White. In the three weeks I have spent here, I have had the opportunity to learn from many experienced CNCs, visiting a new specialty area each day, at St George Hospital and RPAH.

On my day with Tracy King, the Clinical Nurse Consultant for Multiple Myeloma I found the role very different from that of a CNC in Germany. Very interesting for me was to see the similarities and differences in treatment and aftercare for bone marrow transplant patients that go beyond what nurses do in providing care. The differences in education these patients received from the nurses here and in German were interesting, although one day might be too short to go deep enough into this subject. In German there is a strong focus on rehabilitation and this is provided as an inpatient.

These three weeks based at the CNRU and meeting CNCs has given me insight about the work nurses are doing here, although I cannot transfer everything to my work in Germany. Very impressing for me is the fact how autonomously nurses are working here in Australia. And with all these great impressions I got here I go back to Germany with a new motivation to develop position there.

Beatrix visits the RPA Museum during her visit. We're all thankful nursing uniforms have evolved over the years!!

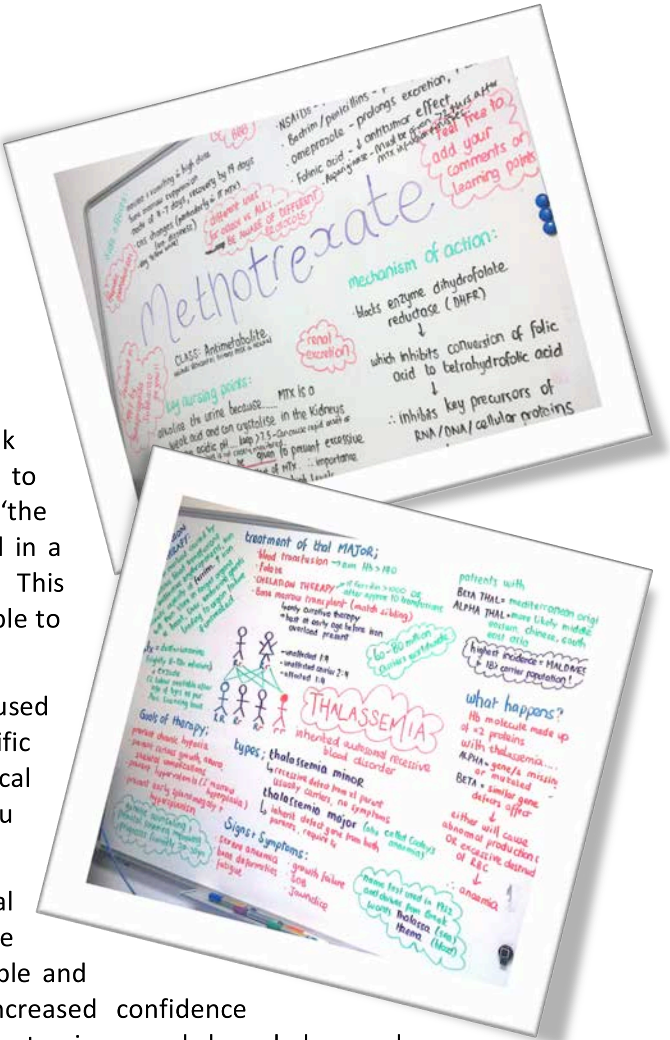
When first approached by Beatrix in early 2013 about coming to spend time with the Cancer Nursing Research Unit and clinical colleagues, I was excited to think that Australia was recognized for the evolution of senior clinical cancer nursing roles. In a short time Beatrix became one of our group, slipping into the clinical care environment with ease. International visits such as this are an opportunity for learning for both parties. I have found listening each day to Beatrix's description of what she has observed, her enthusiasm and excitement for what she was learning, her awe of the autonomy and professional recognition of the CNCs, gave me pause to stop and reflect. It is easy to focus on what has not been achieved, or isn't working. More importantly we need to take stock of what is working, recognize and celebrate the success and the contribution nursing roles make to cancer care in Australia. If you haven't considered travelling to visit a different centre, I would strongly encourage you to do so. It has been a pleasure to have Beatrix spend a brief time with us, and we hope she will return again.

Professor Kate White, Director, Cancer Nursing Research Unit

The Writing's on the Wall: An innovative approach to improving ward education

Jane Anderson, RN

Sydney Children's Hospital



When completing my mandatory chemotherapy accreditation at Sydney Children's Hospital last year, learning the mechanism of action, side effects and nursing responsibilities for all the different agents used in multiple different paediatric treatment protocols proved extremely daunting and overwhelming for me. From previous adult learning experiences, I knew that visual aids were an effective tool for me and I wondered if such tools might be helpful for my colleagues in a similar situation. And so 'the Board' was born.

After seeking approval from my ward manager, I targeted a blank whiteboard in our units nursing and medical handover room to summarise the most common chemotherapy agents. The nature of 'the Board' allowed for repetitive exposure to the information presented in a physical environment where both nurses and doctors frequented. This meant all staff, regardless of their shift patterns, were exposed and able to take part in the education and discussions that 'the Boards' generated.

Following the successful presentation of approximately 8 commonly used agents, 'the Board' then became a new medium for ward specific education directed at the needs and requests of the nurses and medical staff. Diseases, drugs, study protocols, treatment side effects…you name it, we've summarised it!

Evaluation through satisfaction and impact surveys is ongoing. Initial feedback is that since the implementation of 'the Board', nurses have expressed a high level of satisfaction to the informal, easily accessible and simplified education modality. Most encouragingly, staff have increased confidence participating in treatment related discussions; education of parents; improved knowledge and understanding of common disease processes, and in general, a greater understanding of their roles and responsibilities.

Another positive aspect that has come from 'the Board' was the positive response from multi-disciplinary teams who also read and learned from the boards. Such teams have since worked with nurses in developing boards with relevant educational information specific to their specialty, such as Palliative Care and Acute Pain Services. Furthermore, following the presentation of this initiative at our hospital's Annual Nurses Year in Review, three other wards throughout the hospital have decided to employ this adjunctive education strategy with very positive responses on their own wards.

For me personally, this project has been a fantastic learning and teaching opportunity as I work to becoming a specialist nurse in the oncology/haematology setting. It perhaps also serves as a reminder to all nurses that professional development and education is our personal responsibility and that simple ideas can often lead to improved satisfaction and confidence in patient care and with colleagues. I encourage others to think outside the square…or in my case, inside it!

A View from the Antipodes: Transplants, Registries and Beyond

Jeff Szer
Professor/Director Department of Clinical Haematology & BMT Service,
The Royal Melbourne Hospital.

CIBMTR
CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

Mortimer M. Bortin Lecture
A View from the Antipodes:
Registries, Transplants and Beyond

Jeff Szer, MBBS
Royal Melbourne Hospital

Thursday, February 27, 2014
7:30 pm - 8:00 pm
Texas B+D G

Jeff Szer receiving the Mortimer M Bortin award from Mary Horowitz (Current CIBMTR Chief Scientific Director) and Tom Shae (CIBMTR Executive Committee Chair).

I was honoured to given the Mortimer M Bortin lecture at the Tandem Bone Marrow Transplant meetings in Grapevine Texas (just outside Dallas) in February this year. The title of this paper is the title I chose for the lecture. The Tandem Transplant Meetings have nothing to do with double autografts in myeloma, rather reflecting the joining of two important organisations in BMT: The American Society of Blood and Marrow Transplantation and the Center for International Blood and Marrow Transplant Research (CIBMTR). This annual meeting now attracts almost 3000 registrants and incorporates some important subgroups such as paediatrics, nurses, pharmacists and administrators of BMT services. The CIBMTR conducts observational research using its comprehensive database of transplants from over 500 international centres (and over 350,000 reported transplants) including 16 centres from Australia and the research arm of the US National Marrow Donor Program. It has been a tremendous force for progress in the field over the past 40 years. The late Mortimer M Bortin was the founder and initial Scientific Director of the Center and served in this capacity until his retirement in 1994. His vision was instrumental in realising that prospective international collaboration would be important in ensuring that universally applicable conclusions could be drawn from transplant outcome data. To honour this great pioneer in BMT, a named lectureship was created and I was asked to deliver the 11th such talk recently.

I have spent most of the last 30 years working on a variety of committees (both scientific and administrative) of the CIBMTR and was the co-organiser of the 2010 meeting in Orlando and I guess my persistence in attending middle-of-the-night teleconferences was what they rewarded me for. I saw my participation in CIBMTR affairs as a way of ensuring that our northern hemisphere colleagues didn't forget about us down here. I think I succeeded. The CIBMTR has always published a map of the world with participating centres highlighted. It took me about 10 years but I managed to get them to remove a yellow dot from the environs of Alice Springs. If ever a BMT service is set up in Central Australia I hope we can reinstate it in much less time than that.

I used the opportunity of the lecture to remind the audience of the contributions of Australian investigators to the field of BMT. I pointed out that one of the first clinical descriptions of BMT was published in the Medical Journal of Australia in 1966 by the late Professor Barry Firkin, who described sequential infusions of syngeneic (identical twin) bone marrow cells to cure a patient with aplastic anaemia.[1] This really was a seminal publication and has often been cited amongst the earliest successful reported transplants. After this, I made reference to the amazing discovery of the controllers of haemopoiesis, the haemopoietic growth factors, by Ray Bradley and Don Metcalf in Melbourne starting in the 1970s.[2] While the eventual development of recombinant human GM-CSF and G-CSF did make a difference to neutropenia post chemotherapy, the application of these agents with the most impact for patient outcome was that of the discovery of the progenitor cell mobilisation properties of filgrastim (rHu-GSF) also made in Melbourne and based on the initial observations of Dührsen.[3]This paved the way for expanding curative and palliative autologous stem cell transplantation[4] for a vastly increased number of patients and eventually created a new stem cell source for allogeneic transplantation.[5] I concluded the science with the observations in a study from Brisbane that filgrastim-stimulated bone marrow as an allogeneic stem cell source had the advantages of blood cells (more rapid engraftment) without the major disadvantage (chronic GVHD).[6] Most recently, I referred to the data presented in December 2013 at the American Society of Hematology meeting of the Canadian-led multinational randomised study in which these benefits were not seen. Several Australian BMT centres participated in this trial.[7] I described the contribution Australian research had made in the use of prophylaxis against cytomegalovirus infection[8] and the ongoing role of the Australasian Bone Marrow Transplant Recipient Registry in expanding understanding of BMT in areas such as long-term survival outcomes and in facilitating research in particular areas such as in second malignancies after BMT.[9,10]

Those who have known me for any length of time will appreciate that I could not pass up an opportunity to weave some Star Trek lore into my talk as well and I was able to draw several of these themes together. The next Tandem Transplant Meeting will be held in Orlando, Florida in February 2015. More information about the CIBMTR and the meeting is freely available at http://www.cibmtr.org.

