December 2012 Volume 6: Issue 3

# Inside:

**Newsletter design and publishing:**
Natalie D'Abrew

# Another year has gone…another HAA success!

Another year gone, another HAA success!! In addition to the excellent programme, Melbourne turned on some great weather that added to the enjoyment.

Combined nursing and medical symposia on Myeloma and Palliative care highlighted the importance of a multi disciplinary approach for the management of the complexities of these issues. Attendees were treated to discussions on the implementation of palliative care in haematology and the essential components of supportive care for patients with myeloma given that for many people it is a chronic disease.

The nurses group invited speaker Dr Karen Syrjala provided us with insights into impact on carers, development and implementation of survivorship services and the importance of a dedicated exercise and rehabilitation program for cancer survivors. *Karen has kindly provided us with copies of her presentations so please contact me if you would like them.*


*Invited Speaker: Dr Karen Syrjala*

It was the second year of 'How to...' sessions and once again all 5 sessions – palliative care, health decisions, survivorship care plans, ethical considerations and critical reviews, were highly subscribed to and evaluations demonstrated the value participants gained from these sessions.

2012 CO-JOINT SCIENTIFIC MEETING 28 - 31 OCTOBER 2012 Melbourne Convention Exhibition Centre, Melbourne, Victoria, Australia

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# A word or two from the President…

It is my pleasure as the new president of the HSANZ Nurses Group to present to you our bumper, new look, post HAA issue of the newsletter. I am honoured to be given this opportunity to represent you all as the incoming President of our HSANZ Nurses Group. During my 2 year term I hope to represent your wishes and aspirations for haematology nursing to the best of my ability. To that end, I invite you all to get in touch with me directly or via your regional chairs so that our work, efforts and outputs are truly representative of members needs.

Firstly on behalf of the Executive and all associate nurse members, I would like to offer our formal thanks to our outgoing president, Moira Stephens. Moira's tireless work over the past 6 years since our inception has been central to the success of our group. I would also like to congratulate Moira on the successful awarding of her PhD this year. This achievement alongside her contribution to Haematology nursing both within Australia and internationally is something few nurses achieve during their career and Moira's is far from over! We all wish you well Moira, as you pursue your research interests outside of cancer and haematology nursing as part of the team at Wollongong University faculty of nursing.

I would also like to congratulate Yvonne Panek-Hudson and her local organising team for a successful, educational, thought provoking and yes, even entertaining nursing stream at HAA 2012 in Melbourne. The time, effort and work involved in developing and hosting the nursing program during HAA requires multiple skills, no least in negotiation; ability; knowledge; professionalism and drive. Yvonne has that with spades on and I would like to convey our thanks and congratulations from the nursing executive and associate nurse members for her efforts and those or her team.

This edition of the newsletter includes a variety of reports from HAA 2012 for your reading pleasure. I hope you enjoy this 'post HAA' edition and are inspired to work towards contributing to future HAA meetings by submitting abstracts of your work, attending conference and offering feedback via your local regional representatives for inclusions in future nursing programs. Thank you to all of you who have contributed to this and past editions of the newsletter. We welcome contributions from all tribes of haematology so please get in touch if you have something to say, promote or report.

For those of you taking time off over the Christmas and New Year period I wish you a happy and healthy holiday. For those covering the wards, clinics and units, we'll be thinking of you when you take a well deserved break later in the year!

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

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The free communication sessions were of a particularly high caliber and we were delighted to offer 3 best abstract awards to Carolyn Greely (Vic), Hayley King (Vic) and Tracey Clarke (NSW). Anne Krishna (NZ) won the best poster prize for her poster on “Outpatient management of stable, severely neutropenic patients following intensive chemotherapy in a nurse led clinic”. All four abstract authors have contributed to this newsletter so please enjoy. In addition Lindsey Scudder and Cindy Bryant were the recipients of the Victorian nurses group conference grants and have written reflective pieces on their conference experience. Thanks to you all!!

The dinner was so much fun and the setting at Docklands was spectacular. As well as a commitment to haematology the dinner attendees demonstrated never before seen expertise in fascinator design, break dancing, gangnam dance moves and Dave Ritchie was an entertaining host and judge of the fascinator competition.

Can I please take this opportunity to thank Karen Syrjala, all the local invited speakers, How to session facilitators, sessions chairs and all of you that had the good fortune to attend, learn, network and be inspired by the high caliber of presentations. Thanks to the Victorian local organising committee and to the nursing national executive. See you in Queensland 2013.

