December 2013 *Volume 7: Issue 3*

Inside:

Plus much more…!

Newsletter design and publishing:
Natalie D'Abrew

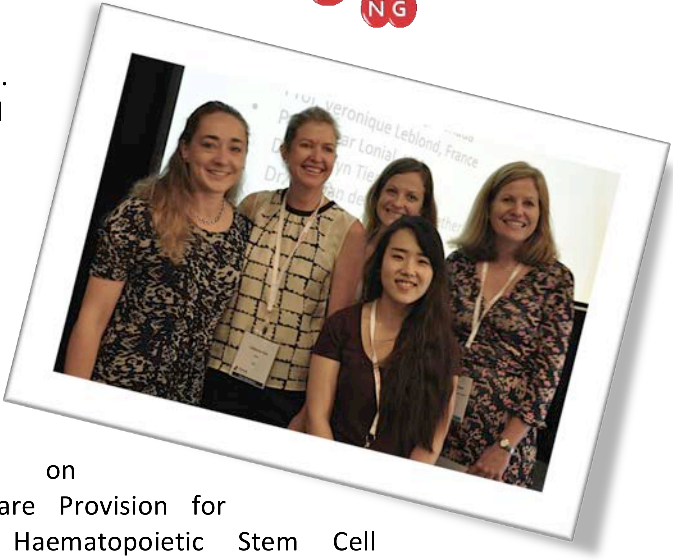
A "Golden" success for HAA 2013 at the Sunshine State!

With the combination of a wonderful, informative programme, fabulous sunny Queensland weather, and a record number of nurses attending, this year's conference turned out to be a highly successful and enjoyable one for all.

Invited Speaker: Monica Fliedner

This year combined nursing and medical symposia on Myeloproliferative Disorders demonstrated the important role around the management of the new oral therapies in CML and CLL and the complexities around the management and compliance of these agents. This was highlighted by our invited nursing speaker Monica Fliedner, an Advanced Practice Nurse with many years experience, and a keen interest in this area, around compliance and the potential barriers to compliance for oral therapies in this population. **Read Monicas article on adherence on page 16.**

The Nursing sessions were a terrific success with musch interest and conversation generated during and after the sessions. The panel session on "Myeloma in the Matrix" was particualy well recieved with much wonderful feedback during and post the sesssion, as well as through the evaluation forms. On that point I was delighted by the amount of evaluations recieved and the amount of feedback given. It really does go a long way in ensuring that each year gets better and better.



The nursing free communications sessions were a great success this year with a very high caliber of presentations and certainly some great abstracts submitted. It was a challenge to choose only 16 to be presented orally. The HSANZ NG was very pleased to be able to award **3 BEST ABSTRACT WARDS** and we would like to congratulate the following nurses: Rebecca Weeks (North Island NZ), Bora Kim (NSW) and Priscilla Gates (VIC). Elise O'Dell from Queensland won the best poster award for her oustanding poster on 'Exploring Palliative Care Provision for Relapsed Allogeneic Haematopoietic Stem Cell Transplant Patient'.

You can read more about the winning abstracts on page 4.

The "How too" sessions again were very well recieved and certainly some terrific ideas have been given to us on the evaluation forms on what you liked, and what you want to hear. This again has been very helping in planning for the upcoming conference in Perth.

The conference dinner brought light relief from the learning and sharing. The Casino Royale theme of the night saw much gambling, boozing and dancing occuring. Much fun was had by all, including myself and our International invited peaker Monica and her lovery husband Bernhard who embraced learning all about the "odd Australian game of 2 UP"!!

On a personal note I would really like to thank all the people involved in making this years conference another successful one! I will undoubtablety forget to mention someone, but you all know who you are. Firstly I would like to thank our invited international speaker Monica Fliedner, all our local invited speakers and the facilators of our how too sessions. I would also like to thank all our session chairs, our nursing volunteer Bora Kim, the conference organisers, the National HSANZ nursing committe and the QLD LOC who all participated in ensuring that the program ran smoothly. It really was a great conference and I look forward to seeing you all in 2014 at Perth.

Top Image Right: L to R, Rebecca Weeks, Catherine Kirk (LOC nurse), (Top) Elise O'Dell (Bottom) Bora Kim, Priscilla Gates

Top Image Left: L to R Carmel Woodrow, Joanne Farrell, Rosita Van Kuilenburg, Stephanie Buhagiar

Middle Image: Left Catherine Kirk (QLD Rep)& Right Monica Fliedner(Invited Speaker)

Bottom Image: Catherine Kirk: *"Relieved to have delivered the nursing program as planned!"*

A word or two from the President…

I'm on the home run! It is with much enthusiasm that I begin my last year leading the nurses group as it continues to expand, grow and mature into the peek body for haematology nurses around Australia and NZ. What a year! Thanks to you all, we continue to demonstrate the fasted growing membership within the HAA family, the fasted growing attendance at HAA each year and have demonstrated our ability by being allocated our own budget to manage autonomously from this financial year onwards. The nursing executive and I thank you all for your on going efforts and commitment to haematology nursing within our global region and look forward to continuing to evolve as a group, together in the years to come.

This edition of your newsletter is packed full of news and reports from the nursing program at HAA Gold Coast. Catherine Kirk and her local organising team hosted a highly successful, collaborative and informative program as demonstrated by various reports included here for your reading pleasure. I would particularly like to congratulate the winners of the best abstracts submitted to nurses stream this year. Priscilla Gates, Bora Kim, Rebecca Weeks for best abstracts presented as oral and Elisa O'Dell for best poster. These nurses demonstrate the capacity of supportive care initiatives and nursing research to contribute to improved outcomes in haematology. We have committed to continuing to fund these grants in the years ahead – so start working on those abstracts for HAA Perth 2014 – we have 4 X $1,000 grants up for grabs! Travel grants for conferences have also been awarded by NSW and VIC this year and we would like to particularly thank Amgen, Bayer, Celgene, Gilead & Pfizer for their on going support of haematology nurses in this regard.

I would also like to show my appreciation and grateful thanks to 2 hard working members of the HSANZ nursing executive who retire from the committee this year for a well deserved break. Yvonne Panek-Hudson has lead the VIC chapter for 4 years, during that time leading the nursing program at HAA 2012 in Melbourne whilst leaving behind a self sufficient, active sustainable local group. Julija Sipavicius has spent 3 years as secretary, typing, scribing and filing! Both have given of their time generously and contributed to the evolution of the nurses group. We don't let capable haematology nurses wander too far from our door - Yvonne remains on as an active member of the local VIC group and Julija stays on as co-editor of the HSANZ NG newsletter. On behalf of myself, the nursing executive and nurse members, we thank you for your service, efforts and energies.

As we head towards the holiday season I would like to wish you and your families a happy and healthy Christmas, especially those of you working on the wards and units. I am travelling home to be with family in the UK, via a quick stop off in Finland and Estonia – YES, I've packed my thermals!

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

Winning Abstracts: HAA 2013

Young adult cancer patient's communication needs: what does online narratives tell us?'

Kim, B[1] , Gillam, D[2] , Patterson, P [3], White , K[1]
[1]Cancer Nursing Research Unit, Sydney Nursing School, University of Sydney, [2]Flinders Univesrity, [3]CANTeen

Background: Young adults diagnosed with cancer are often faced with complex and multiple challenges. These can include interruption to education or career preparation, impact on relationships, employment, housing, and emotional development. Many young people have no experience of illness or the health care system prior to their diagnosis, nor life skills in managing competing priorities at this time in their life.

Aim: The overarching objective for this research is to improve the delivery of supportive care for young people diagnosed with cancer. There are three components to the work 1) Systematic review of the literature 2) Exploration of experiences and gain a better understanding of young adults affected by cancer (YAACs) by examining their online narratives (also known as Web logs or blogs) (this paper). 3) The final component will examine supportive communication needs from perspective of both YAACs and health care professionals.

Methods: Drawing on established procedures for reviewing Websites, inclusion and exclusion criteria were used to identify eligible Web sites. Blog content generated in 2011 was collected, authored by a 34 female and 12 male writers and included 136 (by female) and 28 (by male) blog entries. Researchers conducted a descriptive qualitative examination of blogs to explore YAACs' experiences during/after cancer.

Results : Ten main themes were identified: physical burdens, future prospects, isolation (physical and psychological), guilt, mortality, images of cancer, creating a positive attitude, healthcare, online social interaction, and cancer survivorship. The Internet provided YAACs with a space in which to express themselves and to share experiences with those who are of similar age and in similar situations.

Conclusions: Blogs can be particularly helpful for health care workers to understand patients' experience through a rich description of their everyday lives. This research illustrated unique difficulties and needs of YAACs through their blog contents. Despite of their complicated cancer journey, haematology nurses may not encounter YAACs often enough to build adequate levels of understanding and communication skills to effectively interact with them.

These results, combined with the literature review, have informed the development of the next phase of the research, which will examine supportive communication needs between YAAC and health professionals.

I feel so honoured to receive one of the awards for best abstract, and I appreciate the effort made by the HSANZ nursing stream to support research activities. I think this will continue to encourage haematology nurses to attentively address ways to improve our patient care and share the valuable findings. I had such a wonderful experience and great support at the conference.

Thank you! ***Bora Kim***

Development of a nurse-led survivorship intervention for long-term survivors of Hodgkin Lymphoma.

Ms Priscilla Gates, Prof John F Seymour, A Prof Meinir Krishnasamy.
Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia.

Background: The increasing numbers of Hodgkin Lymphoma (HL) survivors has raised awareness of the need to optimise long-term health outcomes and quality of life for this group of people.

Objective: To develop and pilot-test the feasibility and potential of a nurse-led survivorship intervention to enhance survivors of HL awareness of health risks and adoption of healthy lifestyle behaviours.

Methods: A pre-test, post-test design. Thirty survivor participants and 30 healthy controls were recruited. Data were collected using the General Health Index and the Health Promoting Lifestyle Profile II at four time points. The intervention included: i) exploration of knowledge of health risks and lifestyle behaviours; ii) delivery of a tailored education package; iii) screening for unmet supportive care needs and iv) development and delivery of a tailored survivorship care plan.

Results: A considerable profile of unmet need was identified. More than half of the survivor participants (57%) reported some level of fatigue for most of the time in the last two weeks; 47% reported feeling a lot of worry; 37% reported sleep problems; and 23% reported feeling depressed. Statistically significant improvements were seen for several domains. These included: physical activity (p=0.014); nutrition (p=0.0005); stress management (p=0.002) and health promoting lifestyle (p=0.005) from baseline to 6 months. No additional resources were required to provide the intervention as all aspects were delivered within existing resources of the haematology late effects clinic.

Conclusion: The nurse-led intervention was shown to be feasible and demonstrated significant potential to improve awareness of health status and healthy lifestyle behaviours. A randomised controlled trial is now needed to further test the efficacy of the intervention; determine optimal dose and the best time to deliver the intervention to prevent the levels of unmet needs reported by this study group, being reported by survivors of HL in the future.

I am very honoured to receive the award of Best Abstract in the Nurses Group HAA 2014. It is a great recognition of this study that was undertaken as part of a Masters of Philosophy at Melbourne University. This study contributes to nursing knowledge regarding survivorship care of survivors of HL. It provides an appreciation of the experience of HL survivors, perceptions of their health status, information needs and health worry/concern, informing the development of new intervention strategies that can be evaluated in future studies.

To date there has been limited evidence of nurse-led survivorship research for adult survivors of HL. This study makes a meaningful contribution to this area of enquiry.

Thank you to the HAA nurses group for their ongoing support of nurses and enabling nurses to share their highly valued work with colleagues.