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RESEARCH PARTICIPANTS WANTED…

Nurse Led Models of Cancer Care

Nurses working in extended roles are invited to participate in a research study into nurse-led models of cancer care. There is growing interest in the development of nurse-led clinics, and this study seeks to examine the potential role, identify priority areas and approaches to outcome evaluation.

The study has been funded by the Chis O’Brien Lifehouse Research Grant and is being led by Professor Kate White (Cancer Nursing Research Unit). You will be asked to participate in an interview that will take 35-40 minutes in length at a time and location convenient to you.

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service.

If you would like more information contact Louise Acret, research officer at louise.acret@sydney.edu.au or by phone on 02 8627 1526.

CNRU | Cancer Nursing Research Unit

Supportive Care Research GiA recipient 2014, Dr. Jordana McLoone et al. at the University of New South Wales

Supportive Care Research Grant-in-Aid

The Leukaemia Foundation is calling for proof-of-concept short applications for a Supportive Care Research Grant-in-Aid in 2015:

There will be one Supportive Care Research Grant-in-Aid awarded in 2015 with an anticipated value of $50,000 for one year, (or 2 of $25,000). Applications are now open and will close on 9th May 2014.

The Supportive Care Research Grant-in-Aid seeks to support new and innovative approaches to addressing supportive care needs of patients and families. The purpose of this funding is to support the collection of proof-of-concept data aimed at improving outcomes for those with blood cancers and related disorders. Those who are awarded a proof-of concept grant-in-aid are expected to use the data collected through this funding to inform a larger funding application to undertake research that focuses on blood cancer patients and/or their families and builds on the proof-of-concept data collected.

Examples of Supportive Care Research include (but are not limited to)

- Management of side effects and toxicities associated with therapy
- Management of symptoms of disease
- Health related quality of life
- Identifying and meeting unmet supportive care needs
- Developing or testing of assessment instruments
- Developing or testing a supportive care intervention
- Models of care and service delivery models
- Psychosocial issues
- Survivorship and late effects

Applications Now Open!

Closing date for SCR GiA Short applications COB Friday 9th May 2014

For application forms and more information please visit: **http://www.leukaemia.org.au/research/current-funding-opportunities/applications**

About us

The Leukaemia Foundation is Australia's peak body for blood cancer, funding research and providing free services to support people with leukaemia, lymphoma, myeloma and related blood disorders.

By providing dedicated support services to these people and their families, and by investing in leading research to improve treatments and find cures, the Foundation is reducing the impact of blood cancer on Australians.

The Foundation receives no ongoing government funding, relying instead on the ongoing generosity of businesses and the community to support its vital work.

1800 620 420
www.leukaemia.org.au

Leukaemia Foundation®
VISION TO CURE
MISSION TO CARE

Fostering innovative research...

2015 Round of Research Awards: call for applications open April 2014

The Leukaemia Foundation actively realises its Vision to Cure through its National Research Program by:

- fostering innovative research into the causes, diagnosis and treatment of blood cancers (leukaemias, lymphomas, myeloma) and related blood disorders; and
- supporting the work of Australia's best and brightest researchers at different stages of their careers as they work on the most promising projects.

Leading Australian haematologists and medical researchers on the Foundation's Medical and Scientific Advisory Committee assess funding applications.

How to apply

For more information including eligibility criteria and application closing dates, visit: **www.leukaemia.org.au/research/current- funding-opportunities**

2015 Funding Opportunities

The Leukaemia Foundation considers funding in all fields of research that will improve outcomes for people with blood cancers and related blood disorders through:

- Grants-in-Aid
- Supportive Care Grant-in-Aid
- Career Establishment Grant
- Post Doctoral Fellowships
- PhD Scholarships
- PhD Scholarships (Clinical)
- Honours Scholarship and New Investigator Grant (WA only)
- Standard project grants via the Priority-driven Collaborative Cancer Research Scheme with Cancer Australia. See:

www.canceraustralia.gov.au/research-data/research/priority-driven-research/call-pdccrs-grant-applications-2014

Sponsorship Grants to HSANZ Nurses Group

Grainne Dunne

The HSANZ Nurses Group were very fortunate recently to receive a total of 'seven' sponsorship opportunities for Australian and New Zealand haematology nurses to attend "*The World Federation of Hemophilia*" congress 2014 in Melbourne.

Three sponsorships were very generously donated by Bayer, which included congress registration, return air flights and accommodation while Baxter provided sponsorship for three congress registration places and Biogen Idec also provided congress registration.

What an amazing opportunity this is for our haematology nurses to learn more about bleeding disorders, meet colleagues who strive to improve the lives of such patients as well as meeting the families and patients living with a lifelong bleeding disorder. The unique element to this congress is the inclusion and participation of patients and their families. This adds great value to the congress as we can understand further (and first hand) the challenges these individuals face together with the challenges posed for medical staff managing such complex rare disorders.

As such then, the seven sponsorships enable our haematology nurses to develop a deeper understanding for bleeding disorder patients; discover the most up-to-date bedside management required; meet the specialist health professionals in this area and build their own personal passion for improving the lives of many haematology patients.

Congratulations to the successful sponsorship candidates.

Baxter sponsorship recipients are:

- Alison Marvin, The Alfred Hospital, Melbourne
- Amy Suddaby, Dunedin Hospital, NZ
- Nikki Waters, Sydney Children's Hospital, Sydney

Bayer grant recipients are:

- Julie Domanski, Royal Darwin Hospital, NT
- Renee Gilmore, Sydney Children's Hospital, Sydney
- Rachel Carter, Auckland City Hospital, NZ

Biogen Idec

- Daniela Karanfilovska, The Alfred Hospital Melbourne

A great geographical spread of very deserving, enthusiastic nurses!

The HSANZ Nurses group would like to thank Bayer, Baxter and Biogen Idec for providing the travel sponsorships for attendance at conference and providing haematology nurses with such a valuable opportunity. HSANZ Nurses Group is aiming to have more travel grants available to nurses to attend 'HAA 2014' in Perth. Priority will be given to HSANZ NG members so another really good reason to become a member. Membership forms can be downloaded from the website at:

http://www.hsanz.org.au/join/documents/2014HSANZ_MemForm_000.pdf

Please contact us if you need any help or advise joining.

Sharing experiences of managing myeloma around the Australasian region: A short adventure in China

与您分享澳大利亚骨髓瘤管理经验 —-记一次中国的短期拜访

Tracy King
Myeloma CNC, RPA Sydney.
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I was very honoured to have recently been invited by leading Haematology departments in China to visit and share my experiences of the clinical management of myeloma from a nursing perspective. Janssen China kindly supported my attendance under the very capable guidance of Zichao Si. Zichao ensured the meetings ran smoothly and escorted me on what was a very productive and enjoyable tour of 3 of the leading Haematology Departments in China.

Little is known about the incidence of myeloma in China so researchers are currently trying to establish clear epidemiological data for myeloma and other malignancies both in China and throughout the wider region. What is known is that the incidence of myeloma in Asia is lower than other countries such as Australia. An epidemiology study of myeloma in Taiwan showed the age-adjusted incidence per 100,000 population was 0.75 (Huang et al 2007) whereas the age-standardised incidence rate in persons in Australia is 6.1 per 100,000 (AIHW 2014). Despite a lower incidence of myeloma the prevalence of myeloma in China is higher than Australia due to China's large population. To put this into some context; the population of Shanghai is just over 24 million. This one city in China has a population greater than that of the whole of Australia!

From my brief experience in China and discussions with clinicians there, it was apparent that the Chinese health system has many similarities with that of Australia. It is primarily a public system and patients with myeloma are treated with similar lines of therapy such as corticosteroids, alkylating agents, high dose melphalan and stem cell rescue, thalidomide, lenalidomide and bortezomib based regimens. The public funding of high cost drugs however, does not seem as widely supported in China as it is in Australia. Patients and their wider families most commonly shoulder the cost of these medications, a factor that reminds me how fortunate we are to have the PBS reimbursement system in place.

What is becoming increasingly interesting and being explored by researchers in the region, is the differences in co-morbidities and experienced toxicities that may be ethnicity related. We know that the prevalence of venous thrombo-embolism (VTE) varies significantly among different ethnic/racial groups although the clinical basis for these differences remains largely undefined (White & Keenan 2009). Anecdotally from talking with colleagues in China on my recent visit, it is thought that the incidence and severity of treatment-emergent peripheral neuropathy in those with myeloma may also be higher. One of the focuses of my talks was to discuss the management of peripheral neuropathy and our experiences with delivering SC bortezomib, a relatively recent change in mode of delivery that can reduce the incidence of peripheral neuropathy by up to a third (Moreau et al 2011). Haematology units in China are beginning to change over to the SC mode of delivery and were particularly keen to learn from our experiences.

Unlike the Australian health system where cancer care is increasingly being delivered in the ambulatory setting, in China the majority of care is delivered in the in-patient setting. Patients are commonly admitted overnight to receive all forms of therapy including a short injection of bortezomib. With the population of greater China nearing 1.4 billion, units are looking at more efficient and cost effective models of care including ambulatory delivery of chemotherapy such as is common place in Australia.

Tianjin: Prof Qiu

First stop on my trip was Institute of Haematology & Blood Diseases Hospital, Chinese Academy of Medical Sciences, Tianjin. Tianjin is a city just south of Beijing in the north of China. Despite recent news headlines of dangerous smog breaking all WHO safely levels, the sun rose to a stunning winter's day. Head of department Prof Qiu, who has a specialist interest in the management of those with myeloma and his Chief Nurse Wang Wen, generously hosted my visit to their unique facility. This 500 bedded Haematology hospital with 200 dedicated beds for Lymphoma and Myeloma, incorporating a BMT unit represents a vast department compared to Australian standards. We began with a meeting attended by the Chief and Lead nurses and many clinical nurses from within the department plus several doctors. The meeting included an overview of the nursing services from Chief Nurse Wen and a talk on the clinical management of myeloma by me. This was followed by question and answers and wider discussions focussing primarily around ambulatory delivery of supportive care and therapies. My Mandarin is not as you may hope so luckily I had a translator there to assist in smooth communications and conversations. My slides were also translated directly into Chinese and during my talk I had to make an effort to speak very slowly. For those of you who know me you may appreciate that was a bigger challenge than my basic efforts at speaking the pleasantries of the local language!