**Yvonne Panek-Hudson**

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# ‘App’ of the moment: *About Herbs*

Presented by Memorial Sloan-Kettering Cancer Centre’s Integrative Medicine Service.

‘About Herbs’ – is a resource that provides evidenced based information about herbs, botanicals, supplements and more. Providing objective information for health professionals and consumers on what products may pose a health risk; which supplements may cause dangerous interactions; and more. On the first day I downloaded this app I used it 3 times in clinic in response to patients queries! (Editor).

Also available as resources via their website: http://www.mskcc.org/cancer-care/integrative-medicine/about-herbs-botanicals-other-products

# HAA Winning Abstracts and Posters

The 3 highest marked abstracts submitted to the nurses' stream by associate nurse members, are awarded a grant to go towards attendance at HAA. An award is also given to the best nurse's poster as judged by 3 panelists including our invited keynote speaker. The winning abstracts and poster are presented in the following pages.

## Albumin Traceability – Lessons Learned from the 2012 Albumex Recall

Carolyn Greely, Christine Michael, Kylie Rushford, Sanjeev Chunilal, Kate Macdermid, Joanne Shaw, Erica Wood.
*Department of Haematology, Southern Health, Monash Medical Centre, Melbourne, Victoria, Australia.*

**Aim**: In keeping with national standards and the Department of Health requirements, blood products should always be traceable from donor to recipient and the reverse to ensure accuracy of the recall process. Hospital laboratory records should be 100% compatible with patient medical records, reflecting whether the product was administered, discarded or returned to the blood bank. We reviewed the accuracy and completeness of albumin traceability from donor to patient in our university teaching hospital.

**Results**: Historically, albumin traceability has been an issue at our health service. In 2009, stocks of albumin were stored in 3 ward areas: Intensive Care Unit (ICU), theatre and Neonatal Intensive Care Unit (NICU). An audit of 48 bottles of albumin showed only 79% compliance with the traceability process. Education to relevant staff took place in these areas. In 2010 a further audit of 32 bottles showed 72% compliance. Consequently stocks were removed from ICU and NICU. Theatre was the only remaining area outside of blood bank with a stock of albumin. In 2011, the hospital transfusion team received several reports of non-compliance with the albumin traceability process. Education and additional prompts were put in place to remind staff of the importance of and process for ensuring traceability. After implementation of these changes a follow-up audit of 47 bottles demonstrated only 87% traceability compliance. Stock was consequently removed from theatre. Following the Therapeutic Goods Administration (TGA) Albumex recall. In March 2012, memos were sent to all staff informing them that all albumin was quarantined. Seven bottles of albumin were returned from unauthorised storage in ward areas in response to the memo. These bottles had been recorded as being administered to various patients. Albumin that was ordered and not used was being stored in ward areas in case of unforeseen emergency, circumventing the traceability process. One batch of Albumex was recalled by the TGA and 100% traceability was achieved for this batch. An audit in June 2012 of 35 bottles of Albumex has shown 100% compliance with traceability requirements.

**Conclusion**: The 2012 Albumex recall highlighted the need for ongoing auditing of albumin traceability. Now that compliance has been acheived monitoring will continue to be performed on an annual basis by the Transfusion Nurse Consultants.

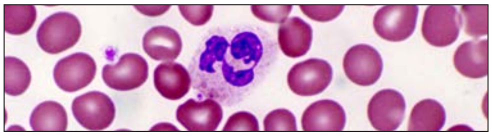
# OUTPATIENT MANAGEMENT OF STABLE, SEVERELY NEUTROPENIC PATIENTS FOLLOWING INTENSIVE CHEMOTHERAPY IN A NURSE-LED CLINIC

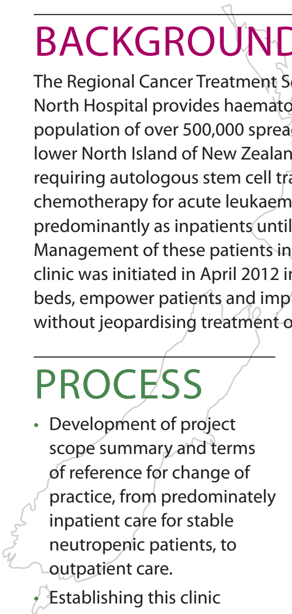
## PRELIMINARY RESULTS OF A PILOT PROGRAMME AT PALMERSTON NORTH HOSPITAL

*Authors: Anne Krishna, Barry Keane, Jane Cullen, Bart Baker,*
*Clinical Haematology Department, Regional Cancer Treatment Service, Palmerston North Hospital, New Zealand*

## AIM

To evaluate the impact of transferring care of stable, severely neutropenic patients following intensive chemotherapy from the inpatient setting to an outpatient-based nurse-led clinic, with respect to inpatient bed days saved, resource utilisation elsewhere in the hospital and patient satisfaction.