Priscilla Gates

Evaluating Mindfulness Based Stress Reduction as a Psycho-Social support intervention for haematology patients

Rebecca Weeks

Leukaemia & Blood Cancer New Zealand, Auckland, New Zealand

Background: Mindfulness is an awareness that emerges through paying attention to the experience of the present moment. The Mindfulness Based Stress Reduction (MBSR) program was developed by Jon Kabat-Zinn in 1979. It teaches participants to deal more effectively with their physical and emotional experience (whether pleasant or unpleasant) as it arises. This enables people to become more aware of their reactions to stressful events and understand the choices they have in how they respond. The effectiveness of *Mindfulness Based Stress Reduction (*MBSR*)* for people living with and beyond cancer has been established. Randomised controlled trials have demonstrated that MBSR is a low cost intervention which can help manage the psychological sequelae of a cancer diagnosis for patients and carers. The majority of research has focused on breast cancer patients, and little is known of the effectiveness of MBSR on those living with a haematological malignancy. **Aim:** To pilot a MBSR program to ascertain its practicality and effectiveness for people affected by blood cancers.

Method: An 8 week MBSR program facilitated by a clinical psychologist, was set up based on the program developed by Jon Kabat-Zinn and modified for people living with cancer by Carlson and Speca. The program consisted of 2 hour classes, weekly, and one full day. It introduced mindfulness and guided participants through meditation, relaxation and gentle yoga exercises. Participants were encouraged to practice mindfulness in between classes. Participants completed the Profile of Mood States (POMS) assessment, Calgary Symptoms of Stress Inventory (C-SOSI) and the Post Traumatic Growth Inventory (PTGI) at the beginning of week one and the end of week eight. These measures are validated in an oncology population and assess physical and psychological responses to stress and measure positive life changes after a life-altering event. A course evaluation was completed at week 4 and week 8, and participants were asked to rate how useful the course had been to them.

Results: The course was completed by 7 participants (4 patients and 3 carers, 4 women and 3 men aged between 50-65). Four different haematological malignancies were represented among the group and one participant was bereaved. 6 out of 7 participants had a reduction in psychological distress with 1 participant remaining the same (POMS) and a *A* reduction in stress was experienced by 6 out of 7 participants (C-SOSI) and 6 out of 7 experienced personal growth (PTGI). *POMS assessments are currently being analysed.* Improved sleep, increased ability to enjoy sensory experiences and manage every day stress, increased perception of calm and acceptance with decreased worry and bitterness were among the results shown. All 7 participants rated the usefulness of the course as 9 or 10 out of 10, and all 7 said they had gotten something of lasting value or importance from participating in the programme. Participants also commented on the benefits of meeting others who shared similar experiences. Specific findings will also be shared regarding the practical aspects of running this type of program for people affected by blood cancer.

Conclusion: In programs following the pilot of MBSR the clinical psychologist has an initial conversation with participants prior to the start of the course. The time of the course has been adjusted to better suit the needs of participants and advertising has been increased. MBSR appears to be an effective program for addressing the psycho-social consequences of a blood cancer diagnosis, and the results of this small pilot appear to reflect the findings of larger studies. However larger studies and RCT's would be necessary for the purposes of confirming the value of MBSR in this patient group.

I would like to say thank you to the HSANZ NG and local organising committee for awarding me the honour of one of the best abstract awards at HAA 2013. The recognition gained by receiving such an award fuels me to want to undertake more local research in my area and continue to look at ways of improving supportive care for those with a blood cancer. I look forward to attending HAA 2014 in Perth.
Rebecca Weeks

'It seems to be the case that if you can be present for your life as it actually occurs, much of the angst of the past and future simply falls away. It may seem hard to believe but this is possible even in the midst of a life crisis like cancer' (Carlson and Speca, 2010 p10)

Poster Abstract Winner 2013

Royal Brisbane and Women's Hospital
Metro North Hospital and Health Service

Palliative care provision for patients that relapse from allogeneic haematopoietic stem cell transplantation

O'Dell, E B [1 2], Gavin, N C [1 2] & Keogh, S J [1 2]

1 Royal Brisbane & Women's Hospital, Brisbane, Queensland, Australia and 2 Griffith University, Brisbane, Queensland, Australia

Background

Allogeneic hematopoietic stem cell transplantation (alloHSCT) is often the only potentially curative therapy available for many patients facing otherwise fatal haematological malignancies and disorders. In recent decades alloHSCT survival times and cure rates have been steadily improving due to a reduction in non-relapsed mortality. Relapse and persistent disease remains the most common cause of treatment failure and death. The World Health Organization recommends palliative care be integrated in all cancer settings to improve quality of life for patients and families facing the physical, psychosocial and spiritual problems associated with life-threatening illness. Referral to specialist palliative care services (SPCS) is being increasingly recommended early in the disease trajectory, particularly for patients with complex issues as found in the alloHSCT patient population.

The Literature

A systematic literature search of the following electronic databases, CINAHL (1993-2012), Medline (1950-2012), PsychINFO (1872-2012) and The Cochrane Library (1999-2012) was conducted using MeSH terms: allogeneic hematopoietic stem cell transplantation, relapse, and palliative care. This search revealed three relevant articles, presenting evidence that was low-level, anecdotal, or qualitative. A growing body of literature indicates palliative care has not been successfully integrated into the broader hematology setting. There is scant literature available regarding palliative care for relapsed alloHSCT patients, and the concept of "the good death" in this setting.

Aims

This study was conducted to generate knowledge regarding palliative care provision specifically for relapsed alloHSCT patients. Study aims were to quantify the characteristics of the relapsed allogeneic haematopoietic stem cell transplant population that die in hospital, explore palliative care integration and end-of-life (EOL) care provision, and benchmark standards of care throughout Australia and New Zealand via nursing insights.

Methods

A descriptive exploratory design guided a retrospective chart review cohort study. The chart review was conducted in a large metropolitan hospital in Australia. Sample group was haematology patients that had received an alloHSCT between January 2008 – December 2012, relapsed, and died in the treating hospital. A quantitative data collection tool was created for the chart review and patient medical records were examined. Main research variables of the chart review were patient demographics, SPCS referrals, and EOL care provision.

A cross sectional survey design guided a national survey. The survey was distributed to one senior nurse at each of the leading allogeneic transplant centres in Australia and New Zealand between March 2013 – April 2013. The sample group was the most advanced nurse involved in patient care at each facility. A quantitative and free text data collection tool was created for the survey and conducted via e-mail or telephone. Survey topics included, services available, referrals to SPCS, EOL discussions and symptom management.

Results

In the five-year period 434 patients received an alloHSCT for a haematological disorder, 24.65% (n=107) of these patients relapsed and 70.79% (n=75) of relapsed patients subsequently died. Of the 75 deceased relapsed alloHSCT patients, 30 had died as in-patients in the treating hospital. Demographics are presented in Table 1.

Table 1. Demographics of chart review	n	%
Total number of patients	30	100
Gender		
Male	19	63.3
Female	11	36.7
Primary disease		
Acute leukaemia	21	70.0
Chronic leukaemia	4	13.3
Myeloproliferative / myelodysplasia	2	6.7
Multiple myeloma / plasma cell disorder	2	6.7
Lymphoma	0	0
Other	1	3.3
Age at death		
16-25 years old	5	16.7
26-45 years old	6	20.0
46-60 years old	13	43.3
61- 75 years old	6	20.0

Median time patients were made "not for resuscitation" was two days prior to death (range 1-29). Median time for cessation of active treatment was one day before death (range 1-9). Median time of review from SPCS prior to death was one day (range 1-277). End-of-life care in Table 2.

Table 2. End-of-life (EOL) care	n	%
EOL discussions with patient documented by medical staff	24	80
EOL discussions with patient documented by nursing staff	12	40
Patient made not for resuscitation	30	100
Active treatment ceased	21	70
Patient reviewed by specialist palliative care service	17	56.7

Senior nurses from 16 transplant centers were identified, response rate of 87.5% (n=14). The majority of respondents (71.4%, n=10) were Clinical Nurse Consultants/Specialists. Median experience in alloHSCT nursing 12 years (range 5-22). Respondents reported the most common reason that prompted SPCS referrals was physical symptoms (57.1%, n=8) or in the terminal phase (42.9%, n=6). The majority of respondents felt referrals should occur upon relapse (53.8%, n=7). Respondents felt the majority of relapsed alloHSCT patients received EOL discussions from their hematologists during the terminal phase (71.4%, n=10). Nurses felt that these discussions should occur upon relapse (78.6%, n=11).

Table 3. Nursing insights	Mean	SD
Do patients/families benefit from early SPCS referrals	8.5	1.23
Does your centre incorporate cure & palliation	4.5	2.62
Does your centre care for physical symptoms	7.9	1.69
Does your centre care for psychosocial/spiritual issues	7.1	1.64

* n=14
* rating scale of 0 – 10 (disagree to agree)

Conclusion

This study reflects poor integration of palliative care and EOL care provision for relapsed alloHSCT patients, as demonstrated in untimely or lack of: cessation of active treatment; not for resuscitation orders; palliative care referrals; and EOL discussions. The results of the survey confirm chart review findings and reflect nurses feel there is substandard symptom management and incorporation of cure and palliation. Results also demonstrate nursing recognition of the benefits of palliative care and support for early integration of palliative care and EOL discussions. More research, education and support is needed to provide best practice palliative care to alloHSCT patients that fail to stay in remission.

Great state. Great opportunity.

Griffith UNIVERSITY

Queensland Government

Travel Grant Winners 2013

VIC Junior Award:

Long Walks on the Beach – and some inspirational learning!

Nadine Borschmann RN, Peter MacCallum
Travel grant winner VIC – best abstract submitted to HAA 2013 VIC junior

I was recently lucky enough to attend the HAA conference on the Gold Coast, thanks to the generous support of HSANZ NG and Amgen. Excited and enthusiastic, but admittedly a little nervous, I arrived in sunny Broadbeach thinking I could get used to the idea of attending conferences!

As a Junior Haematology Nurse, working at the Peter MacCallum Cancer Centre, I was keen to open my eyes to the world of Haematology that existed beyond the walls of my ward, attending lectures and workshops held by both local and international experts in the field of Haematology, Blood Transfusion as well as Thrombosis and Haemostasis. Perhaps the most striking symposium during the conference was the focus on management of the Haematology patient in the home. These series of presentations challenged my understanding and beliefs of where and how, care of Haematology patients could be provided. An innovative service in Western Australia is meeting consumer desire and providing a range of chemotherapy regimes at home, regimes I would have never imagined could be provided in the home environment such as Hyper CVAD, High Dose Methotrexate and HiDAC. Not only does this meet patient desires as they don't have to worry about transport, parking, shared rooms or hospital food, the program also reports added benefits such as decreased rates of febrile neutropenia, improved quality of life, improved treatment related side effects such as nausea and vomiting as well as improved experiences of fatigue. This presentation highlighted to me the importance of changing the dynamics from a 'health care centred focus', by doing what works for us as health care providers, to a 'patient centred focus', by doing what works for our patients. Furthermore, the presentations highlighted the expanding and integral role of community based care for our patients as well as the need for innovative practice, with an aging population and increasing incidence of cancer, resulting in capacity issues for inpatient beds.

The experience and knowledge gained at the HAA conference was an extremely valuable opportunity both personally and professionally. I look forward to implementing and disseminating the knowledge gained, as well as encouraging and supporting colleagues to attend future HAA conferences. Each afternoon as I walked along the beach, I felt somewhat

VIC Senior Award:

An Exploratory Study of the Care Experiences of Patients Diagnosed with Myeloma

Kristen Houdyk[1], Meinir Krishnasamy[2], Miles Prince[2]
1. Myeloma Foundation of Australia Inc. Richmond, Australia.
2. Peter MacCallum Cancer Centre, East Melbourne, Australia.