应用硼替佐米治疗多发性骨髓瘤
患者的临床护理

皇家阿尔弗雷德王子医院骨髓瘤临床护理专家
悉尼大学护理学院临床研究访问学者
澳大利亚 悉尼
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万公里, 拥有582,000 名员工
工的母语不是英语，居家使用另一种语言
普通话, 粤语 阿拉伯语, 希腊语....
皇家阿尔弗雷德王子医院血液病研究所
– 8 名悉尼大学的血液病专家
– 35-40项涉及血液肿瘤、BMT、血浆分离置换、血友病、血库、实验室 & 临床研究的临床试验
– MM、APL、铁离子螯合等热点研究实验室
– 病房、BMT病房共 26 张床位 (60-70 张/年)
– BMT日间治疗病房、化疗日间病房、血浆分离置换病房 (800张/年)
– 专家门诊– 35位/周

Following our formal meeting Chief Nurse Wen and colleagues kindly showed me around their comprehensive haematology department. The nurses and staff were all very welcoming and friendly and showed me their patient information resources and educational programs, the clinical areas and even the staff ping pong tables! An initiative I am very keen to apply to our department within RPA in Sydney! I was particularly aware of the significant role relatives and friends were encouraged and allowed to play in the care of their loves ones within the inpatient units. The nurses explained to me how much they rely on family to provide much of the patients care as a supplement to that provided by nurses. The central and important role of family was evident and something I feel perhaps we could learn from in Australia.

I left Tianjin having made new friends and with promises to keep in touch and share and exchange information in the future. I have to admit to being somewhat jealous of Prof Qiu's 'Haematology Hospital' with 200 or so new myeloma patients diagnosed every year and a floor per disease.

Chief Nurse Wang Wen, right, and colleagues on Haematology ward

Front centre: Prof Lugui Qiu Director Institute of Haematology & Blood Diseases

Hangzhou: Prof Jin

After a quick flight south we arrived in Hangzhou, a city just south of Shanghai. Prof Jie Jin is head of the Haematology department at The First Affiliated Hospital of College of Medicine, Hangzhou. Prof Jin and her team had invited me to participate in an educational supper meeting for nurses in the region. Prof Jin's team generously showed me around their unit before the meeting. The haematology unit sits within a modern large hospital buzzing with life. Dr Lou Sai and I chatted about myeloma, realising we have much in common in regard to challenges in the management of this group of patients. Returning to the hotel, the evening started with a supper in the revolving restaurant on the roof of our hotel. I thought I was quite skilled at using chop sticks but was soon put in line as my new friends made light work of a banquet of tasty food, including grapes 'al la' chop stick!

After dinner we began our meeting with Dr Lou Sai acting as my translator for the evening, fielding questions and facilitating an energetic period of discussion after the formal talks. The program ended with a local doctor giving a short presentation on treatment emergent peripheral neuropathy in myeloma. Despite the slides being solely in Mandarin it seemed to me that PN is as much of a challenge for Chinese patients to manage, as it is those with myeloma in Australia. We ended the evening keen to remain in contact and having invited the whole room to HAA in Perth this year! Prof Jin having visited Perth in the past keenly supported Perth as an attractive holiday destination for all.

Image Above: Prof Jin Jie Head of Dept Institute of Haematology, First Affiliated Hospital Zhejiang University, Hangzhou (2nd from right). Tracy King middle.

Image Right: Haematology nurses from First Affiliated Hospital Hangzhou

Image bottom right: Nurses picture board on the ward.

Shanghai: Prof Hou

An early train journey the next morning had me in Shanghai with 40 mins spare to run and see the 'Bund', the iconic Shanghai waterfront area. Our last meeting of the visit was hosted by Prof Jian Hou Director of the Haematology Unit at Shanghai Changzheng Hospital. Another leading myeloma expert in China, Prof Hou chaired our final nurses meeting of the visit. A/Prof Juan Du a colleague of Prof Hou's, acted as my translator and good friend for the meeting. It turned out Juan had visited our unit in Sydney a few years ago having met with Doug Joshua at past meetings and spent some time visiting Australia to present her research and work. The Haematology world is a small place.

The meeting again focused on the clinical management of myeloma with nurses participating keenly in discussions around SC bortezomib and neuropathy. I was able to share some photos of our team at RPA. Those of nurses in full PPE administering chemo caused quite a giggle and stir! Apparently the 'duck' masks and head to toe purple PPE are quite unique!

To end the meeting one of Professor Hou's colleagues gave a comprehensive clinical update on myeloma and its management for the nurses present and again, without understanding all the slides it was clear to me that there are more commonalities with our management and care of those with myeloma, than difference.

Prof Jian Hou Director Haematology Changzheng Hospital Shanghai

A/Prof Juan Du Centre for myeloma and Lymphoma Shang Hai Chang Zheng Hospital Shanghai – my translator & new myeloma email buddy!

I would like to personally thank Prof Qiu; Prof Jie; Prof Hou and A/Prof Du and their extended nursing teams for their kind invitation to join them in a series of educational events around the clinical care of myeloma in the region. Their hospitality was warm and engaging and we all learnt so much from each other. I hope this partnership of sharing experiences in the goal of improving care for those affected by myeloma, continues.

我非常感谢邱教授、金教授、侯教授以及他们护士团队的盛情邀请与款待。在中国期间，我们就骨髓瘤的临床护理互相学习了很多。

我也邀请你们有机会来澳大利亚参观访问。

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Granulocyte collections: the who, why, what and how?

The "G" word strikes dread into the heart of every apheresis nurse who has been handed the task of arranging these collections. Invariably a last minute request there is an expectation that these little wonders of sepsis fighting muscle can be plucked innocently from the blood of anyone who stands still long enough. Sadly not true… granulocytes are Trouble.

The reasons are multifactorial – almost all aspects of granulocytapheresis are difficult. At the centre of the vortex is a seriously unwell patient, often in Intensive Care, with an intractable bacterial or fungal infection that is not responding to antimicrobial or anti-fungal therapy. The patient will be neutropenic ($<0.5 \times 10^9$/L neutrophils) and have suffered a prolonged period of neutropenia – perhaps post induction chemotherapy for acute leukaemia or post allogeneic bone marrow transplant. The family are distraught and now they need to help recruit an unknown number of potential donors.

The recruitment of donors is usually required at short notice with collections needed within days (preferably yesterday!). Due to the large volume of erythrocytes collected concurrently during granulocytapheresis (more of this later) donors need to be ABO compatible, meet the general requirements of a blood donor, and have suitable venous access and a negative infectious disease screen, often including CMV negative status[1]. Finding suitable donors who meet the above requirements and are willing to consent to G-CSF and steroid priming (necessary to augment marrow production of neutrophils to enable the collection of therapeutic doses of granulocytes[1]) and who are available for a weekday appointment is challenging. This may be extra difficult if the family and immediate circle of friends live out of town or interstate.

With the inevitable clamour to recruit donors, overeager family and friends should be counselled against using social media to aid their cause – the inundation of phone calls and requests from well meaning potential donors can be overwhelming to say the least and counter productive in the long run.

The task is then to arrange for blood testing, screening and assessment of potential donors, and because donations may be required for several weeks and depending on institutional protocols and recipient response may be needed daily or second daily lots of donors may be needed.

Amongst this feat of coordination and organisation there needs to be a lot of education to ensure that donors are aware of what is expected and the risks of the procedure. Although apheresis is a generally well tolerated process it is not without risk, and care must be taken to ensure that donors are not adversely affected by the donation procedure or the use of growth factors. Conversely, donor selection in patients who may proceed to allogeneic transplantation should also factor the risk of alloimmunisation to minor histocompatibility antigens that can occur with the use of family members[2].

Donors need to be available not only on the day of donation but the night before to attend the hospital to receive G-CSF injections (5-10 micrograms/kg) and 8mg oral dexamethasone. The G-CSF and steroid combination is a well recognised primer to improve the numbers of circulating cells available for collection and there is a strong correlation between the donor's pre-apheresis absolute neutrophil count (ANC) and cell dose collected[1, 3]. The addition of glucocorticoids aids in marrow production, helps to maintain circulating neutrophil numbers and demargination from the vascular endothelium thereby delaying the transit of neutrophils from the circulation into the tissues[2, 4].

Now that our willing donor is primed and ready to proceed, the fun begins. Granulocytes are difficult cells to collect in therapeutic numbers, generally considered to be a minimum of 100 x 10^9/L polymorphonuclear cells (PMN) but often quoted at much higher numbers in the international literature[1, 5]. Teasing them from the layer of red cells in which they like to cohabit is tricky. As both young erythrocytes and granulocytes have similar specific gravity and sedimentation the addition of a high molecular weight starch is required to sediment the red cell layer, enabling the efficient removal of granulocytes[5]. In the US and Europe, 6% hydroxyethyl starch (HES) is routinely used in granulocytapheresis[1, 2, 3] to sediment the erythrocytes however this product, to the best of my knowledge, has never been available in Australia for this purpose.

Historically Dextran 70 has been used in Australia to enhance erythrocyte rouleaux (coin stacking appearance of red cells on blood film) and thereby improve red cell sedimentation[6]. Dextran is no longer readily available for use and so Apheresis units must meet the challenge to harvest granulocytes by other means either by altering the separation dynamics of the blood cell separator to enhance collection or by using alternative solutions as sedimentation agents.

However this is achieved, the final product must meet other specifications before transfusion – most notably granulocyte concentrates require irradiation (minimum dose of 25Gy) to prevent the proliferation of passenger T lymphocytes and the potential for transfusion associated graft versus host disease (TA-GVHD)[2, 7].

The infusion of concomitant Amphotericin B in the patient should be separated from granulocyte transfusion by several hours to avoid pulmonary reactions, although the evidence to support adverse reactions of this nature has not been consistently demonstrated and most centres prefer to err on the side of caution[2]. Granulocyte transfusions have been implicated in pulmonary reactions because circulating granulocytes initially gravitate to the lungs where a combination of cytokine release and infection may result in pulmonary infiltrates[2]. Therefore close monitoring of patients receiving granulocyte transfusions is essential.

Granulocytes should be transfused as soon as possible, usually within 6 hours of collection[6] although studies have indicated storage up to 24 hours may be acceptable - this remains controversial given the uncertainty of neutrophil viability and function ex vivo[8]. Ultimately this prevents pre-collection and storage of cells, adding to the complexity of these collections as decision making regarding further donation is made on a daily basis. Collections need to continue until resolution of infection or sustained neutrophil engraftment (>0.5 x 10^9/L on two consecutive days).