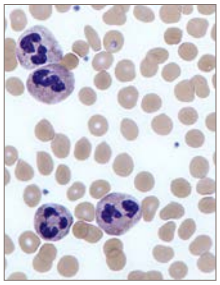


## BACKGROUND

The Regional Cancer Treatment Service based at Palmerston North Hospital provides haematology services for a population of over 500,000 spread across the central lower North Island of New Zealand. Traditionally, patients requiring autologous stem cell transplantation or intensive chemotherapy for acute leukaemia, have been managed predominantly as inpatients until neutrophil recovery occurs. Management of these patients in a new nurse-led outpatient clinic was initiated in April 2012 in order to free up inpatient beds, empower patients and improve patient satisfaction, without jeopardising treatment outcomes.

## PROCESS

- Development of project scope summary and terms of reference for change of practice, from predominately inpatient care for stable neutropenic patients, to outpatient care.
- Establishing this clinic required planning for the shift in workload from the inpatient ward to the day-stay facility and for the weekend arrangements for these patients.
- Ensuring there is sufficient space and equipment in the outpatient clinic to support a nurse-led outpatient service.
- Identifying the documentation and clerical support required for the service.
- Identifying the clinical support for the proposed service including the impact of the service on existing clinical staff.
- Achieving buy in from all key stakeholder departments.



## OBSTACLES

- Problems around requirement for different processes at weekends.
- Confusion about new process, particularly over weekend, despite education.
- District nurses, day care facility nurses and inpatient charge nurse not wanting any extra work for their staff over weekends.
- Day stay facility manager not wanting extra work from patients requiring transfusions during week.

## RESULTS

| Month | Diagnosis | Pts No's | Pts visits to clinic | Inpatient days saved | Day care facilities for transfusions | Re-admissions |
|---|---|---|---|---|---|---|
| May 2012 | **Lymphoma post ASCT 3; Myeloma post ASCT 1; ALL 1** | 5 | 20 | 41 | 8 platelets & 6 RBC | 3 sepsis |
| June 2012 | **Lymphoma post ASCT 1; Myeloma post ASCT 1; AML 1** | 3 | 16 | 20 | 1 platelets & 1 RBC | 3 sepsis, 1 bone pain |
| July 2012 | **AML 2** | 2 | 6 | 8 | 1 platelets & 1 RBC | None |
| August 2012 | **AML 3; ALL 1** | 4 | 12 | 14 | 4 platelets & 2 RBC | 1 sepsis |
| Sept 2012 | **Lymphoma post ASCT 2; AML 2** | 4 | 25 | 35 | 4 platelets & 4 RBC | 1 sepsis |
| Total | **Lymphoma post ASCT 6; Myeloma post ASCT 2; AML 8; ALL 2** | 18 | 79 | 118 | 18 platelets & 14 RBC | 8 sepsis & 1 bone pain All good outcomes |

## EVALUATION

Patients and family/whanau have responded very positively to this initiative although waiting times for results of blood tests and parking fees have concerned a minority.

Evaluation from inpatient charge nurse, and weekend registrars revealed that some inpatient staff were unaware of change of practice and pilot even though education given. Now patient's names are written on wards board to see registrar on Saturday and Sunday so staff are aware.

## CONCLUSION

**The change of practice has been challenging but successful. It has empowered patients and improved their cancer experience. The length of stay for these patients has been shortened, freeing up beds in the inpatient ward.**

## REFERENCES

Walter, R., Lee, K.M., Chai, X., Shannon-Dorcy, K., Appelbaum, R., & Estey, E.H., (2011). Outpatient management following intensive induction chemotherapy for myelodysplastic syndromes and acute myeloid leukaemia: a pilot study. Haematologica, 96 (6), 914–917.

Hutchison, C., (2011). Overview of nurse-led clinics and their scope of practice. Journal of Cancer Nursing Practice, 10 (9), 29–35.

Lewis, R, & Hendry, M., (2009). A review comparing the effectiveness of nurse-led follow up for cancer with conventional care. Journal of Nursing Times, 105 (37), 25–27.