I would like to thank the VIC HSANZ Nurse's group for providing me with a travel grant sponsored by Celgene to attend and present my study at HAA 2013 meeting. My research is designed to explore the unmet physical and supportive care needs of older patients diagnosed with myeloma. Recent developments in the treatment of myeloma have resulted in better disease outcomes for some groups but survival has not improved for older patients.

The primary objectives of the study are;

1. To examine patients' experience of care from diagnosis to 6 months post;
2. To identify gaps in service provision from the perspective of treating clinicians and GPs.

Travel Grant Winners 2013 Cont'd

20-30 newly diagnosed myeloma patients or patients who have relapsed disease, aged over 65 years, not eligible for an ASCT and commencing treatment will be recruited. Patients will be recruited from metropolitan and non-metropolitan centres, and from the public and private health care sector in Victoria. Patients will complete validated measures at T1 (3 to 6 weeks post commencement of treatment) and T2 (8-12 weeks post T1). Measures include the EORTC QLQ 30 and the MY20; the Distress thermometer and problem checklist; the HADS; Morisky Medication Adherence scale-8 and the Supportive Care Unmet Needs Scale. Measures are posted to patients with a stamped self-addressed envelope to return completed measures. At six months patients will participate in an audio tapped interview to describe their experience of care and living with myeloma. Patients' treating clinicians and GPs will be invited to take part in a taped interview to explore their perceptions of service gaps in care provision. Disease and demographic data with be collected from patients' medical records.

Ethics approval has been granted. Sixteen patients have been approached to participate in this study. Two declined to participate and three passed away while on study. Eleven patients are enrolled and/or completed the study.

Findings from this study will be used to develop a novel model of nurse-led, case management that will target gaps in the provision of care and services for older people diagnosed with myeloma. I hope to present the outcomes of this study at the HAA 2014 meeting.

VIC Senior Award:

Being Comfortable in Your Skin-the evolution of the role of the Cutaneous Lymphoma Nurse Practitioner (CLNP)

Odette Buelens, Peter MacCallum Cancer Centre, Department of Cancer Medicine, Melbourne, Australia

I was lucky enough to be offered a grant by HSANZ and Gilead to attend the HAA conference on the Gold Coast this year. I presented a poster pertaining to the evolution of the CLNP role. This was my first HAA conference and I will certainly be attending more of these in the future.

Cutaneous lymphoma (CL) is a rare blood condition manifesting as patches, plaques or visible tumours in the skin. The presentation, treatment, diagnosis and long term implications of Cutaneous B Cell Lymphoma (CBCL) and Cutaneous T Cell Lymphoma (CTCL) are varied. The rare and complex nature of the disease means specialist care is essential to maximise patient health outcomes. The CL service provides an interdisciplinary model of care to patients with CL throughout Australia.

The role of the CLNP was developed to complement the existing service by improving access to care and management of the complex issues experienced by these patients. The CLNP evolved from a nurse consultant role to improve access to specialist interdisciplinary care in a timely manner. Expert knowledge and clinical skills are central to the role in the management of symptoms such as intractable pruritus, chronic skin infections and the psychosocial implications of a disease such as CL. Collaboration, dissemination of information and education of staff, patients and families on a national level is required in order to deliver optimal care for this unique group of patients. The CLNP is an essential service providing comprehensive, collaborative disease specific care across disciplines and states.

The HAA conference was inspiring, interactive and full of novel interventions to improve care for our patients. Thank you to the wonderful HSANZ team and Gilead for giving me the opportunity to attend this event. I had an invaluable learning experience

NSW Local Awards:

Katrina Wilczek, CNS Haematology & BMT Unit, RPA Sydney

I was very lucky to be given the opportunity recently to attend the HAA conference on the Gold Coast. Along with colleague, Sally Taylor (CNS Haematology), we applied for and were awarded scholarships by Amgen through HSANZ NG. Josie Busuttil (RN Haematology) was awarded a Junior Haematology Nurse scholarship by Bayer and HSANZ NG.

Personally, I have a great interest in the long term follow up (LTFU) and survivorship issues of HSCT transplant patients, and found the conference so beneficial in this regard. The sessions on quality of life in transplant patients, and survivorship in haematology patients was especially interesting, providing me with many fresh ideas. As a senior haematology nurse, I was also inspired and encouraged by the sessions on nurse led clinics and the integration of nurse practitioner roles in transplant services. The conference also gave me an opportunity to form relationships with health professionals from other centres throughout Australia; gaining understanding about their models of care and service delivery in LTFU. I established valuable contacts that I have since shared information with and look forward to future collaborations with in this area.

Sally felt the conference provided a great deal of information, inspiration and innovative ideas to help improve current practice at our facility. The effectiveness of the 'telehealth" system in rural Townsville, the financial benefits it offered and prevention of long travelling times for patients and family members were especially interesting. As a senior chemotherapy nurse, Sally was also inspired by "chemo at home", a concept, which aimed to help increase the quality of life of the patients. Sally also presented a poster entitled "Meeting the information needs of those with a haematological malignancy: development and adaptation of a service guide for patients"; a collaboration with Tracy King (Myeloma CNC) and Hannah Mangan (Haematology CNS). The poster presentation night was an excellent opportunity to be able to display current research as well as to establish professional relationships with other health care professionals.

As a junior haematology nurse, Josie Busuttil found the conference an incredible learning experience. Presentations comprising of work of haematology nurses throughout Australia shone a new light on the world of haematology. A focus on quality of life for patients with haematological disorders in sessions such as "Myeloma in the matrix" provided her with a new perspective on the patient experience and better equipped her with the information and knowledge to support these patients. The orations detailing the pioneering work of inspirational Haematologists was both intriguing and entertaining. Workshops such as "how to make the world your oyster" was well directed towards junior haematology nurses, presenting options to further enhance skills and identify potential paths in her nursing career.

We would all like to encourage both junior and senior haematology nurses to apply for the travel grant through HSANZ NG to attend the conference in October 2014 in Perth. The experience was extremely valuable for gaining and sharing knowledge, making useful connections with other health care professionals and inspiring development and implementation of better initiatives for haematology patients in our service.

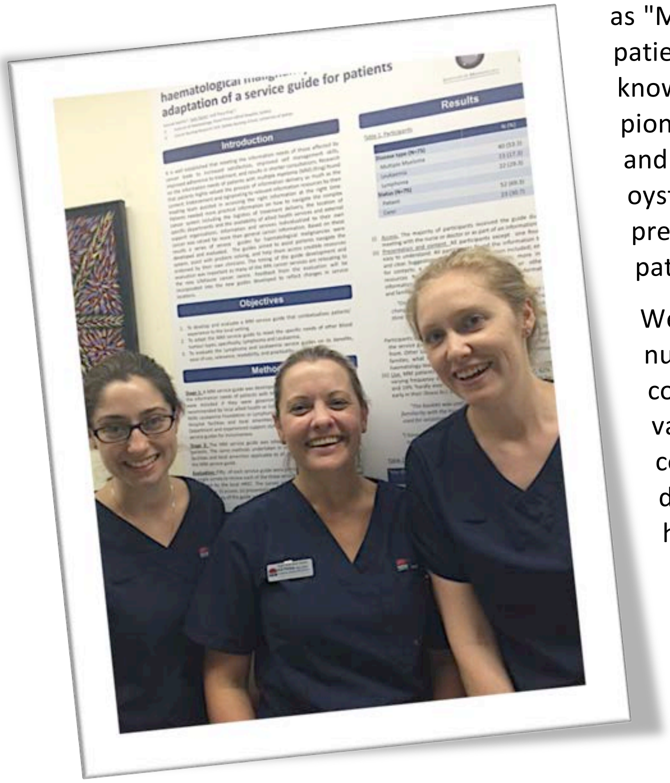


Photo: Josie, Katrina and Sally – back at work displaying Sally's poster on the ward.

Meeting the information needs of those with a haematological malignancy: development & adaptation of a service guide for patients

Hannah Kaehler[1], Sally Taylor[1] and Tracy King[1,2]
1) *Institute of Haematology, Royal Prince Alfred Hospital, Sydney*
2) *Cancer Nursing Research Unit, Sydney Nursing School, University of Sydney*

Introduction

It is well established that meeting the information needs of those affected by cancer leads to increased satisfaction, improved self management skills, improved adherence to treatment, and results in shorter consultations. Research on the information needs of patients with multiple myeloma (MM) (King) found that patients highly valued the process of information delivery as much as the content. Endorsement and signposting to relevant information resources by their treating team assisted in accessing the right information at the right time. Patients needed more practical information on how to navigate the complex cancer system including the logistics of treatment delivery, the location of specific departments and the availability of allied health services and external support organisations. Information and services individualised to their own cancer was valued far more than general cancer information. Based on these results a series of service guides for haematological malignancies were developed and evaluated. The guides aimed to assist patients navigate the system, assist with problem solving, and help them access credible resources endorsed by their own clinicians. The timing of the guide development and evaluation was important as many of the RPA cancer services are relocating to the new Lifehouse cancer centre. Feedback from the evaluation will be incorporated into the new guides developed to reflect changes in service locations.

Objectives

1. To develop and evaluate a MM service guide that contextualises patients' experience to the local setting.
2. To adapt the MM service guide to meet the specific needs of other blood tumour types, specifically, Lymphoma and Leukaemia.
3. To evaluate the Lymphoma and Leukaemia service guides on its benefits, ease of use, relevance, readability, and practicality.

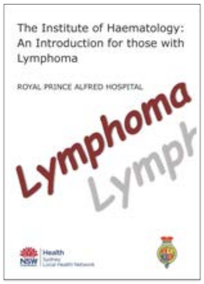
Method

Stage 1: A MM service guide was developed based on the results of research on the information needs of patients with MM. Services and information sources were included if they were government supported, routinely used or recommended by local allied health or listed in Cancer Council, Cancer Institute NSW, Leukaemia Foundation or Lymphoma Foundation publications or websites. Hospital facilities and local amenities were also included. The Head of Department and experienced support staff within the organisation reviewed the service guides for inclusiveness.

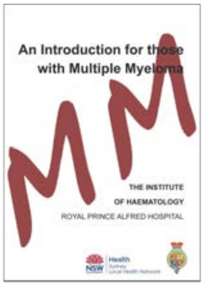
Stage 2: The MM service guide was adapted for Leukaemia and Lymphoma patients. The same methods undertaken in stage 1 were carried out. Hospital facilities and local amenities applicable to all patients were taken directly from the MM service guide.

Evaluation: Fifty of each service guide were printed and distributed to patients. A single survey to review each of the three service guides was designed and then approved by the local HREC. The survey asked questions about the guides in three areas: (i) access, (ii) presentation and content and (iii) use. All patients who received a copy of the guide were invited to participate.

Results

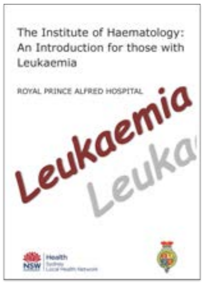

The Institute of Haematology: An Introduction for those with Lymphoma

ROYAL PRINCE ALFRED HOSPITAL


An Introduction for those with Multiple Myeloma

THE INSTITUTE OF HAEMATOLOGY

ROYAL PRINCE ALFRED HOSPITAL


The Institute of Haematology: An Introduction for those with Leukaemia

ROYAL PRINCE ALFRED HOSPITAL

Results

Table 1. Participants

	N (%)
Disease type (N=75)	
Multiple Myeloma	40 (53.3)
Leukaemia	13 (17.3)
Lymphoma	22 (29.3)
Status (N=75)	
Patient	52 (69.3)
Carer	23 (30.7)

(i) Access. The majority of participants received the guide during their first meeting with the nurse or doctor or as part of an information package.