So with all of these complications and challenges it begs the question are granulocyte transfusions worth the effort? In controlled trials reported in the literature, efficacy is correlated with the dose of PMN infused with positive results seen more commonly in doses >170 x 10^9 (2). Studies of neutrophil kinetics have demonstrated that transfused granulocytes are able to travel to the site of infection and that their functionality appears to be normal[1, 2, 8]. Efficacy has clearly been demonstrated in small cohorts of patients with bacterial and fungal sepsis, and is frequently reported to be a life-saving therapy[2].

Isbister[6] listed indications for granulocyte transfusion as “desperation, pre-desperation, routine, pre-emptive (p.15)”. Anecdotally collections always appear to be scheduled at the desperation phase of clinical treatment and as such sometimes they can be amazingly effective, with amelioration of clinical symptoms such as fever and stabilising of blood pressure and sometimes be a case of too little, too late. However the final decision rests with the clinicians and no doubt opinion will be tempered by the availability and ease with which these procedures can be arranged. I use the term ‘ease’ lightly!

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Music Therapy: A sound practice for Haematology / BMT

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A post RMH BMT patient enjoying some music therapy with her son and Emma O'Brien (The Herald Sun Newspaper March 2011)

'Start spreading the news, I'm leaving today, I want to be a part of it New York New York'. Jane was undergoing a matched unrelated bone marrow transplant and her donor cells were being flown in from New York. "Better play them a song to help them feel welcome" Jane requested

Music is good for your health, we know this in our hearts, and there is also medical research to support this. We know that music reduces stress and anxiety in cancer patients, (Cochrane review of 2011). There are numerous studies that demonstrate music's impact on the immune system and improving people's quality of life and mood.

Music therapy has been an integral part of caring for the whole patient physically and emotionally in our Bone Marrow Transplant unit at the Royal Melbourne Hospital (RMH) for over 15 years. All BMT patients are offered music therapy during their treatment. At the pre admission interview they are given information about the service and once they are admitted to the inpatient unit a music clinician will endeavor to meet with them early on.

Live music (mostly voice and guitar) is used at the bedside to comfort, uplift and support the patient. The music therapist also works closely with the patients and their families to create original songs to help them express their feelings, and the songs can sometimes be written as thank you songs for family and friends. The Music Therapy Program follows the patients' journey and does not ever 'discharge' a patient from the service. We will see a patient as regularly as possible when they are inpatients, and on a needs basis from their perspective. We also offer weekly group relaxation session in the inpatient BMT unit. Following patient discharge we then see patients in the outpatient unit and they also have the opportunity to attend the music therapy studio for ongoing sessions.

Many of patients remain with the music therapy service for years following their transplant. As an example recently I played for a patient over many years. I met him in 1999 during his initial therapy for BMT, saw him regularly as an outpatient post-transplant, and then sadly I played for him as he died in 2011 in ICU at the family's request. Then I played his favorite songs at his funeral.

The philosophy of the service is to meet patients' needs, physically and emotionally, by offering quality of life experiences through music and the therapeutic relationship and partnership between patient and therapist. The music therapy service at RMH works in a person and family centered model of care. Patients do not have to be musical to benefit from Music Therapy.

Some particulars about the Music Therapy Service

The music therapy service has one full time clinician manager, one full time senior clinician and one part time clinician and health musician who plays in the general areas of the hospital (not a trained music therapist). We also have volunteer musicians playing in the general areas of the hospital. The managerial role oversees the fundraising aspects, governance, research projects and works clinically for 2 days / week, in haematology and BMT for both in and out patients. Additionally the manager offers music therapy for neurology and will accept hospital wide referrals, a priority being for long stay patients.

The senior music clinician works in hematology oncology palliative care, is a sound engineer for our studio therapy projects, and coordinates the staff choir. A part time music clinician works in neurology services. An additional health musician comes in twice a week and contributes to the atmosphere of the hospital by playing in general waiting areas such as the Emergency Department, Haematology / Oncology Day Centre, and general hospital pathology department. The program is funded by Philanthropic support and fundraising activities.

Our RMH Music Therapy program offers opportunities for increased self-expression, positive experiences and an increased sense of meaning. By meeting patients' changing needs, music therapy aims to improve their quality of life. Music therapy follows the patients' journey and does not ever 'discharge' a patient from the service. Patients are seen as regularly and where possible on a needs basis from their perspective.

The service at RMH is world renowned for their songwriting program and more recently their studio therapy program. If you would like to see what we do *Like us* on the Facebook site and visit the you tube channel sites here to hear some songs written at the bedside, see some original music video clips and hear some personal patient stories.

www.youtube.com/user/StudioTherapySongs

www.facebook.com/StudioTherapySongsFromTheWard

For additional reading and some evidence behind the benefits of music I recommend the following articles:

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Scholarships, Travel Grants & Bursaries

Dr Cathy Barnett, *Cancer Nursing Research Unit, Sydney Nursing School, University of Sydney*

There are many types of funding opportunities if you want to research, study or travel domestically/overseas for educational purposes. The internet has many organisation websites where you might find funding relevant to your area of interest, , or if you fit their criteria in some other way. You should review these criteria carefully, and think creatively about whether you are eligible, as criteria might be general, nursing specific, cancer specific, or personally relevant to you in some way (eg grants for women researchers, indigenous scholarships, remote or rural grants). You might also be able to hold more than one grant at a time for the same purpose, although this would be relatively unlikely!

The table below is not exhaustive and gives some idea of the different types of organisations (with some examples of scholarships) where you can look for funding. It focuses on Australia, but there may be funding opportunities from overseas groups as well which are worth considering. In terms of Haematology, there are a number of grants and scholarships from various organisations, which you should consider. The table below sets these out, along with some other suggestions.

A Guide to applying for Scholarships and Grants

The following hints and tips are modified from the JASON website (see Table below) and the University of Melbourne Graduate Research Scholarships website: www.services.unimelb.edu.au/scholarships/research/scholarships_research/

1. CLARIFY YOUR PROJECT. Ensure that the institution (and department) you wish to study/research with (or travel to), can accommodate you with respect to supervision, resources or educational opportunities. Also, ensure that you satisfy any admission requirements to the institution for study/research purposes. The scholarship application is separate to this, but funding is dependent on you having acceptance to a place of study/research. Similarly, for travel grants, research your itinerary and have visits pencilled in/lined up.
2. CHECK YOUR ELIGIBILITY CRITERIA FOR THE GRANT/SCHOLARSHIP. If you do not meet the criteria, do not apply and instead, look at other funding options. Gather information about the funding body's philosophy, aims and objectives and tailor your application to their requirements whilst maintaining integrity with your own research priorities.
3. MAKE YOUR APPLICATION PROFESSIONAL. Spend time on your application so that you present it as professionally as possible. Most applications take time to finalise. They almost always require supporting documents which might in themselves take a few weeks to collect (eg ordering a birth certificate, letters from referees etc, quotes for travel or letters of invitation from overseas institutions). Some applications will provide you with a document checklist to assist with this, but if not, you will have to check (and double-check) that you have provided everything. Ensure that you answer all the questions and provide documents *in the order* that they are asked for *and in the form* that they are asked for (eg certified copies or original). Make sure that your referees are suitably qualified to comment on you and your research project and keep referees advised of all your scholarship applications, so that if they are contacted they can speak knowledgeably about you and your project. Write (or type) legibly and consistently and include all your contact details.
4. SUBMIT A COMPLETE APPLICATION BEFORE THE CLOSING DATE. It is important to start the application process early and have time to review it (and perhaps ask trusted others to review it as well; particularly those who have been successful at getting grants and funding). If you miss the closing date, your application will not be accepted.
5. FOLLOW-UP AS APPROPRIATE. If you are going to be away around the time of the funding announcement, make sure that someone suitably qualified can check your mail etc and accept a scholarship on your behalf. If you are successful, respond promptly!
6. DON'T GIVE UP IF YOU MISS OUT! Obtaining funding for research and travel is very competitive. Keep exploring other funding opportunities and seek advice from experienced researchers who are successful at getting funding. Remember that each scholarship, fellowship, bursary or grant is different, so don't re-hash old applications. Apply to

each funding opportunity individually, and respect that these organisations or funding bodies are potentially giving

JASON website: Joint Academic Scholarship Online Network – a postgraduate scholarship search engine for a range of Australian scholarship opportunities. www.jason.edu.au/

THE GOOD UNIVERSITIES GUIDE: Also has a search engine within the website for scholarships. You can specify your criteria/areas of study.

UNIVERSITIES

- Eg. The University of Sydney – General research awards (eg APA, UPA etc), Specific research awards, Medical/Health scholarships & Other types of funding.

  www.sydney.edu.au/scholarships/research/

GOVERNMENT SITES

- Cancer Australia – a range of awards and scholarships http://canceraustralia.gov.au/research-data/research/grants-and-funding
- NSW Dept of Health – Scholarships offered each year to registered nurses and midwives wishing to undertake postgraduate study (worth up to $6K to go towards educational expenses) in (i) Clinical studies (ii) Education (iii) Management.
- Cancer Institute of NSW – various research grants and funding opportunities for higher degree and early career researchers www.cancerinstitute.org.au/research-grants-and-funding

PROFESSIONAL & OTHER BODIES

- HSANZ Nurses Group – provides grants for best abstracts at HAA each year alongside a range of travel scholarships provided by individual States, Territories. To find out more contact your local nursing representative www.hsanz.org.au
- Many hospitals and centres provide their own local grants and scholarships to nurses. Check with your department managers and local educational committees to see what's available.
- Australian College of Nursing – also has a number of postgraduate research & travel scholarships www.acn.edu.au/scholarships
- Cancer Nurses Society of Australia (CNSA) – various research and travel grants (some offered twice yearly) for cancer nursing research or cancer nursing related conferences. Certain conditions apply. www.cnsa.org.au/grants_scholarship_research_travel.htm
- Leukaemia Foundation – have funding opportunities for research grants and PhD scholarships amongst other opportunities. www.leukaemia.org.au/research/current-funding-opportunities
- Australian Federation of Graduate Women – for study at University with a number of limited Fellowships for postgraduate research: www.afgw.org.au/
- Churchill Fellowships – www.churchilltrust.com.au/
- 'My future website' (with career information) has relevant nursing scholarships - 'Country Women's Association Scholarship for Nursing' and 'Postgraduate Nursing and Midwifery Scholarships': www.myfuture.edu.au/
- Ovarian Cancer Australia has a new Postgraduate Scholarship Scheme open to all health researchers worth $75K over 3 years for ovarian cancer research: www.ovariancancer.net.au/
- The Sidney Myer Health Scholarship awarded every 3 years for PhD students in community-based and public health research: www.myerfoundation.org.au/
- The National Breast Cancer Foundation has doctoral, early career, post-doctoral , practitioner and career fellowship research funding opportunities: www.nbcf.cloudapp.net/Research/For-Researchers/

Tandem BMT Meeting, Grapevine, Texas, February 2014

Catherine Wood

Clinical Nurse Specialist, Wellington Hospital, NZ

I was very fortunate to attend the Tandem Bone Marrow Transplant (BMT) meetings in Texas. The Tandem meetings are a number of combined BMT meetings that run concurrently. As a registrant for the conference, the attendee is able to dip in and out of any of the meetings. The concurrent meetings include:

- A BMT data management meeting
- A medical and scientific meeting
- A bone marrow transplant nurses meeting
- A bone marrow transplant pharmacists meeting
- A mid-level practitioner meeting (for nurse practitioners, nurse specialists and physician assistants).

BMT Nurses Meeting: The nursing conference had a number of very important presentations. Highlights include:

- Transplant and palliative care – This session talked about the benefits of having the hospital palliative care team involved with transplant patients right from the beginning of transplant. They are able to help out with symptom control in the early stages of the transplant. If it looks as if the patient isn't going to survive, then the team is already known to the patient and the family and makes the transition from active treatment to terminal care much smoother.

- Infection prevention – there were a couple of sessions about infection prevention in this patient population. Transplant patients are taking a number of immune suppressing drugs which makes them susceptible to picking up infections. There was an excellent session about preventing infection in patients with intravenous central lines. This is a constant issue with our patients and this was a good update of current guidelines and practices. There was also a very good session about preventing clostridium dificile infection – another common infective problem with our patients. Both of these sessions were very practical.

Mid-Level Practitioner Meeting: This was a very valuable meeting and had some excellent sessions. Highlights include:

- An excellent session about giving serious or bad news to patients and their families. The presenter gave good information about how patients and families perceive the information that we give them. He then went on to give some excellent guidelines about how serious or bad news is best delivered to patients.

- Chronic graft versus host disease (GVHD) – this was an excellent session about this very frequent complication of transplant. Chronic GVHD has a significant impact on a patient's quality of life. This session gave some useful information about how to better assess and treat this complication.

- Renal complications – this was a useful session about the renal complications that may arise with stem cell transplantation. The presenter gave a good overview of the causes of renal impairment and some good references that will be a useful reference.

Pharmacy Meeting: I attended two pharmacy sessions which will provide useful information for staff caring for bone marrow transplant patients. The first was a session about how a dental expert treats chronic oral GVHD. This is a significant problem for patients and it had some very practical guidelines for managing and treating patients with this often debilitating condition. The other session was one about drug interactions that are present with a number of the drugs that are used for bone marrow transplant. There was good guidance on how to manage these drug interactions which will be very useful.

Medical and Scientific Meeting: The medical and scientific conference also had some very good presentations. The highlights of this meeting were sessions about:

- Survivorship and late effects. There were many sessions about long term survivors post-transplant and the issues that they faced with late effects. These sessions challenged me to improve the service that we currently provide to our patients. It will be exciting to put these ideas into place in our post-transplant clinic.
- Hepatitis – this was an excellent session about how to manage patients who need a transplant and have either hepatitis B or C infections. This is relevant to the NZ patient population as a number of our Māori and Pacific patients have had prior exposure to hepatitis B.

There were also two poster sessions with representation from all the different meetings that were present at the conference. There were some interesting posters which will stimulate some discussion with my transplant colleagues. This has been an excellent meeting to attend. It was stimulating and thought provoking. There has been a lot of information provided that will stimulate discussion with colleagues and that may lead to practice changes.

HAEMATOLOGY TEA ROOM QUIZ

Grainne Dunne – Haematology / Apheresis CNC Sydney Children's Hospital

(Answers available on page 30.... NO cheating now!)

Questions

1. What is the major complication associated with the chemotherapy agent 'Cyclophosphamide'?
2. What is the average lifespan of the Red Blood Cell in a human body?
3. What is Non Hodgkin's Lymphoma?
4. What are the 3 main different types of Non Hodgkin's Lymphoma?
5. Who invented the mercury thermometer and in which century?
6. What is the most common type of Leukaemia in children?
7. 'Thalassaemia Major' is inherited from 1 parent only or from both parents?
8. In normal haemoglobin production, at approximately what stage after birth will 'Adult' haemoglobin replace 'Foetal' haemoglobin?
9. What is the shelf life of a unit of platelets, from the time of donor collection?
10. Children with Triosomy 21 have a higher risk of developing leukaemia. What is Trisomy 21 otherwise known as?
11. What is the Five year survival rate for Acute Lymphoblastic Leukaemia (ALL)?
12. What is the drug 'Exjade' used for and in what form does it come?

Haemophilia Patients… Are Doing It For Themselves!

For years now individuals with severe haemophilia have been administering haemophilia factor replacement therapy at home by themselves. This consists of an intravenous bolus dose usually injected every second or third day at home - for life. Sometime dosing is more frequent depending upon the patients need and if they have an active bleed. Intravenous access may be via peripheral butterfly needle or Central Venous Access Device e.g. port a cath. Both mechanisms are taught to the patient and/or their carers by the Haemophilia Treatment Centre's (HTC's) specialist nurse.

Haemophilia Factor replacement is expensive. An average adult patient with severe haemophilia may inject approximately A$350,000 - A$400,000 worth of factor replacement per annum at home, as standard prophylaxis. Naturally then, additional costs accumulate when the patient is treated for additional bleeds as more frequent and higher dosing is required.

Australian patients are amongst the 'lucky ones'. Yes within the enigma of a severe haemophilia diagnosis they are indeed very lucky to be Australian! The reason is - the Australian Health Department picks up the factor bill for every Australian citizen living in Australia. The grave comparison is the haemophilia patient living in some other country e.g. Asia. Here they must pay for factor from their own pocket or in many cases do not even have access to haemophilia replacement therapy or bleeding disorder medical knowledge. In these cases patients live a life with debilitating limb deformities or early death due to a bleed. In Australia this would usually not eventuate to death. So yes Australian patients are amongst the *lucky ones*.

To help the Australian government and HTC's better manage our annual usage of Haemophilia Factor supply in Australia and to account for the high expenditure; we must rely on our patients to record and report their correct factor usage at home. As such, Australian patients are now launching into a new electronic method for recording home factor injections, called "My ABDR" (My Australian Bleeding Disorder Register), provided to them by the National Blood Authority (NBA). Until now, HTC's and the Australian government relied upon patients to maintain paper diaries for home dosing administration. In the last few years some smart phone apps arrived on the market offering electronic diaries to patients. Both these systems have been somewhat 'hit and miss' regarding its acceptance, usage and therefore value. The aim of "MyABDR" is to improve the recording of home administration and to facilitate more appropriate usage of factor in the home.

'My'ABDR is an extension to the already existing ABDR which has been used in every Australian HTC for the past 3 - 5 years. ABDR is a national database allowing each HTC to input what data they have on their bleeding disorder patients i.e. medical history, investigation results, personal details, hospital interactions, inpatient factor administration, factor home deliveries and where possible home administration. To improve this data collection and enable the patient to take greater responsibility for their factor usage, data collection has extended to "MyABDR". Each patient is linked in with their personal login allowing them to input their home medical activity. MyABDR is an online system available via smartphone (Android and iOS), iPad apps and website. It connects directly with the relevant Australian HTC. Each HTC can see what dose the patient is administering, the regularity, bleeding activity, expiry and batch numbers which is important for tracing factor if a batch recall occurred. It also creates an easy pathway for communication between the patient and the HTC as messages and clinic reminders can be passed back and forth. MyABDR enables haemophilia data managers to transfer patient's data onto the national ABDR which is then used for analysis – both medically and financially.

As nurses we need to help the bleeding disorder community by encouraging all bleeding disorder patients/families to link into MyABDR. Encourage them to integrate this new technology into their medical lives which will in turn improve their overall medical management.

For more information visit http://www.blood.gov.au/myabdr
Gráinne Dunne
CNC Haematology/Apheresis, Sydney Children's Hospital

Patient & Family Information Resources

"Knowledge is power" – Sir Frances Bacon 1597

Tracy King,
Myeloma CNC RPA Sydney.

We know how important it is to provide the right information at the right time in the right format to patients and family members. We know that the provision of information is crucial to help patients learn to understand and begin to manage health concerns. This is of particular importance when patients begin on complex medication regimens in order to assist with compliance and improve outcomes generally. A vast range of information resources are available to people affected by blood cancers and diseases and I thought it was timely to update you to a few of those I've found particularly useful recently. The non-profit sector continues to provide a comprehensive range of information resources on a range of blood diseases, treatment modalities and supportive care areas such as diet and exercise. Most resources are available to down load so you can send email copies to your patients as well as hard copies for those who prefer that modality. A range of simple fact sheets are also available alongside more comprehensive booklets. Some I've found particularly useful recently include:

• Exercise for People Living with Cancer	Cancer Council
• Complementary and alternative therapies	Cancer Council
• About Bortezomib – Fact Sheet	Leukaemia Foundation
• Understanding Autologous Transplants	Leukaemia Foundation
• Peripheral Neuropathy	Myeloma Foundation
• The FISH test (Myeloma)	Myeloma Foundation

Increasingly they also provide online resources, opportunities to share and learn via social media portals and programs such as Twitter, Facebook, Webinars and other online media resources. Make sure you book-mark the non-profit organisations related to your area of work and regularly take a look at their sites to see what's new.

Myeloma Foundation of Australia	www.myeloma.org.au
Cancer Council	www.cancer.org.au
Leukaemia Foundation	www.leukaemia.org.au

International Organisations

A wide range of international organisations produces excellent patient information resources available to download direct from their websites. You can be sure patients and family members will be looking widely for the best information to suit their needs, why not us. Its worth reviewing the guides first to make sure they include content that matches the Australian health system when it comes to content around therapies and treatment modalities. A couple organisations I find useful when it comes to information on all things transplant are:

Why not go one step further?