(ii) Presentation and content. All participants except one found the guides easy to understand. All participants found the information to be accurate and clear. Suggestions for additional information included; email addresses for contacts; a more detailed table of contents; more information on resources for those with language difficulties or other languages; information on patient rights and privacy; and more information for carers and families in terms of supporting patients.

> *"Once you are admitted to hospital with lymphoma there is a huge change to those left at home, i.e. visiting hospital…anger and sadness. I think there should be something the family can take home so they know what to expect and how they can help"*

Participants also made suggestions about prioritising existing information in the service guides by placing emergency contacts and any warnings at the front. Other suggestions included emphasising counseling for patients and families, what to do in an emergency and more information about the haematology team and who to contact

(iii) Use. MM patients who had had the guide for at least 12 months reported varying frequency of use. 19 % used the guide 'regularly', 62% 'sometimes' and 19% 'hardly ever'. Patients considered the guide would be most useful early in their illness but also useful later on for reference.

> *"The booklet was useful in the early days of treatment until familiarity with the hospital and a routine was established! Now its used for occasional reference to websites or information booklets"*

> *"I have often used this booklet. I have found it invaluable for finding out about support services available…the list of phone numbers, people and websites is fantastic."*

Table 2. Overall understanding gained from the service guide

"Has the booklet helped you…"	N (%) 'Yes' responses
Understand the haematology service available to you at RPA? (N=72)	72 (100%)
Understand the wider hospital services and processes? (N=71)	66 (93%)
Access the hospital and medical and allied health services? (N=68)	67 (98.5%)

Conclusion

Participants found these service guides to be useful, informative and well presented. The guides are particularly valuable for newly diagnosed patients and their carers. More can be done to highlight key messages in the guide and to direct readers to key staff able to assist on specific items.

With the transition to a new service environment in late 2013 feedback can be incorporated into the necessary update of these service guides.

Acknowledgements: Cathy Barnett & Louise Acret

Jessica Watt: Bayer Junior Haematology Nurse Travel Grant Recipient NSW

I am a registered nurse at Sydney Children's Hospital; I work in the medical day unit within the Kids Cancer Centre. I was awarded the Junior Haematology Nurses Travel Grant to attend the HAA Conference 2013 sponsored through HSANZ NG NSW and Bayer.

I was thrilled to be able to attend the conference in the Gold Coast. The nurses' symposium provided access to the most recent research and ideas in haematology nursing. While much of the convention was adult based, I enjoyed the exposure to this area of haematology nursing and could relate it to my area of care in paediatrics. The nurses' symposium with a focus on management of the haematology patient in the home was particularly interesting and a new area of consideration for me as much of the care of the patients I observe is hospital based.

In the week prior to going to the conference I had to return a blood product to blood bank as the patient I was caring for had had a potential transfusion reaction. This was my first experience with such a blood transfusion incident. Following this recent event it was very interesting to learn more about anaemia, transfusion and the use of blood products in Australia. I came back so appreciative of our current blood product service and with renewed confidence about how I approach and handle blood product transfusions.

Both the workshops and the masterclass were a great addition to my conference experience and I gained knowledge from both the presenter and others sharing their experiences in haematology nursing. I am very grateful to HSANZ NG NSW and Bayer for supporting me to attend the conference, and am excited to share information gained with my colleagues.
I'm already looking forward to next years HAA in Perth!

Jessica Watt, RN, Sydney Children's Hospital

HAEMATOLOGY TEA ROOM QUIZ

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

A new section for the newsletter – why not test your knowledge in our quick haem quiz!

Questions

1. If you have Haemophilia A, which clotting factor are you deficient in?
2. What is the definition of 'Absolute Neutropenia'?
3. True or false, haemophilia is an inherited disorder only?
4. Is there any cure for Thalassaemia Major?
5. What is Tranexamic Acid?
6. What do the acronyms in the apheresis procedure 'PBSCC' stand for?
7. Tue or false, both boys and girls can be born with haemophilia?
8. Wiskott–Aldrich syndrome (WAS) is a rare disease affecting which blood cell?
9. What is the normal range for serum Ferritin levels in humans?
10. What is Ritiuximab (trade names Rituxan and MabThera)?
11. What type of bleeding disorder patients will receive the clotting factor concentrate "Biostate"?
12. What class of medication is 'Vincristine'?

(Answers available on page 22.... NO cheating now!)

Looking Ahead – HAA 2014
Perth, WA

As the nurses stream organiser for HAA 2014 I invite you all to WA in October 2014. It is anticipated that more than 1000 delegates from Australia and New Zealand, including clinicians, scientists and nurses, will attend 'HAA 2014'.
A comprehensive range of topics including haematological malignancies, stem cell transplantation, transfusion medicine, haemostasis and thrombosis and other non-malignant haematological disorders will be covered by international and local speakers.

The nurses stream will be, once again, packed with great speakers; international, national and local. Our invited international speaker is Dr Kathryn Tierney. Kathryn is an oncology Clinical Nurse Specialist at Stanford University Medical Centre with a keen interest in haematopoietic stem cell transplantation. Her areas of expertise include the care and management of patients with chronic and acute graft v's host disease, sexuality following BMT and care of the elderly patient in this setting. Kathryn is an active member of many professional organisations including ONS and is the Chair-Elect of the nurse's special interest group of ASBMT. Kathryn also holds the position of Assistant Clinical Professor, Department of Physiologic Nursing, University of California, San Francisco. Her research and subsequent publications are centred on her interest of transplantation and Quality of life issues in this population.

We will be once again be running 'How To' workshops on a variety of topics to immerse you in up-to-date haematology and Kathryn Tierney will be presenting a nursing Masterclass. A call for abstracts will be made well in advance of the meeting so start thinking of the work you would like to present to your peers and colleagues now. Combined sessions with HSANZ and the opportunity to attend any session within program will allow everyone the opportunity to learn from a wide range of local and international expertise that will be invited to join HAA at this comprehensive scientific conference.

According to TripAdvisor, some of the most visited attractions are Kings Park, Cottesloe Beach, City Beach, Rottnest Island & Scarborough beach. Margaret River in our South West or Monkey Mia on our North West coast. The sights are endless, like our beautiful beaches!

Tempted? Why not plan to stay a little longer and you will be impressed with what WA has to offer. The local organising committee for HAA 2014 welcome's you all to attend the meeting in Perth, Western Australia next year.

Cassi Lawrence: Cancer Nurse Coordinator Haematology.
Local organising committee HA 2014 Perth WA.
Cassi.lawrence@health.wa.gov.au

HAA 2013 – What Did You Say?

Allan Hayward, SA/NT Chair.

Evaluation of the Nurses Stream from HAA has been an important element for the HSANZ Nurses Group, both in receiving feedback about how the conference has gone but in planning for the next year. Firstly, thank you to everyone who has completed an evaluation and returned them to us, they are hugely helpful!

This year, there were 153 nurse registrations for the HAA conference with 49 evaluations completed and compiled. We also had a whopping 85 requests for Certificates for Continuing Nurse Education points. Feedback about the conference remains overwhelmingly positive with many people making comment on the variety and the quality of presentations and posters in the nursing stream.

Some of the *general feedback* about what people enjoyed the most about the conference included:

- “Being able to see how other treatment centres approach different subjects as well as meeting other staff from different regions and building professional friendships”
- “Meeting people, networking and learning lots”
- “Great excitement about haematology nursing! Great to see expanding programme year by year.”
- “The high level of nursing innovations presented”
- “The variety of presentations and relevance to my practice”
- “Friendly, welcoming atmosphere”
- “Networking with enthusiastic nurses”
- “Great papers, well balanced, one of the best meetings.”
-

The *posters* this year were also praised, with comments such as:

- “Very interesting and broad range of subjects”
- “A lot of effort with interesting abstracts/posters”
- “Some excellent posters presented”
- “Very helpful to my practice”
- “Had a poster myself and got to discuss with a number of “admirers”

There was great feedback regarding Monica Fliedner, the invited international nurse speaker. Monica presented several sessions including a master-class on adherence and compliance to oral medications. Some of the comments included:

- “Monica Fliedner was excellent”
- (Monica) “Helped me understand much more about the complexities of adherence and the need to not blame patients:
- “Interesting, relevant, helpful”
- “Really great to have an open discussion format” (like the Masterclass)
- “Excellent speakers, very interested in Monica’s research, inspired me to be more aware of factors influencing adherence and to make a tool to assess patient readiness to comply with medication regimens”

The “How to” sessions were presented as five concurrent sessions at two sessions, allowing participants to see more than one of the sessions – a great idea, especially with so many to choose from. These sessions were very well received and highly rated with comments such as:

- “Interesting, helpful for our local situation”
- “Well presented, captivated my attention”
- “A great speaker who had the audience interested”

- “Excellent”
- “Great info, great speaker”
- “Session was very helpful, informative, interesting and comprehensive”
- “Wonderful workshop”
- “Really good, very useful and practical session”

All of the sessions were rated highly, though there were two sessions which were particularly well received: The free communications session: Focus on Support held on Sunday morning and Myeloma in the Matrix: Quest for the Oracle held on Monday afternoon. The focus on Support session included topics on mindfulness based stress reduction, a national MDS survey, support for myeloproliferative neoplasms as well as young adult cancer patients and what online narratives tell us about their experience:

- “Best session of the meeting!”
- “Fantastic speakers, well presented, well researched, one of the best sessions I have been to”

Myeloma in the matrix was presented as a detailed case study presentation with a moderated panel discussion. The panel included a number of people able to comment on various aspects of the case study, from medical/nursing management of Myeloma, apheresis and psychology.

- “Best session, absolutely fantastic and everyone I spoke to agreed”
- “Awesome format”
- “Dynamic, relevant, interesting, collaborative”
- “I want to be a myeloma nurse!”
- “Myeloma matrix - excellent format!”

The HSANZ Nurses Group Annual General Meeting was also well attended this year, which was great to see! Thank you to all who attended and your feedback as well.

- “Moved quickly, lots of information, inclusive to all”
- “I’m a non-member but after this meeting (AGM) I know now what HSANZ NG does, so I’m thinking about joining”
- “First time at HSANZ/HAA, AGM a great meeting for an update”

A lot of ideas for future topics were also put forward which is really helpful in planning the HAA conference each year, so keep those coming! Any ideas on future topics can be forwarded to any of the committee members for feedback – you might even consider presenting what you and your unit are doing at the next HAA to be held in Perth in 2014…these sessions are really interesting for others around Australia and New Zealand to hear, not only as a chance to network with each other but to hear how others have tackled similar issues in their workplace. Lastly, congratulations Queensland for putting on a fantastic conference!

Adherence to oral chemotherapy: the challenge of the 20th century

Monica C. Fliedner, ANP, University Hospital Bern, Switzerland
monica.fliedner@insel.ch

Monica summarises below some of the work she presented during conference this year as the International Nurse Speaker at HAA 2013.

The treatment with oral anti-tumour drugs in patients with cancer started in the early 1940's when chlorambicil was successfully used for the treatment of lymphoma. Since then the treatment modalities developed rapidly and the introduction of imatinib around the turn of the century initiated a new era of treatment options for various types of cancer. Nowadays the treatment with oral anti-cancer drugs is established for several cancers.