The information resources produced are always developed in conjunction with clinicians. If you have a passion for improving the information available for your patients and family members or have an idea for a new resource, why not approach one of the support organisations and work in partnership to help update existing resources or develop new ones?

CIBMTR Patient information resources

Post-Transplant Guide for Patients. Also available for clinicians.
http://www.cibmtr.org/ReferenceCenter/Patient/Guidelines/pages/index.aspx

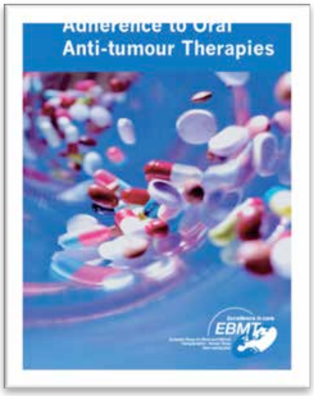
EBMT Nurses Resources

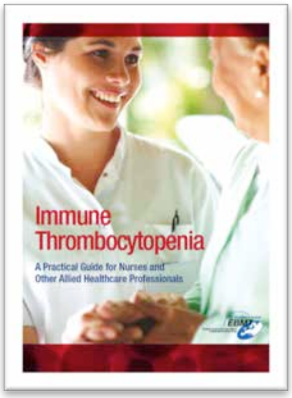
A range of useful resources directed at nurses information and learning needs are available to download direct from the EBMT website. Bookmark the link so you can regularly check what's new.

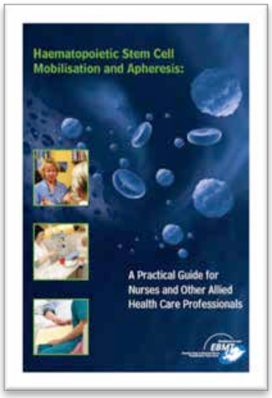
http://www.ebmt.org/Contents/Resources/Library/Resourcesfornurses/Pages/Resources-for-nurses.aspx

Here is a small selection of the educational booklets produced by clinicians in the speciality. Available in pdf direct from the site: Adherence to oral therapies; Immune thrombocytopenia; Mobilisation & Apheresis.

Keeping medicines on track







NPS has a range of resources for consumers to help understand or keep track of the medicines they are taking. You can either download these from their website or order a supply to keep in your units. I keep a supply of the blank medicines lists to give to my patients and families to help keep track. Some prefer to use the smart phone Apps, others prefer the hard copy. www.nps.org.au

Pharmaceutical companies also provide a range of useful information resources alongside resources to assist people track their appointments and medications. A more recent one is the RevLife™ support and information program from Celgene for those with myeloma receiving treatment with revlimid.

What are RevLife program resources?

- Regular newsletters delivered either by post or email. Designed to address issues that may be faced by patients who are being treated with revlimid. For example, a section on reducing the risk of infections and practical ideas to help reduce the effects of constipation or diarrhoea. Other content will include tips for remembering to take medication, patient stories, details on patient support organizations, meal ideas and gentle exercise suggestions.
- RevLife welcome kit in the mail which includes:
    - 1st in the series of RevLife newsletters
    - supply of MedSkeds (compliance tool to help patients keep track of daily revlimid doses)
    - Feverscan Thermometer

How to enrol in RevLife or find out more information:

- Patients can enrol in RevLife by filling in an enrolment form and posting or faxing it back to the program administrator
- Patient enrolment forms are available for healthcare professionals through your local Celgene representative and can also be found in the latest revlimid new patient information packs (also available from your local Celgene representative)
- Alternatively you can contact Celgene on 1800 235 4363 (option 5) to request enrolment forms be sent to you

Other MM patient resources available from Celgene include

- MyRevlimid patient compliance app for MM patients - coming soon.
- An access code will be required to download the app – contact your local Celgene representative for a supply of patient leaflets with the access code
- **Revlimid Patient Information Pack**

  New compendium-style design; contains patient information booklet, caregiver booklet, RevLife enrolment form, and a refillable diary
- **Thalomid Patient Information Kit**

  Handy satchel with zip; contains a diary, patient booklet, caregiver booklet, leaflet on peripheral neuropathy, and a supply of MedSkeds (to assist patient compliance with Thalomid.

Have a useful resource you would like to share with others? Why not send it in and we'll mention it in the next edition of this newsletter. Got a good idea for a new information resource <u>but don't know how to make it happen</u>? Get in touch and together we'll see what we can achieve. Tracy.king@sswahs.nsw.gov.au

Cancer Institute NSW Update

In 2012, the Council of Australian Government (COAG) endorsed eviQ to be adopted nationally as the primary data base for evidence based cancer treatment protocols Following from this, all states and territories have now formally agreed for clinicians to participate in the protocol critical appraisal process, ensuring the continuous expansion and usage of eviQ protocols nationally.

This process enabled eviQ to host a national Haemopoietic Progenitor Cell Transplant (HPCT) Reference Committee meeting at the end of January2014, at Cancer Institute NSW in Sydney. It was encouraging to have clinician involvement from every state and territory, to guide the further development and translation of eviQ HPCT protocols for use around Australia.

We would like to introduce Gemma Dyer to the eviQ team. Gemma has extensive experience in Haematology and Blood & Marrow Transplant (BMT) nursing and comes to us from the Agency for Clinical Innovation, working as the Clinical Nurse Consultant and Project Lead for the BMT Network Long Term Follow Up Project.

A/professor Ian Kerridge shall remain the chair of the eviQ HPCT Reference Committee for 2014 and am pleased to announce that Dr Sharon Avery, Haematologist from the Alfred Hospital in Melbourne, has taken up the position of co-chair.

Three autologous and six allogeneic conditioning protocols were discussed at the recent meeting and we are currently working to publish these protocols in addition to reviewing and updating existing protocols. Detailed information can be found on the eviQ HPCT homepage.

For any more information regarding the eviQ HPCT content, please contact:

Aisling Kelly aisling.kelly@cancerinstitute.org.au or Gemma Dyer gemma.dyer@cancerinstitute.org.au

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

About Myeloma

National Myeloma Day | 21 May 2014

With the incidence of myeloma increasing at one of the fastest rates of all blood cancers, please take a few minutes to learn about this disease today.

What is myeloma?

Myeloma, also known as multiple myeloma, is a cancer of plasma cells in the bone marrow. Myeloma cells crowd out healthy cells and weaken the immune system.

Who does it affect?

More than 1500 Australians are diagnosed with myeloma each year, equivalent to 4 people every day. The cause is unknown.

What are the symptoms?

They include bone damage, pain, anaemia, fatigue, kidney problems and frequent infections.

How is it treated?

There is currently no cure. Treatment aims to help control the growth of the disease and can continue for a long period of time. This is why family, friends and support networks can play an important role in helping the person with myeloma manage day to day.

If you, or someone you know has myeloma, please call 1800 620 420 or visit leukaemia.org.au/myeloma to find out about the services available to support you.

A Leukaemia Foundation initiative for National Myeloma Day 2014.
The Leukaemia Foundation funds myeloma research and provides free services to support people with myeloma.

Health
Western NSW
Local Health District

Living Well Together

CHEMOTHERAPY NURSE

3MONTH SECONDMENT
TREE CHANGE

COMMENCING MAY 2014

Cowra Health Services are offering an exciting opportunity for a three month secondment for a suitable experienced Chemotherapy accredited Oncology Nurse to have a tree change experience in Cowra.

Essential Criteria:

Significant experience in the delivery of Chemotherapy regimens.

Capacity to work independently,
Ability to undertake problem solving within own delegation.

Superior cannulation skills

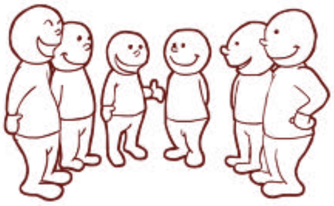
Good communication skills.

To apply for this position, please contact :

Pauline Rowston on 02 63402330

- **Free accommodation**
- **Newly renovated unit**
- **Friendly and supportive work environment**

Living Well Together



The Talking Corner

Toni Lindsay
Clinical Psychologist
Psycho-Oncology Team
Chris O'Brien Lifehouse, Sydney.

The psych's are back (by popular demand perhaps?), but Nicole is on leave, so you are stuck with me and my thoughts!!!!! A couple of good questions have come our way!

Q1. I have a patient who completed treatment last year for early stage NHL. They have been calling me a couple of times a week with pains, symptoms and are sure that they have relapsed. I am sure that they are fine, but they are causing me lots of stress. What can I do?

A. When we live in the health care system, most of our energies and expectations are focused on active treatments, relapse and symptom management, and so when patients have finished treatment we often assume that they will just go back to normal and everything will be ok for them. The reality for our patients is that they are often on a form of 'autopilot' during treatment and are stuck in the routine, and then when they finish they feel lost and confused as the emotions of everything that has just happened catches up with them. Before our patients become unwell, they are often not at all aware of the possibility of becoming sick, but when they finish treatment they are acutely aware that bad things can happen, and worry that this might happen again. Often, no amount of reassurance can help this sense, and time is the biggest factor in patients regaining a sense of "the new normal" and making sense of their treatment and diagnosis.

So what can I do to help?
The thing that is often helpful for the patients is for you to share your wisdom and acknowledge how scary it is for them to be outside of the hospital system, as well as how normal it is for them to be worried and anxious about the future. Sometimes just acknowledging or checking in with them about how they are going is all people need. If you think they need more, or if when you are talking with them they feel that finishing treatment and worrying about the disease coming back causes them lots of distress, offer a referral to the counselling team. More often than not, patients are relieved that people are hearing them and that they can get support.

Q2. People keep talking about *uncertainty* in the context of haematological malignancies. I don't really know why this matters.

A. Managing uncertainty is a theme that often arises in conversation with haematology patients and their families. In the context of having a diagnosis of a malignancy there is often a sense of having the world turned upside down, and patients often struggle to make sense of what's going on. A nice analogy is to think about us as the locals working in an airport. We know what things mean, where things are and most importantly, we speak the language. For our patients, they arrive into the airport as foreign travellers, with perhaps only a couple of words. Over time, the environment and language become more familiar, but it remains that there are many things that are unknown that there are not answers too.
People talk to us about worrying about what will happen next, if they will relapse, how long remission will last after transplant, feeling depressed and hopeless about the future, anxiety about making plans for the future, getting frustrated and irritable at everyone else's life moving on and feeling particularly anxious for doctor's appointments and bloods. Although these things all seem quite different from each other, the constant is the uncertainty: not knowing what's around the corner.

For our patients, they will often become fixated on details about tests, bloods, scans and the small details that their team might mention. Although for us, this can be difficult to manage, the mechanism for the patient is simply about trying to put some structure, sense of control and certainty into a situation that doesn't make much sense. The thing that is most helpful is giving clear concise information, and giving them the option to ask questions as well as having time to process things. One of the things that can be quite helpful is to help them find something in their everyday world that they can put some structure in, to make the uncertainty feel less overwhelming. For instance, encouraging them to make a bit of a plan for their day (particularly when an inpatient) so that they have some details to focus on and put some energy into. In addition to this, let them talk about their worry and fears about the future and reassure them when you can.

Useful resources you may like to take a look at

When I was looking through a bunch of resources the other day I came across this article that I love lots called '***The Tyranny of Positive Thinking***'. It's quite an old chapter now, but I think it's a nice perspective on the idea that our patients should be positive all the time, and how its actually pretty unhelpful advice! Check it out on http://www.humansideofcancer.com/chapter2/chapter.2.htm .

Conference of note

ANZCHOG is coming up in Sydney in June and it looks like there will be a whole bunch of great speakers, so if you are in paediatric oncology/haematology its worth a look. http://www.anzchogmeeting.org/index.php

And, finally, a non-haematology specific tale, but this link http://www.onbeing.org/blog/an-empathy-video-that-asks-you-to-stand-in-someone-elses-shoes/5063 came across my desk a couple of weeks ago. I strongly recommend watching; will make you think differently about our everyday encounters with people.

Got a question for Toni or Nicole? Troubling case, tricky questions?
Send them to the Editor and we'll address the best ones next edition.

Until next time…

Answers to Haematology Tea Room Quiz p22.

1. Haemorrhagic cystitis.
2. 120 days.
3. A cancer of the lymphatic system, which is part of the immune system.
4. Lymphoblastic Lymphoma; Burkitt 's lymphoma; Large Cell Lymphoma.
5. Daniel Gabriel Fahrenheit, in the 1700's.
6. Acute Lymphoblastic Leukaemia (ALL).
7. Both parents - in an autosomal recessive pattern.
8. Six months of age. In Thalassaemia Major, this is when symptoms start to appear.
9. Five days only.
10. Down syndrome.
11. 80% – 90%.
12. Chelating agent taken daily to remove excess iron from the body. Oral form only.

Medicine, Nursing and Health Sciences

The Myeloma and Related Diseases Registry

Why do we need a Myeloma and Related Diseases Registry?

- The information on the Myeloma and Related Diseases Registry (MRDR) provides clinicians and researchers with an important resource for investigating the causes and treatments for myeloma and monoclonal gammopathy of undetermined significance (MGUS).
- Different centres currently manage patients with myeloma and MGUS in slightly different ways, and more information is needed about which treatments work best and how useful they are.
- Although we know roughly how many new cases of myeloma are diagnosed in Australia and New Zealand each year, we don't know how severely patients are affected, precisely how they are treated or how their health changes over time.

The registry will tell us all of these things. It will also:

- Provide guidance and a framework for design of future research and health care services.
- The registry's steering committee consists of clinical experts, and a nurse and consumer representative from Australia and New Zealand with a special interest in myeloma. The steering committee meets regularly to discuss findings from the registry.

Why are Monash University and The Alfred involved?

- Monash University's Department of Epidemiology and Preventive Medicine is Australia's leading institution for clinical registries, and has the required infrastructure and expertise in public health, epidemiology, biostatistics and management of large databases of confidential information.
- Monash is an independent academic unit, working closely with an established network of haematologists at The Alfred Hospital, the Australian Centre for Blood Diseases and other clinical experts in malignant and general haematology.
- Monash and The Alfred have existing partnerships with key players in health improvement, such as the Victorian Cancer Council, the Victorian Department of Health, Myeloma Foundation of Australia, and major hospitals throughout Australia and New Zealand.

How do patients participate?

Patients recently diagnosed with myeloma or MGUS are identified by their clinician. Clinicians ask patients to participate before their details are entered into the registry. Patients can request for their details to be removed from the registry at any time, even after their details have been entered, without any consequences for their treatment or care.

Inclusion on the MRDR does not involve any change in patient treatment or any procedures beyond those usually involved in the management of the patient. Nurses at some sites are involved in collecting and entering this data. Data is drawn from the medical notes collected during standard medical care. Quality of Life is also measured.

How is patient privacy safeguarded?

The MRDR has been designed in accordance with the strictest privacy principles, including State and Commonwealth privacy laws, and has been reviewed by independent ethics committees from hospitals around Australia and New Zealand. No identifying information about patients will ever be released to any third party (except in the very rare case of a court order) and hospitals will only be able to view the details of their own patients.

Why should patients and hospitals participate?

- The project will provide important information that will help improve the way that patients with myeloma and related diseases are cared for in the future.
- Every patient is like a piece of a large jigsaw puzzle – each one gives us only a tiny amount of information, but together, they build a picture. The more pieces of the puzzle we can collect, the clearer the picture will be, and the greater the benefit to all patients.

Recruitment

- Data collection began in early 2013. There are currently 12 sites with ethics approval and over 310 patients registered.

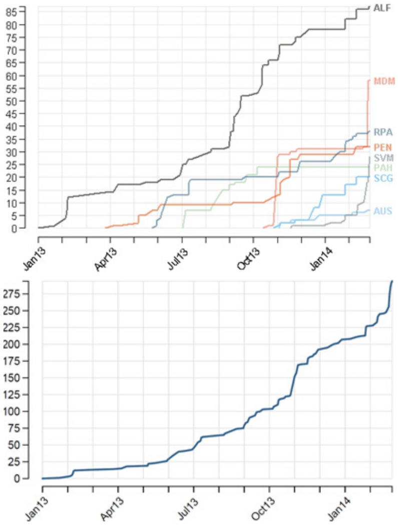


Figure 1 – Cumulative MRDR patient recruitment since 1st January 2013 to 21st February 2014 across all sites (left panel; total recruited = 294) and by each site currently entering data (right panel). Y-axes represent number of MRDR patients. Hospital key: ALF (Alfred), RPA (Royal Prince Alfred), PEN (Frankston Hospital, Peninsula Health), MDM (Middlemore), PAH (Princess Alexandra), SCG (Sir Charles Gairdner), AUS (Austin), SVM (St Vincent's).

What other research will information on the MRDR support?

- A biobank of blood samples from a subset of patients with myeloma and related diseases is currently being established by staff from Monash University and The Alfred Hospital.
- When established, the biobank will link information contained on the MRDR to patient blood samples, enabling researchers to better predict individuals at risk of developing myeloma and also those who are more or less likely to respond to particular therapies.

The MRDR is being supported by Australian grants from Novartis and Celgene.

How can you help?

If your hospital is not participating in the MRDR and you would like information about how to join the registry, contact the research team on: 1800 811 326 or email *torc.sphpm@monash.edu*

SAVE THE DATE: Wednesday 24th September 2014

Blood & Bone Marrow Transplant Education Day for Nurses

Hosted by Institute of Haematology RPA in collaboration with CNRU, HSANZ Nurses Group
Supported by Amgen and Sanofi Aventis

Dr Nicky Gilroy
(Infectious diseases consultant BMT Network / St Vincent's Hspt): Opportunistic infections post BMT

Dr Angela Hong
(Radiation Oncologist Lifehouse): TBI

Prof Kate White
(Prof Cancer Nursing): Sexual Health and GVHD

Transplant Coordinators RPA, Eleanor Romney & Katrina Wilczek
(CNS's RPA)

Paul Maulu
(Apheresis CNC RPA)

When: Wednesday 24th September 8.00am – 4.30pm
Where: Kerry Packer Education Centre – Royal Prince Alfred Hospital Sydney.

For more information or to register your interest contact:
Hannah Kaehler Transplant Coordinator RPA
Hannah.kaehler@sswahs.nsw.gov.au

CNRU Cancer Nursing Research Unit

Clinical Trials Corner

Rebecca Meti

CNC, Haematology Research Unit, RPA

This month we would like to put the spotlight on the real heroes of clinical trials and that is our patients. We would not have the treatments to offer today without the contribution of our wonderful patients who are willing to participate in clinical trials. I sat down for a chat with one of our patients Bob who has MDS to find out a bit more about his experience participating in a clinical trial.

So how did Bob come to a diagnosis of MDS?

Prior to Bob being diagnosed with MDS he was very fit, walking or swimming 4-5 days a week and was proud to reveal he took no medications at all, his only medical history was bronchiectasis. Over a period of a few weeks Bob began to feel very unwell. He was feeling tired, short of breath and had an unexplained rash so took himself off to the GP. A blood test revealed something was seriously wrong and Bob found himself rushed off to the Emergency department and a Haematologist was alerted. Bob was diagnosed with MDS and started on twice weekly blood and platelet transfusions. It was around this time that he was given some information about a clinical trial at another hospital that he might want to participate in. Bob was keen to find out more so referred to us here at RPAH.

I asked Bob what it was like being *screened* for a trial and then *treated within the context* of a clinical trial.

Bob described the screening phase as an emotional rollercoaster. Having recently been diagnosed with a condition he had never heard of, having regular hospital appointments for blood product support and now having to to deal with the *"will I or wont I be eligible for the study"*. However through his commitment and hard work plus collaboration across two units he was eventually enrolled on the QUAZAR study for MDS. This phase 3 multicentre randomized double blind study compares the efficacy and safety of oral azacitidine plus best supportive care versus placebo plus best supportive care. (see Haematology NSW ClinTrial Refer App for more information).

As a research nurse I often feel that the extra tests and investigations that are required within the context of a clinical trial could be arduous and a burden for the patient and their family to undertake. But interestingly when I questioned Bob more about this he said quite the opposite. Bob described the intensive screening and consenting process as being "very thorough" and in many ways reassuring to him and his family that every detail about his condition, his health and his treatment was being investigated and reviewed by the medical team. Bob provided me with insight into why we have a thorough screening period and reassured me that comfort and reassurance can be gained from such intensive monitoring.

So what has it been like for Bob taking part in a clinical trial so far?

Bob likens his experience to holding down a full time job, more to the point, a job he would happily be retrenched from!! Taking part in the clinical trial has required a huge adjustment for him, from someone who was "drug free" and healthy to now attending haematology clinics across 2 separate hospitals for blood transfusions and trial visits. Organising his time between hospitals and trial visits would not have been possible without the unwavering support and dedication of his wife who has been there beside him whilst he works.

So why does Bob do it?