For many patients the treatment of a potentially lethal disease with oral drugs offered more independence from hospital-based medical care shifting to outpatient clinics with minimal scheduled contacts with the professional team but more options for a relatively normal lifestyle.

Adherence in taking oral drugs for successful treatment was not thought to be an obstacle because initially in oncology it was assumed that patients facing a life-threatening disease would fully comply with the treatment as agreed to. But we now know that also these patients need to learn self-care management strategies to arrange their lives facing an often life-long oral therapy. The definition of adherence (Haynes et al 1979) is the basis for understanding and managing the complex issue.

We know that complying to long-term oral medication is a challenge worldwide – also in patients with cancer (WHO 2003). Several tumour-specific studies published data on adherence rates ranging between 16% and 100%, depending on the individual therapy, the complexity of treatment and measurement method used.
The assessment of risk factors for non-adherence should guide multifaceted inter-professional prolonged individualized interventions that are needed to support the patient and his family in the long-term oral treatment against cancer.

Risk factors for non-adherence are multidimensional and can be found in the area of the *health care system* (e.g. relationship between patient and health care provider and the support by members of the multi-professional team), *social/economic* (e.g. financial or social obstacles that are not supportive for the patient), *therapy-related issues* (e.g. complexity of the treatment and/or side effects due to treatment and its effectiveness), *condition-related* (e.g. status and presence of symptoms of the disease) and *patient-related* (e.g. knowledge and understanding of the disease, health literacy, motivation and expectations in the treatment). Usually a combination of several factors contribute to supporting the patient in being adherent.

The degree of adherence can be measured either directly (observation or assay in blood, urine or saliva) or indirectly (self- or collateral report, pill count or monitoring of prescriptions, measuring success of the treatment or through electronic event monitoring) but all procedures have diverse methodological difficulties and cannot always guarantee to be valid and reliable. It is more important to define the degree of adherence of a patient to reach therapeutic success and discuss the risk factors with him in detail.

Individualised tailored interventions and educational strategies to support these patients in their daily life to reach and maintain successful therapy management – ideally based on the identified risk factor and a thorough assessment of the personal situation and motivation, his health beliefs and habits. Interventions can include self-monitoring, corrective feedback, patient education and motivational interviewing as well as finding reminder devises or telephone follow-up. It is of utmost importance that the interventions are reviewed and offered on a continuous basis as adherence might diminish in the course of the disease.

I would like to encourage all professionals to share effective management strategies among each other and publish data on educational programs and experiences to enhance adherence in oral anti-cancer therapies. An extensive reference list can be obtained from the author (monica.fliedner@insel.ch) upon request.

A booklet for teaching professionals on the basics of adherence can be downloaded from the EBMT website: www.ebmt.org/Contents/Resources/Library/Resourcesfornurses/Pages/Resources-for-nurses.aspx.

This booklet includes theoretical concepts and basics on patient education and it will be revised in 2014.

Monica and her husband enjoying travelling around parts of Australia after the HAA conference.

What you should know about Haemophilia Clotting factor availability in Tasmania.

Helen Starosta, CNC Oncology-Haematology, Royal Hobart Hospital

Haemophilia Tasmania Centre

The Tasmanian population is approximately 500,000 in an area of 68,401 square kilometres. Greater Hobart has a population of 210,000, Launceston's population is 105,000, Devonport/Latrobe area is 30,000 and Burnie is 25,000. Compared to mainland states Tasmania may seem small yet due to the mountainous nature of the state and country roads travel times can be longer than expected.

The current Tasmanian health model is divided into 3 distinct health services (Tasmanian Health Organisation). This model provides care in 4 major hospitals and a number of community hospitals. The major hospitals are the Royal Hobart Hospital, Launceston General Hospital, North West Regional Hospital, Burnie & Mersey Community Hospital, and Latrobe (near Devonport). Larger community hospitals such as those at St Helens, Queenstown, and Swansea are staffed by General Practitioners for emergency care.


Burnie to Launceston 150km, 1hr 40 min

Burnie to Queenstown 150km, 2hrs 10 min

Launceston to St Helens 150km, 2hrs 10 min

Launceston to Hobart 200km, 2hrs 20 min

St Helens to Hobart 250km, 3hrs 20 min

Queenstown to Hobart 250km, 3hrs 30 min

Where is the clotting factor product?

Tasmanian persons with severe haemophilia A and B receive their product via home delivery from the products manufacturers. There are no patients with severe Haemophilia in the North West region of Tasmania. As a result Tasmania only keeps emergency supply of recombinant factor products at the Royal Hobart Hospital and Launceston General Hospital. This supply is sufficient for emergencies as stocks can be replenished quickly from the mainland. Haemophilia clotting factor is extremely expensive so this strategy has resulted in a significant decrease in product wastage.

Community hospitals will only routinely stock Biostate if there is a local patient in that area and do not routinely stock recombinant products. Transporting emergency products to rural areas of Tasmania can be very difficult and in the past the ambulance service has had to assist. This is especially important if a patient is on the west coast of Tasmania, which can be very isolated especially due to snow in winter.

MonoFIX (Factor IX): several years ago a decision was made not to stock MonoFIX as it had not been used in the state for several years.

Product Locations

Royal Hobart Hospital & Launceston General Hospital

- BIOSTATE (Plasma derived FVIII & VWF)
- XYNTHA, Kogenate (FVIII)
- PROTHROMBINEX (Plasma derived FII, FIX, FX & a low level of FVII)
- BeneFIX (FIX)
- NovoSeven (FVIIa)

North West Regional Hospital & Mersey Community Hostile

- BIOSTATE (Plasma derived FVIII & VWF)
- PROTHROMBINEX (Plasma derived FII, FIX, FX & a low level of FVII)
- NovoSeven (FVIIa)

What to tell patients who are moving to Tasmania?

Notify us at the Haemophilia Treatment Centre (HTC) and we can organize:

- Medical review with a Haematologist
- Emergency plan and place alerts on the patient information system and medical records
- Access to Factor product. Ideally move to Tasmania with a 2 to 4 week supply of product if you are on prophylaxis.

What to tell patients who are visiting Tasmania?

Notify us at the HTC and we can organize:

- Emergency plan and place alerts on the patient information system
- Advice regarding hospitals and their facilities.

See Carol Doherty's article on page 24 about her experience doing this Grad Cert! ***Editor***

Chemo@home: Same treatment, different view

Cancer primarily occurs in people aged 65 and over, with approximately 50% of all people in this age group expected to be diagnosed with cancer in their remaining lifetime. By 2020, the incidence of cancer in Australia will reach 150,000, a 40% increase over the 2011 numbers.

Future prevalence, however, is likely to be much higher than current projections because of:

- Improved survival;
- Increased retreatment rates; and
- Improved treatment of disease where there was previously limited treatment options (e.g. prostate cancer, myelodysplastic syndrome)

It is therefore clear that there is an absolute need to provide additional capacity and throughput in the health care system without costly outlays on capital works.

There are a number of clinical reasons why home substitute therapy should be considered for cancer patients receiving chemotherapy including:

- Decreased complication rate
  - Febrile neutropenia (55% vs 15% in AML patients on HiDAC consolidation)
- Improvement in compliance, increased likelihood of remaining on therapy
  - Possible improvements in OS, less relapse and retreatment
- Improvement in on time delivery of chemotherapy
  - 5% ↓ in cycle dose intensity with each day delay
  - Delays negate effect of expensive supportive care drugs (e.g. granulocyte colony stimulating factor)

In addition, there are numerous psychosocial and financial advantages to patients and their carers including

- Greater knowledge about disease
- Greater sense of control, better able to cope
- Improvements in well-being, mood and appetite
- Ability to keep working
- Reduced need for additional child care
- Decreased loss of productivity
- Reduced travelling and parking issues
- Reduced financial cost

Accreditation standards now mandate that health care and services are delivered in the most appropriate setting and that consumers participate in planning, delivery and evaluation of services. Given the overwhelming patient desire to be treated closer to home and consistent reports on the stress involved with travelling and parking at hospitals, is it *ethical* not to offer a service that patients want?

chemo@home
we see health differently

The Patient's View

"If I were to be granted a wish, it would be for this service to be available to every cancer patient and their family."
Carer of AYA ALL patient

Young man with Hodgkin's Lymphoma, who worked night duty, wanted to keep working to support his family. He continued on dose escalated BEACOPP, sleeping through most of his nurse visits and working at night. This would not have been possible if he had to make the one hour drive to and from the hospital each day for treatment.

"I don't know what all the fuss is about – my treatment wasn't too bad. I sat on my balcony, had a coffee and watched the ocean whilst the nurses did my treatment. The view was great." Patient treated with HyperCVAD chemotherapy for ALL.

AYA patient with an intellectual disability required sedation and a personal guard when admitted to hospital. Chemotherapy at home meant his parents could continue caring for him, resulting in far less stress on the family.

76 yo woman on azacitidine, had difficulty getting to hospital for treatment. Her daughter was struggling with a "roster" for the trips. Chemotherapy at home has kept her on treatment.

It is important to remember that hospital substitute treatment, is exactly that – a substitute for hospital. This means that the hospital substitute health service should provide the same interdisciplinary approach and standards of clinical care as the patient would receive if they were having chemotherapy in the hospital setting. Hospital substitute health services therefore need to be staffed by an appropriate team, with specialist skills, who manage and deliver care at home.

Julie Wilkes Managing Director, Chemo@home
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Parent support group at Sydney Children's Hospital, Randwick, NSW

Living with a chronic illness can be isolating both for the patients and their parents and carers. This is especially true for carers of young children living with Haemophilia, and even more so for first-time parents when their child is diagnosed shortly after birth. At Sydney Children's Hospital (SCH) in Randwick, we treat many children with bleeding disorders per year. However, despite the large number, it's very rare for the patients and families to meet each other. Most are able to manage their care as out-patients, coming to the day unit and clinic at different times.

As such, in 2006 the Clinical Nurse Consultant, Grainne Dunne and I started a parents and carers support and psycho-educational group for the families attending SCH. The group is attended by carers (parents and grandparents) and over time, the members have reaped the benefits of peer support and ongoing education and information. Speakers in the past have included: a Geneticist; Psychologist; Dentist; a university student living with severe Haemophilia and a representative from Sydney IVF – just to name a few.

After an 18 month hiatus, our group came together again in August this year. We had 10 members attend – including parents and grandparents. Carers came from Sydney and more regional locations, and their children were aged between 6 months and 13 years old. All children had either severe Haemophilia A or B.

Dan Credazzi, is both a Dad of one of our patients, and the president NSW HFA. Dan started off the formal part of the morning, with a presentation on what the National and NSW HFA do. He explained where the funding comes from; new initiatives in the world of Haemophilia; and what supports families can access. This information was really helpful for all who attended. A discussion opened up about the upcoming annual family camp in November. Those who had attended before were able to share their positive experience of camp, for the families who had never been. And we also started to discuss next year's World Federation of Haemophilia Congress in Melbourne. There was lots of excitement and interest shown from the families, who were also encouraged to look out for funding opportunities that may be available through the HFA.

The next speaker was Dr. Gnana Spaile the dentist in the hospital. The title of her presentation was "Dental Care for a Healthy Mouth". The message in this talk included general dental care for all children, as well as extra information about oral hygiene in the context of caring for a child with a bleeding disorder. Dr Spaile provided tips on dental products that are available for oral health, and ways to reducing mouth problems that would be more problematic for people living with a bleeding disorder. Carers were able to participate and ask questions throughout.
The informal aspect of the group is the peer support. Parent peer support is valuable and significant in meeting the needs

for many parents of newly diagnosed children with Haemophilia and those whose children are approaching new milestones and transition points in their life. Parents report that sharing daily experiences of caring for the child with another parent who understands, reduces their sense of isolation and increases their sense of feeling understood. In our group, carers are able to share experiences of caring for their child; how they administer intravenous clotting factor; how they manage day-to-day life and bleeds; explaining the diagnosis to their children and teaching their children how to self administer their own clotting factor. Because our attendees care for children over a broad age range, there are always valuable contributions to be made.

The need to support a parent's capacity to cope with their child's diagnosis and lifelong treatment is supported by research – which has demonstrated that improving a parent's ability to cope can positively impact a child's ability to cope. We received lots of positive feedback from our August group, and we hope to be able to continue to run these groups for a long time to come.

Written by ***Kate Lenthen***, Senior Social Worker, Sydney Children's Hospital

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In conjunction with ***Grainne Dunne***, CNC Haematology /Apheresis, Sydney Children's Hospital

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Answers to Haematology Tea Room Quiz p13.

1. Factor viii.
2. WCC ≤ 0.5 X10^9/l.
3. False. A form called 'acquired haemophilia 'can develop later in life. More common in elderly.
4. Yes, in selected cases. BMT.
5. Antifibrinolytic. It helps prevent clots from breaking down.
6. Peripheral Blood Stem Cell Collection.
7. True. Though mostly affects boys.
8. Platelets (thrombocytopenia).
9. 20-300 ug/L.
10. 'Monoclonal antibody' - used to destroy B cells.
11. Haemophilia A and/or von Willebrand Disease.
12. Vinca alkaloid.

Haemophilia Awareness Week at "The Sydney Children's Hospitals Network", NSW

Grainne Dunne, CNC Haemophilia, Sydney Children's Hospital, Randwick
Robyn Shoemark, CNC Haemophilia, The Children's Hospital at Westmead

The Sydney Children's Hospital Network consists of 2 large children's hospitals, located approximately 35 km apart in Sydney. Together both hospitals serve the children of NSW, ACT and sometimes beyond this area. During National Haemophilia Awareness week (Oct 13 – 19), both hospitals celebrated awareness for Haemophilia and Bleeding Disorders in similar yet different ways.

Sydney Children's Hospital (SCH), Randwick

Preparation for the week was led mainly by the haematology day ward CNS Brigitte Montzka & CNE Kim Traish with guidance from their haemophilia CNC. The aim of the week was to educate staff and visitors about bleeding disorders. Haemophilia and other bleeding disorders are rare, hence this was an ideal opportunity to bring bleeding disorders to the surface. For weeks prior, staff prepared educational decorations for the ward (fun blood droplet cut outs with bleeding disorder questions & answers on them); informative posters about Haemophilia; 'fun' fundraising was arranged e.g. count the red lollies in the jar competition, red cake sales; colouring in competition for the children which showed off some great budding artists!!

On Thursday, we held 'Red Cake Day' where all staff dressed in red, sold their greatly baked red cakes and other yummy treats. Then during meal breaks, everyone grazed in the tea room until no more party food could possibly be had!! Altogether $166 was raised & donated to the Haemophilia Foundation NSW. Bleeding disorder in-services for the staff were arranged for each day. Speakers consisted of CNS's from the haematology ward, CNC for haemophilia, the NSW Haemophilia Foundation president and pharmaceutical reprehensives. The in-service week ended with a mind blowing haemophilia quiz where the haematology day ward competed against the haematology over night ward! There was lots of positive energy flowing and great team spirit in making Haemophilia week a fun yet very productive week for haemophilia awareness and learning.

The Children's Hospital at Westmead (CHW)

Haemophilia Awareness Week kicked off on Monday 14th October with an information stand located in the hospital foyer. The stand was refilled with leaflets and balloons each day as people passing had depleted stocks from the previous day. The information was getting out there as leaflets and colouring in flyers were taken with enthusiasm. On Wednesday, for Red Cake Day, Haematology doctors and nurses baked red velvet cupcakes and sold them to staff to raise awareness and funds for HFNSW. A total of $246 was donated. Well done bakers.

On Thursday, the team from Pfizer joined us for a fun filled day with the Medikidz superheroes. Following a competition, patients Javonte Leung and Ryan Morales will become characters in the new edition of Medikidz Explain Haemophilia Comic Books. Congratulations to both boys. We had many great entries. Thank you to all that entered the competition. We celebrated the day with balloons, superheroes and visits from local newspapers that the boys featured in later that week.

Graduate Certificate in Nursing Science Apheresis Nursing, University of Adelaide

Carol Doherty, CNS Oncology,
Kids Cancer Centre, Sydney Children's Hospital, Randwick, NSW

I have just recently completed the Graduate Certificate in Nursing Science Apheresis Nursing via correspondence through the University of Adelaide. I was very fortunate to receive a scholarship to complete the course through the Bone Marrow Transplant Network of NSW; this enabled me to complete the course without the stress of the financial burden. I encourage all apheresis nurses who have not completed a course such as this to do it, especially nurses who are relatively new in the area of apheresis.

I have been working in apheresis for two and half years now and I found that I was struggling when I was called in on the weekend or afterhours to complete an emergency procedure. I had very limited or sometimes no one to ask for support or guidance. I felt that I did not have the knowledge or confidence to be able to give advice or information about the number of plasma exchanges, the type of replacement fluid we should use or whether to change the type or rate of anticoagulant being used. The course taught me about apheresis history; the different types of machines; different disorders which apheresis is utilised to treat either as primary or adjuvant therapy; understanding the different types of replacement fluid and in which situations they should be used; the many possible adverse effects which can occur during apheresis and also the accreditation and legal requirements required.

Coming from a paediatric centre this was a steep learning curve for me, as most of the clinical scenarios diseases/disorders investigated were either adult diseases/disorders or those vary rarely seen in paediatrics. However I found this very interesting as it taught me about the different uses for apheresis and how this might be transferred into the paediatric setting. My class, which recently completed the course, consisted of 5 students including myself and from 3 different states. I learnt a lot from each student's presentations in our online-classroom. As a result of completing the course our unit is currently reviewing some of our procedures/guidelines and changing a few practices to be inline with best-practice guidelines. Despite all the hard work and the many hours of studying, I do thoroughly recommend the course to anyone who wants to learn more about apheresis.

I would also like to take this opportunity to thank the BMT Network NSW for their financial support through the scholarship, my colleagues at my hospital and apheresis colleagues from adult institutions and the Australian Red Cross for all their help and support. Without all of you I would not have been able to complete this course and I am forever grateful.

Australian Haemophilia Nurse’s Group celebrates 25 years in existence.

Beryl Zeissink, CNC Haemophilia,
Queensland Haemophilia Centre, Royal Brisbane & Women’s Hospital

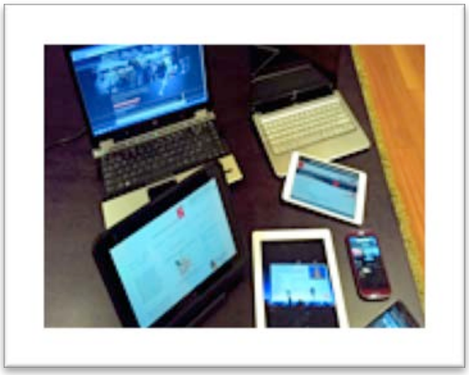
This year, the Australian Haemophilia Nurse’s Group (AHNG) celebrated their 25th Anniversary since the group was first founded. We were very pleased to have Dawn Thorpe (one of the original haemophilia nurse’s of the group) come and reminisce about the “early days” of managing Australian haemophilia care, in what was then called the Haemophilia Foundation Australia – Nurse’s Association. At that first meeting 12 nurses’ attended. In 2013 we had 23 members at our annual general meeting.

Most of the current nurse’s that make up what is now called the “Australian Haemophilia Nurses Group” have been in their roles less than 15 years. In our current work life, we all know that there have been lot’s of changes in the last 10 year’s, moving to recombinant haemophilia replacement products and hopefully in the near future “longer acting” products. However at our recent anniversary celebration, Dawn was able to put some of the many other changes in the world of haemophilia into perspective for us. In the early days, we did not have a National Bleeding Disorder’s Registry; Dawn had a rolodex with all her patient’s names and phone numbers. Some nurse’s didn’t have access to email, let alone a computer. There were no haemophilia nursing guidelines. It was in these early days with great foresight that the Haemophilia Foundation of Australia wrote to the hospital’s involved in Haemophilia care, and “invited” a local nurse to attend the first Haemophilia nurse’s meeting in 1988.

The early aims of the group were “to establish a network of Australian Haemophilia Care Nurses”, and to “provide a forum where nurse’s involved in Haemophilia care can meet to problem solve, expand their knowledge and gain support from each other”. Today, these aims remain an integral part of the groups current “Terms of Reference”, but really are a lot broader than in those early days. We are honoured that we advocate for the haemophilia community in a professional capacity, and that our group’s opinions are sought after by the National Blood Authority and The Haemophilia Foundation of Australia. Today our group is made up of representation from up to 16 haemophilia centres with about 20 “executive members” and invitation open to further “associate members”.

We know there will be many other changes ahead of us, which we welcome. We are pleased to say that we have a strong committed group that will continue to move forward on this journey of change with the haemophilia community.

The Engine Room then!



The Engine Room now!

BloodSafe eLearning Australia

Michele Wood, Program Manager

BloodSafe eLearning Australia (www.bloodsafelearning.org.au.) would like to thank the HSANZ members for its continued support. Did you know that our registrations have exceeded 209,000 with over 8,000 course completions monthly! This represents a significant volume of eLearning.

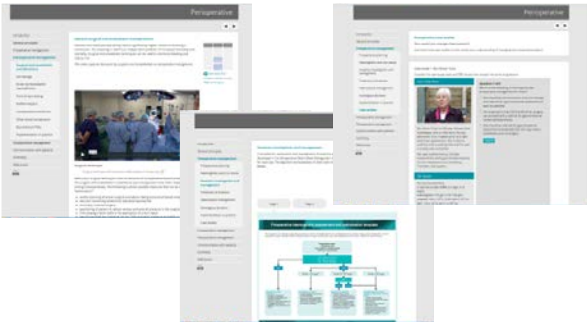
Our **Clinical Transfusion Practice (CTP)** course was updated, 5 April 2013, to reflect changes to the ANZSBT guidelines, in the Administration of Blood and Blood Products (released late 2011), which included:

- Inclusion of the Stewardship Statement endorsed by the Australian Health Ministers
- Changes to transfusion indicators
- Additional guidance on specimen labelling e.g. must occur at the patients' side
- Changes to frequency of observations and additional monitoring e.g. oxygen saturations

A summary of the changes is available on the 'Introduction' page of the CTP course.

There is also increasing completion of other courses as well as CTP. We encourage you to inform your colleagues, about our range of free courses. Did you attend the 2013 HAA Conference? You may have seen a presentation, by Louise English, on our new courses being released this December;

Patient Blood Management (PBM)
– A short module that seeks to explain the concept of PBM. Providing an overview for everyone involved in patient care and hints and tips on how to get a PBM program started in your workplace.



Perioperative
– A course based on the PBM guidelines, which includes showcases from hospitals in Australia, on how to apply the three principles of PBM in a perioperative setting.

Other PBM courses available

Iron Deficiency Anaemia (IDA)
This course aims to increase knowledge to diagnose, investigate and manage IDA. It is based on the Pasricha, S et al, 2010, Diagnosis and management of iron deficiency anaemia: a clinical update, Med J Aust, 193 (9):525-532.