Bob described to me 2 main factors that drive his participation in the clinical trial. The first has been the benefit the study may bring to other patients through his contribution to medical advancement and perhaps a cure. Secondly Bob said selfishly he hopes that he would get some benefit from the trial. Selfish? I think not! It is a huge responsibility committing to a trial, the requirements can be very demanding, it is us who should be thanking Bob and all trials patients who give their time toward the advancement of medicine.

So what have I learnt from sitting down with Bob to discuss his participation in the MDS study?

Firstly I've learnt not to assume to know how a patient may feel about participating in any given trial. Will they find the screening tests too much? Will they manage all the visits? I've also re-framed how I provide support in that crucial early stage when a patient is undergoing screening and may be experience extra stress and anxiety as they await to hear if they will be suitable for the study and meet all the exacting criteria. As Bob put it – that "will I won't I" phase. I also take extra time to acknowledge the huge commitment each trial patient make's and last but not least ill be sure to say "Thank You".

Further reading:

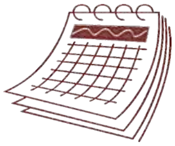
1. TRUONG, T. H., WEEKS, J. C., COOK, E. F. & JOFFE, S 2011, 'Altruism among participants in cancer clinical trials', *Clinical Trials,* vol.8, no. 5, pp, 616-23.
2. WOOTTEN, A. C., ABBOTT, J. M., SIDDONS, H. M., ROSENTHAL, M. A. & COSTELLO, A. J 2011, 'A qualitative assessment of the experience of participating in a cancer-related clinical trial', *Supportive Care in Cancer*, vol.19, no.1, pp.49-55.

Meetings

Biannual investigator meetings

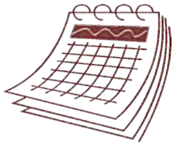
- 6-9th May, Melbourne
- 11-14th November, Sydney

To find out more or register to attend please see details on the ALLG website: www.allg.org.au



Conference Calendar

Date	Conference	Details
May 2014		
6th – 9th May	**ALLG Meeting**	Melbourne Australia http://www.allg.org.au/events.html
11th – 15th May	**World Federation of Haemophilia World Congress**	Melbourne Australia http://www.wfh.org/congress/en/WFH-2014-World-Congress
14th – 16th May	**Transfusion Update 2014**	http://www.transfusion.com.au/iTransfuse/transfusion_update Melbourne Australia
14th – 15th May	**World Marrow Donor Association Spring Meeting**	http://www.worldmarrow.org/ London, UK
June 2014		
5th – 7th June	**Cord Blood Symposium**	San Francisco, USA Abstracts submission closed Registration open: closes 30 May http://www.cordbloodsymposium.org/
19th – 21st June	**ANZCHOG ASM** **CNSA Winter Congress**	Melbourne, Australia Abstract submission closed Registration open: early bird deadline 31 May http://www.worldcancercongress.org/cosa-annual-scientific-meeting
July 2014		
24th – 26th July	**CNSA Winter Congress**	Melbourne Australia Abstracts submission closed Registration open, early bird deadline 30 April http://www.cnsawintercongress.com.au/home
October 2014		
19th – 22nd October	**HAA ASM**	Perth, Australia Abstract submission: not yet open. HAA invite you to sign up for email alerts re abstract submission availability Registration: not yet open http://www.haa2014.com/



Conference Calendar (cont'd)

November 2014		
11th – 14th November	**ALLG Meeting**	Sydney Australia http://www.allg.org.au/events.html

December 2014		
6th – 9th December	**American Society of Hematology (ASH)**	San Francisco, USA Abstract submission and registration not yet open http://www.hematology.org/meetings/annual-meeting/

Regional Round up!

HSANZ NG – regional groups are made up of nurses willing to contribute their time and energy to improve the care of those with a haematological condition within Australia and New Zealand. They do that by hosting educational meetings that not only give us all an opportunity to learn, but also to network with other like-minded nurses. These groups and meetings are only possible with the generous support of pharma but also, by the contributions, drive, and *engagement of us all*. If you have the time to contribute on a local committee, or offer some ideas for meeting topics, speakers, perhaps even present your work yourself; then we would all love to hear from you. Please take the time to get involved with your local group in some way.

North Island, New Zealand

Catherine Wood

The lower North Island is running four education sessions for the 2014 year, split between Wellington and Palmerston North. Topics selected for each year are based on the evaluations and suggestions received from the previous year. Tentative dates and topics for the 2014 education evenings are as follows:

Date	Location	Topic
6th May	Palmerston North	Bone Marrow Biopsy
28th May	Wellington	ALL
13th August	Palmerston North	NHL
12th November	Wellington	Bone marrow biopsy and intrathecal chemotherapy

We are grateful for the continuing support of our sponsors. We would not be able to run these education evenings without their generous support. For the 2014 year we have enthusiastic sponsorship from Janssen, Gilead and Roche. If anybody would like further information about any of these meetings or would like to attend then please feel free to get in touch with me. I can be emailed at Catherine.Wood@ccdhb.org.nz

South Island, New Zealand

Jane Worsfold

Six nurses will attend the branch meeting for HSANZ this week in Palmerston North – 2 presentations from staff. We are organising a "Pub quiz" with haematology-based questions in May (funds raised to assist with nurse education. Last year we had a couple of attempts to video conference with our colleagues from satellite centres around the S.I, however there was only a small amount of interest displayed. We will endeavour to get these other areas to join in at our next tele-conference in July/August.

Jane.Worsfold@cdhb.health.nz

Western Australia

Cassi Lawrence

A short update from WA as we have been focussing our efforts on preparing for HAA this year but we still have plans for a few regular local meetings for nurses and allied health with a haematology interest. The first will be in May and the second event will be after the HAA conference in December. The Back2Basics pre conference educational day will be open to all seeking a refresher on aspects of haematology, ideal for those working on the fringes of haematology. Keep eyes on your inbox for further information regarding both HAA 2014 & local education events.

Cassi.lawrence@health.wa.gov.au

Victoria

Jenelle Peppin

We have had Yvonne Panek-Hudson at the helm of the Victorian Nurses Group for the past four years. As the new Victorian Representative, I would like to thank Yvonne for her tireless effort and commitment to the group. Yvonne is staying on as part of the local organising committee in 2014, as we welcome some new and dynamic nurses to the team.

The topic for our first educational meeting for the year was Myeloproliferative Neoplasms. We had the privilege of having Consultant Haematologist, Dr Ali Bazargan from St Vincent's Hospital and the National MPN Coordinator for the Leukaemia Foundation, Ms Samantha Soggee, present for us. The session generated much interest with an attendance of 42 haematology nurses from both metropolitan and regional centres within Victoria. The feedback from the event was extremely positive. In keeping with our Memorandum of Understanding with the Cancer Nurses Society of Australia (CNSA), our next meeting will be in conjunction with our colleagues from CNSA. We are delighted to have Professor Kelly-Anne Phillips presenting 'An Overview of Medical Prevention of Breast Cancer – Implications for Hodgkin's Disease Survivors '. We look forward to seeing many of you at this meeting, as well as subsequent meetings to come. Jenelle.Peppin@mh.org.au

Tasmania

Gillian Sheldon-Collins

We had the first session for this year on 14th March, which was a huge success. HSANZ NG once again collaborated with CNSA to provide a program of interest for all oncology/haematology nurses. Forty nurses attended a dinner sponsored by Amgen at Hotel Grand Chancellor in Hobart, which is the biggest audience we have had so far. We had two local speakers, a doctor who gave a presentation about medulloblastoma, including the role of BMT in treatment of this rare tumour, followed by a cancer care coordinator regarding lung cancer in Tasmania.

The evaluations returned lots of ideas for future events and many nurses stated that they enjoyed having local speakers who provided an interesting Tasmanian context and were able to discuss local treatment, outcomes and survivorship for patients our nurses could relate to. We are hoping to conduct another educational dinner later this year. Twice a year seems to meet with local nurses expectations at the moment and these dinners have become a feature on the local calendar. Gillian.sheldoncollins@dhhs.tas.gov.au

New South Wales/ ACT

Tracy King

Our first meeting of the year brought a tear to the eye, not just because we had a sneak peek at Prof Harry Iland as a young man care of the latest edition of the ALLG newsletter.
http://www.allg.org.au/documents/Newsletters/ALLG_Newsletter.pdf

….but through the Sydney Children's Hospital (SCH) latest promotional song a dance clip brought to us by Grainne Dunne Haematology and Apheresis CNC SCH Sydney. I encourage you all to review the clip and while the tissues may be close at hand remember this is why we each work hard to excel at what it is we do. http://www.racingforlife.org.au/

Prof Iland's contribution to haematology in Australia and internationally is well known, especially in the field of acute promyelocytic leukaemia. We were grateful he was able to join us to present "Acute promyelocytic leukaemia – the agony & the ecstasy". A clinical disease alongside a review of APL studies demonstrated just how far we have come in improving outcomes for those with APL in such a relatively short period of time. Cath O'Dwyer CNC Sydney Youth Cancer Services followed with a case study presentation showing us all why we're glad to have moved through our teenage years relatively unscathed. The Youth Cancer Services provide such a valuable service in NSW we were all keen to hear of their work.
I would encourage you all to review the service to find out how they can help your 15-25yr patient population. http://www.youthcancer.com.au/Youth-Cancer-Services/new-south-wales-and-act/sydney-youth-cancer-service/about.aspx

Grainne provided us with our regular 'show and tell' look at a haematology unit in NSW by presenting her department, Haematology at Sydney Children's Hospital.

The 2014 calendar is filling up with meetings planned throughout the year. Full details will be sent to units closer to the time. As has been our practice in the past, and due to demand outstripping availability, with your support we rely on key contacts within in each unit to help allocate places at each educational meeting.

Date's 2014	Location
10th April	Gosford Area
May/June Date Pending	Sydney Metro
12th June Myeloma Education Day in partnership with Celgene	Sydney Metro
14th August	Wollongong
24th September In partnership with Institute of Haematology RPA & CNRU Sydney Nursing.	Royal Prince Alfred Hospital
13th November	Sydney Metro

NSW committee would like to express their gratitude to the companies who so generously support these educational events. Without such support we would not be in a position to host any meetings. The ongoing unconditional support for our meetings is testament to their support of Haematology nursing but also the quality of the meetings that are hosted. With thanks to Amgen, Bayer, Baxter, BMS, Celgene, Janssen, Novartis and Novo Nordisk for their support during 2014. Tracy.king@sswahs.nsw.gov.au

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