Postpartum Haemorrhage (PPH)
This course aims to increase knowledge of the pathophysiology, prevention and management of postpartum haemorrhage. It outlines the pathophysiology of pregnancy; causes, prevention and diagnosis and management of PPH; advance fluid resuscitation; secondary PPH and anaemia management.

Critical Bleeding
This course aims to increase knowledge of the effective management of patients with, or at risk of critical bleeding/massive transfusion, to ensure best patient outcomes. The importance of early recognition and stopping bleeding, fluid resuscitation and pharmacotherapy and Massive Transfusion Protocol.

Visit www.bloodsafelearning.org.au for more information on our **FREE** courses today.

eviQ Cancer Treatments Online

Cancer Institute NSW Update

November 2013

Patient Information Project

Lisa King (eviQ Content Author) is currently undertaking a review of the patient information on eviQ. The project has full ethics approval and consists of a patient questionnaire through a nominated site and clinician feedback. There is a link to the clinician survey on the eviQ home page and each tumour stream home page. If you would like to contribute, please don't hesitate to complete the survey and tell us what you think! www.eviq.org.au

Haematology

The haematology reference committee was held recently during which many of the lymphoma protocols were reviewed. You may notice some changes and new protocols for both Hodgkin and non Hodgkin lymphoma over the coming weeks. While we weren't able to review all of the lymphoma protocols during this meeting due to the number of protocols we currently have, the remainder will be reviewed and updated in 2014.

If you are interested in contributing to the review of haematology content or know of any clinicians who may be interested please contact patricia.ryan@cancerinstitute.org.au

HPCT

The HPCT team is working hard to organise their reference committee meetings for 2014. For further information or to be involved in the HPCT reference committee, please contact aisling.kelly@cancerinstitute.org.au

Nursing

We are looking for nurses to assist us in reviewing our growing list of documents on the site. We plan to run the reviews "via remote" using email and teleconference. If you are interested in providing input to the nursing content on eviQ please contact Danielle.peterman@cancerinstitute.org.au and provide us with your area of interest.

Education

The blended eLearning antineoplastic drug administration course (ADAC) is used by over 180 sites in Australia and has recently received international interest including New Zealand and WHO.

Current ADAC facilitators have recently been advised that by January 1 2014 the current version of ADAC will be updated with version 2. Version 2 will improve access by enabling use on laptops and iPads, anywhere at any time. eviQ Education supports and assists health facilities to implement the course through 'train the trainer' sessions and the new facilitator forum on the web page.

Keep a close watch on new projects including Paediatric ADAC, Radiation Oncology and Community Care. If you have any queries about eviQ Education, please contact eviqed@eviq.org.au

Feedback

Don't forget the feedback email: contactus@eviq.org.au for any feedback you may have, requests for protocols or technical issues. We will always endeavour to answer your enquiries within 3-5 working days.

Working together to lessen the impact of cancer

NSW GOVERNMENT | cancer institute NSW

SYDNEY NURSING SCHOOL

THE UNIVERSITY OF SYDNEY

CANCER AND HAEMATOLOGY NURSING

IMPROVING OUTCOMES FOR SURVIVAL AND OPTIMAL RECOVERY FOR CANCER PATIENTS

Specialist education for nurses who work in all areas of cancer and haematology nursing

Cancer is the single largest cause of premature death and represents nearly one-fifth of the total burden of disease in Australia. This is set to increase substantially over the next decade.

TAKE THE NEXT STEP IN YOUR CAREER

The Cancer and Haematology Nursing program offered by Sydney Nursing School could well be the next step in your nursing career.

With an excellent reputation in cancer teaching and research Sydney Nursing School is perfectly placed to be educating the cancer and haematology nurses of the future.

We provide specialist education for nurses who work in all areas of cancer and haematology nursing, including care delivered in specialist units, community care, acute care, inpatient and home-based care.

Nurses make up the largest group in the cancer workforce and Sydney Nursing School understands the importance of professional education to support their needs.

Cancer is the single largest cause of premature death and represents nearly one-fifth of the total burden of disease in Australia. This is set to increase substantially over the next decade. In this context there is increasing recognition that specialist cancer services improve outcomes and benefit both survival and optimal recovery for cancer patients.

Nurses are essential to providing support to patients and their families. With specialised skills and knowledge you will contribute to important decisions about future trends in treatment, patient care and disease prevention.

COURSE OVERVIEW

The Cancer and Haematology Nursing program is offered at graduate certificate, graduate diploma and master's degree levels. The graduate certificate and graduate diploma are embedded within the master's degree. There is one intake each year in March.

Master's Degree

Credit points	60
Full-time enrolment	1.5 years (or part-time equivalent)

Graduate Diploma

Credit points	48
Full-time enrolment	1 year (or part-time equivalent)

Graduate Certificate

Credit points	24
Part-time enrolment	1 year

Each unit of study has four compulsory on-campus study days per semester offered in block mode. The study days are supplemented by flexible and independent online study, supported by the University of Sydney's eLearning platform.

PhD PATHWAY

If you have a particular interest in research, you have the option to take a research stream within any of Sydney Nursing School's specialty degrees, This stream will develop your research skills and knowledge. It is also a pathway into the PhD program at Sydney Nursing School.

Closing Date for Enrolment: 31st January 2014

Shannon Philp, Course Coordinator Cancer and Haematology Nursing

WHO SHOULD APPLY?

This course provides specialist education for nurses who work in all areas of cancer and haematology care.

RECOGNITION OF PREVIOUS STUDY

Registered nurses who have completed graduate studies may apply for prior recognition towards the graduate diploma and master's degree. Credit towards the course is determined on an individual basis.

HOW TO APPLY

Please apply online. You can also upload certified copies of your documentation and any other forms required as part of the online application process. Both domestic and international students submit your applications at http://sydney.edu.au/courses/programs/master-of-cancer-and-haematology-nursing

The application closing date for the March intake is 31 January.

WANT MORE INFORMATION ABOUT THIS COURSE?

You can find more nformation about the Cancer and Haematology Nursing program, including fees, on our website: sydney.edu.au/nursing/course_information/specialty_courses/specialty_courses_index.shtml

WHAT WILL YOU STUDY?

YEAR 1 PART TIME STUDY PATTERN		YEAR 2 PART TIME STUDY PATTERN	
SEMESTER 1	SEMESTER 2	SEMESTER 1	SEMESTER 2
ASSESSMENT AND CLINICAL JUDGEMENT	CANCER AND HAEMATOLOGY NURSING PRACTICE	RESEARCH IN NURSING AND HEALTH CARE	*STUDENTS MUST CHOOSE 2 UNITS FROM THE FOLOWING 3 OPTIONS:* CREATING A CULTURE OF SAFETY AND QUALITY
THE BIOLOGY OF CANCER AND HAEMATOLOGY	NAVIGATING THE CANCER EXPERIENCE	EXPANDING CANCER AND HAEMATOLOGY PRACTICE	CONTEMPORARY NURSING LEADERSHIP
			SIMULATION-BASED LEARNING IN HEALTH

YEAR 3 PART TIME STUDY PATTERN

SEMESTER 1	CAPSTONE (WORK-BASED PROJECT) OR CAPTSONE (THESIS)

CAPSTONE

The Capstone is an important feature of Sydney Nursing School's postgraduate master's degrees, providing an excellent opportunity for you to extend and develop your knowledge and skills on a topic of professional interest. The Capstone (Research) is also a pathway into the PhD program at Sydney Nursing School.

GRADUATE CAPABILITIES

Graduates from this course will be recognised as having advanced knowledge relevant to cancer and haematology nursing.

While developing discipline-specific knowledge and skills, graduate certificate students will develop the skills required to explore the complexity of and uncertainty in practice and build a capacity for practice thinking. This will enable them to become highly knowledgeable and skilled in this specialty area.

Students studying at a master's level will develop an advanced capacity for clinical judgement through engagement with the ambiguities and complexities of practice and discipline knowledge.

Master's students will be able to perform as autonomous learners capable of integrating prior learning while exploring professional contexts and the sociopolitical climate.

LEADING ACADEMIC AND CLINICAL EXPERTS

You'll be learning from leading academic and clinical experts in cancer and haematology nursing. The course coordinator is Shannon Philp. Shannon has nearly 20 years experience in cancer nursing and is an endorsed Nurse Practitioner. She works conjointly in a senior clinical role as a Nurse Practitioner at Chris O'Brien Lifehouse.

You will also have access to the expertise of the Cancer Nursing Research Unit. Led by Professor Kate White the Cancer Nursing Research Unit is an innovative collaboration between Sydney Nursing School, the Cancer Institute of New South Wales and the Sydney Cancer Centre, Royal Prince Alfred Hospital.

FOR MORE INFORMATION CONTACT

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SYDNEY NURSING SCHOOL

THE UNIVERSITY OF SYDNEY

CRICOS Provider No.00026A

Closing Date for Enrolment: 31st January 2014

Clinical Trials Corner

Jenelle Peppin
Clinical Haematology and BMT Research Nurse
Royal Melbourne Hospital

So it’s no secret that our haematology nurses are working tirelessly within their specialised areas, as evidenced by the fabulous work presented at the HAA Conference and outlined within the pages of this newsletter.

As the end of year fast approaches, the work continues within the area of research. What’s that saying – cancer doesn’t stop, because it’s Christmas...nor does the work of a clinical trial nurse. Unfortunately, clinical trial protocols do not take into account that people want to stop for pudding on Christmas Day, or bubbles to bring in the New Year!

So, for this final edition of the Clinical Trials Corner for 2013, I thought I would highlight the wonderful work of a group of haematology research nurses who will not stop for pudding or bubbles in lieu of navigating their way through the complexities of screening, coordinating and treating patients who are enrolled in a Phase 1 clinical trial known as the ABT-199 Study.

It is important to acknowledge that despite not constructing an abstract, or presenting at a conference, the research nurses involved with this study have been recognised at both a local and global level for their efforts and expertise, in the coordination and intricate care of these study patients. Watch this space – as the results of this Phase 1 study are proving to be very promising...

SPOTLIGHT ON A TRIAL

Protocol Title: A Phase 1 Study Evaluating the Safety and Pharmacokinetics of ABT-199 in Subjects with Relapsed or Refractory Chronic Lymphocytic Leukaemia and Non-Hodgkin Lymphoma

Objectives: The primary objectives of this study are to assess the safety profile, characterize pharmacokinetics (PK), determine the maximum tolerated dose (MTD), determine the recommended phase 2 dose, and determine the lead-in period regimen of ABT-199 in subjects with relapsed or refractory chronic lymphocytic leukaemia (CLL) and non-Hodgkin lymphoma (NHL). The secondary objectives are to evaluate preliminary efficacy data regarding the effect of ABT-199 on progression-free survival (PFS), objective response rate (ORR), time to progression (TTP), overall survival (OS), and duration of response. Biomarkers and pharmacogenetics will also be evaluated.

Number of Subjects to be Enrolled: Approximately 130

Main Inclusion Criteria:

1. Subject must be ≥ 18 years of age.
2. Subject must have either relapsed or refractory CLL/SLL or relapsed or refractory NHL.
3. Subject must have adequate bone marrow independent of growth factor support.
4. Subject must have adequate coagulation, renal, and hepatic function.
5. NHL subjects who have a history of an autologous stem cell transplant must be > 6 months post transplant.

Main Exclusion Criteria:

1. CLL subject has undergone an allogeneic or autologous stem cell transplant.
2. Subject has tested positive for HIV.
3. Subject has consumed grapefruit, grapefruit products, Seville oranges or Star fruit within 3 days prior to the first dose of study drug.
4. NHL subject has undergone an allogeneic stem cell transplant.
5. NHL subject has been diagnosed with Post-Transplant Lymphoproliferative Disease, Burkitt's lymphoma, Burkitt-like lymphoma, or lymphoblastic lymphoma/leukaemia.

Dose: All subjects begin dosing with a lead-in period with step-wise dose escalation to the designated cohort dose.

Mode of Administration: Oral

Main Adverse Events: Tumour Lysis Syndrome (e.g., fever, chills, tachycardia, nausea, vomiting, diarrhoea, diaphoresis, hypotension, muscle aches, weakness, paresthesias, mental status changes, confusion, seizures etc.).

For further information regarding the ABT-199 Study, please feel free to contact the Haematology Research team at the Royal Melbourne Hospital on (03) 9342 7000

Remote control: Regional Families' with Bleeding Disorders and Healthcare Professionals' Attitudes towards Telehealth Services

Ms Joanna McCosker

Haemophilia Clinical Nurse Consultant, Haemophilia Treatment Centre, Royal Children's Hospital, Brisbane

HAA 2013 at the beautiful Gold Coast was such a whirl of activity: a jam packed program full of quality talks & fantastic speakers. There was so much in the program to choose from it was difficult to decide when, where & who! The Haemophilia team from Brisbane were very busy in the weeks beforehand frantically preparing posters & talks. I presented a quality initiative on the use of telehealth to engage families & health professionals with bleeding disorders living in regional Queensland, and their attitudes towards Telehealth Services, which I will briefly summarise here for you.

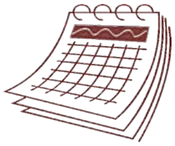
As the tertiary referral hospital for Haemophilia in Queensland we have the problem of how to provide access to specialist care, education, support and management to those who live in rural and regional communities? Queensland is the 2nd largest state in Australia and we have a population of 4.5 million; two thirds of this population live in SE Queensland and most specialist services are centralised in our major cities. The families experience significant cost, time and transport requirements due to the distance and issues with equity of access to health care specialists. For example to drive from Cairns to Brisbane would take you approximately 19 hours and you would cover 1700 kilometres versus an hour by car to cover the 80 km from the Gold Coast. So to enhance access to treatment for regional families we developed regular outreach clinics to provide face-to-face contact for families in their local hospital settings at various regions in Queensland.

What is Telehealth?: Telehealth is the delivery of health services and clinical support via online communication methods such as video conferencing, email and telephone consultations. This model of care is aimed at regional and remote areas and benefits children and their families by overcoming the challenges with distance, access to specialist care and cost of travel.

Does Haemophilia care fit this model?: The Queensland Children's Haemophilia Centre (QCHC) is a state-wide service consisting of a multidisciplinary team which provides treatment, care, and support for all families with inherited bleeding disorders who live in Queensland or Northern NSW. The aims of our study were to assess the attitudes of healthcare professionals and families to telehealth clinics and ascertain the effectiveness of this strategy to improve the care for families in rural and regional Queensland. Regional families and healthcare professionals who attended the telehealth clinics over a period of one and a half years were emailed a questionnaire using a 5-point Likert-type scale to assess their satisfaction and experience of using the telehealth clinics.

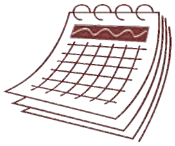
Results: Using the Telemedicine model in Haemophilia care we have discovered we experience the same benefits as has been previously documented in other patient populations: cost savings, user satisfaction, improved equity and access to HCP's, and less disruption of family life. Results showed families were highly satisfied with the telehealth experience and reasons rated as "highly important" were: ease of attending, reduced time and cost, involvement of both local hospital and health care professionals.

Overall both families and staff expressed positive attitudes towards telehealth clinics however there were some components of care considered better addressed in face to face clinic reviews, such as assessment of musculoskeletal issues. Nonetheless, telehealth clinics have allowed the Haemophilia Treatment Centre (HTC) to ensure appropriate clinical follow up (for example 6 monthly reviews for families with severe haemophilia) where previously at most, annual reviews were only possible. The HTC team plan to continue telehealth clinics and to build on this improvement in patient management for regional and remote families with inherited bleeding disorders.



Conference Calendar

Date	Conference	Details
December 2013		
7-10 Dec, 2013	**2013 ASH 55th Annual Meeting and Exposition**	Ernest N. Morial Convention Center, New Orleans, LA. For more information ⇨ http://www.hematology.org/ *Members-only registration opens:* **24 July, 2013** *Abstract submission deadline:* **8 August. 2013**
1st – 4th Dec 2013	**24th Regional Congress of the ISBT (international society of blood transfusion)**	Kuala Lumpur Convention Centre, Kuala Lumpur, Malaysia Early bird registration closes 6th October 2013 http://www.isbtweb.org/malaysia/welcome



Conference Calendar (cont'd)

Date	Conference	Details
February 2014		
February 26th - March 2nd	BMT Tandem Meeting CIBMTR	Dallas TX USA http://www.cibmtr.org/Meetings/Tandem/Pages/index.aspx
March 2014		
30th March to 2nd April	EBMT 40th Annual Meeting	Milano Italy http://www.ebmt2014.org/ Early bird registration: January 15th 2014
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
18th – 21st June	Australia New Zealand Children's Oncology Haematology Group ANZCHOG 2014 ASM	Sydney, Australia http://www.anzchog.org/news-and-events/news/2013/06/18/anzchog-2014-asm
July 2014		
24th – 26th July	CNSA Winter Congress	Melbourne Australia http://www.cnsawintercongress.com.au/home
November 2014		
11th – 14th November	ALLG Meeting	Sydney Australia http://www.allg.org.au/events.html

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 had its final education evening for 2013 on the 19th November. This is the fifth one we have run this year . Three have been held in Wellington and two will have been held in Palmerston North, about two hours' drive north of Wellington. Topics covered this year include allogeneic stem cell transplant, multiple myeloma, AML, fertility for haematology patients and transitioning patients from intensive treatment back to normal life. We are a small area but have averaged around 20 – 25 attendees coming along for each event. The education evenings wouldn't be possible without sponsorship. We have had generous sponsorship this year from the Wellington Division of the Cancer Society of NZ, Janssen, Gilead and Roche.

Planning is underway for the 2014 year. We are always keen for suggestions for topics and events so please feel free to contact Catherine if you want to be involved or have any ideas. I can be emailed at Catherine.Wood@ccdhb.org.nz

Victoria

Yvonne Panek-Hudson

Thanks to everyone for a wonderful 4 years as Victorian representative of the HSANZ nurses group. I am handing over the reigns to ***Jenelle Peppin*** (jenelle.peppin@mh.org.au) and staying on as part of the local organising committee. I feel privileged to be a part of a committed group of nurses who strive for optimising the patient experience and dissemination of expert knowledge and clinical practice. Personal highlights of the last 4 years include:

- Increase in local membership and educational opportunities for haematology nurses in Victoria
- Development of conference grants to attend HAA (5 in 2013)
- Collaboration with regional/rural sectors to provide nursing education
- HAA Melbourne 2012

I'd like to congratulate our conference grant recipients for this year: *Odette Buelens* – best poster abstract, *Kristen Houdyk* – best oral abstract, *Kaye Hose* – best oral abstract, *Nadine Borschmann* – junior haematology nurse and *Donna Lever* – rural haematology nurse. Each makes an enormous contribution to patient care and expert nursing practice. I'd also like to thank our grant sponsors who make it all possible and continue to demonstrate their support of haematology nurses. Thanks to Amgen for 2 grants, Celgene, Gilead and Pfizer.

Our final meeting was on the 26th of November. We had 4 brilliant speakers presenting "Highlights from HAA Gold Coast 2013". If you would like further information please contact me on yvonne.panek-hudson@petermac.org Thanks to Tracy King and the executive nurses group for their tireless efforts, commitment to haematology nursing, ongoing support and all the fun…

South Australia/Northern Territory

Allan Hayward

We have had a total of five education events in SA and NT this year, which is a great effort! Two events have been held in Darwin, two in Adelaide and another in the Barossa Valley.

Darwin has been host to a Paediatric / Young Adult Cancer Care Education day in June with 20 attendees, mostly from the Royal Darwin and Darwin Private Hospitals. A Transfusion education day was also held in September, supported by Novartis. This saw 45 people attend (no mean feat, given it was held on the day of the AFL Grand Final as well as Darwin's Relay for Life event!) Thanks to the support of Novartis, attendees from other parts of the NT were able to attend (Alice Springs, Katherine and Nhulunbuy) along with a very strong contingent of nurses from Darwin hospitals and Red Cross Blood Collection Centres.

Adelaide hosted an evening on Apheresis and Transfusion Guidelines in July with 60 people attending. The Adelaide Blood Club's 17th Annual Scientific Weekend in the Barossa Valley in August also included a Nurses Education Day. Approximately 20 people attended this event from various hospitals around Adelaide. Presentations included the work of Priscilla Gates (invited nursed speaker from the Peter Mac / Australian Survivorship Centre in Melbourne, a consumer presentation as well as getting to hear from local nurses and nurse practitioner candidates about their work. Our final event for 2013 is a "wrap-up" of the recent HAA conference held on the Gold Coast with 20 people expected.

I would also like to take the opportunity to thank our supporters who contribute to making these education sessions happen; Sonya Rayner from Novartis, Angela Porter from Amgen, Linda Pfeiler from Specialised Therapeutics Australia as well as Sue James and Jane Campbell from Icon Cancer Care. Additionally I would like to thank Bek Lamb for all the hard work that goes on behind the scenes and on the evening in holding these events.

Planning for a programme of events for 2014 will begin shortly with dates/topics to be announced early in the New Year. Feedback and evaluations from these events continues to be overwhelmingly positive and we look forward to continuing these events in the coming year. If you have an interest in contributing to these events (Whether in the organisation or in the presentation of you or your workplace's work) we would love to hear from you! Please contact me at allan.hayward@health.sa.gov.au . It is an opportunity to give back to your fellow nurses as well as an excellent opportunity to develop yourself professionally!

New South Wales/ ACT

Tracy King

We welcome Kathlene Robson to our organising committee for NSW & ACT. Following on from a successful meeting in 14th Sept on AML Kathlene aims to host 2 meetings per year in the greater ACT area with a focus on haematology nursing. Watch this space for dates and topics ahead for 2014.

Our recent activities have included a successful collaboration with the new and may I say, spectacular, Orange base hospital. Fran, Ben, Collette and the team hosted Prof Kate White and myself to run a nurses and allied health day focussing on blood malignancies. Over 60 nurses, pharmacists, allied health and Drs were present to hear a range of clinical disease updates and nursing practice updates. Dr Doug Lenton and Dr Scott Dunkley and the wider team are expanding their haematology practice in the region and we look forward to supporting nurses in their haematology education and experiences in the years ahead. The educational day was preceded by a patient and family afternoon hosted by the Leukaemia Foundation with Michelle Powel. Over 70 people were able to make the most of a comprehensive panel of clinicians presenting on a range of topics from advances in haematology through to nutrition and exercise. We would like to thank Amgen and Celgene for their generous support of the Orange meetings made particularly exciting by storms, closed airports, lost & swapped luggage amongst other acts of GOD. Looking ahead to 2014, NSW / ACT are planning a range of events in metro and regional areas. 1st meeting of the year is 20th Feb Sydney with guest speakers Prof Harry Iland giving a clinical update on APML and Wendy Londal Paediatric issues in acute leukaemia. We look forward to meeting many of you at our meetings throughout the year. Tracy.king@sswahs.nsw.gov.au

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