## Why Make That Call? - An Evaluation of the 1800 MYELOMA Help Line

Hayley King[1], Tracy King[2,3]
*1 Myeloma Foundation Australia, Melbourne, Vic, Australia*
*2 Institute of Haematology, Royal Prince Alfred Hospital, Sydney, NSW, Australia*
*3 Sydney Nursing School, Cancer Nursing Research Unit, Sydney, NSW, Australia*

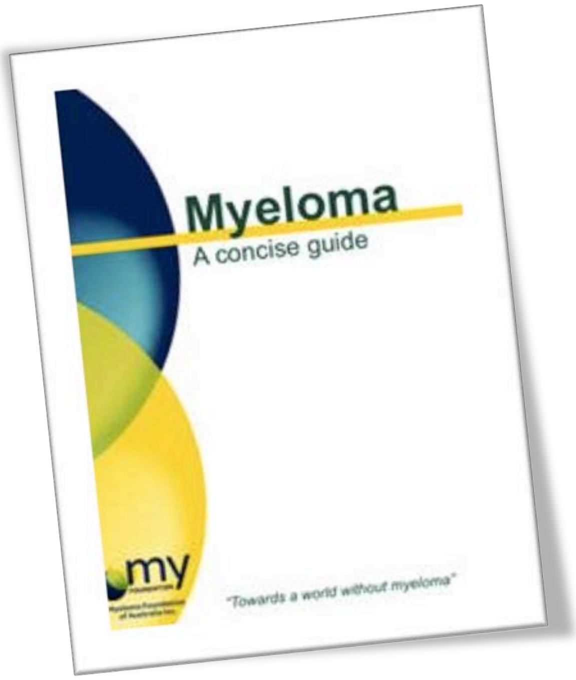
**Introduction:** Despite improvements in survival outcomes, myeloma remains an incurable malignancy with people living longer in a chronic state of relapse. Although their own health professionals, particularly doctors, are considered authoritative information sources, there is evidence that patients also seek information elsewhere. Nurse-led help lines are often implemented to provide reliable health-related information. The Myeloma Foundation of Australia (MFA) have maintained a national database of their nurse-led help line since September 2010.

**Aim**: This project aims to evaluate the volume and nature of helpline calls to better understand patient and carer information needs and to direct future information resources.

**Method:** All calls from a 19 month period were analysed (n= 403). Data included caller role, primary and secondary reasons for calling and call length. A basic measure of success was assigned by the nurse at the time and graded as met, almost met or not met. Only calls with reasons provided were considered evaluable. Valid percentages were used when data were missing.

**Results:** 340 calls (84%) were evaluated. 68% were from patients and 33% from family members; average length of call was 22 minutes (range: 5-90 mins). Quality ratings were given for 214 calls. Caller needs were met or almost met in 98% of cases. Over 50 separate reasons for calling were listed. The most common reason for calling was myeloma the disease (cited 75 times; of which 24% related to being newly diagnosed), followed by transplant (cited 25 times), pain (cited 21 times) and peripheral neuropathy (cited 19 times) respectively**.**

**Conclusion:** The help line is utilised by those directly and indirectly affected by myeloma, and while a broad range of information is required, information about myeloma the disease is most frequently requested. Thus, the helpline appears to be an opportunity to supplement and reinforce information given by primary health providers. A new, more comprehensive myeloma patient guide being produced by MFA will address the focus on disease specific information being requested by callers.



The 2012 edition of the Myeloma Foundation of Australia's concise guide is now available. It can be accessed online at: www.myeloma.org.au or hard copies are available on request from the foundation. If you require copies for your unit please contact:

**Hayley King**
Support Nurse Manager
Ph: 1800 693 566.
E: hayley.king@myeloma.org.au

## Clinical Networks: Challenges for the Successful Development of a Network Focusing on Malignant Haematology

*Tracy Clarke*
*BMT Network, Agency for Clinical Innovation (ACI), Chatswood, NSW, Australia*

**Aim**: The goal of this project is to provide recommendations for the expansion of the ACI Blood and Marrow Transplant (BMT) Network into malignant haematology and develop a model of care for haematological malignancies commencing with AML.

**Method**: Consultation with haematologists, nurses, allied health staff and patients across NSW was undertaken to identify the challenges they face, the goals they see as important and their key priorities for enhancing services and ensuring positive outcomes for patients in an expanded BMT Network. The typical haematology patients' journey was mapped for rural and metropolitan patients and a literature review of similar models was undertaken.

**Results**: Key themes within each discipline consulted are identifiable across sites within NSW providing care to patients with a haematological malignancy. These emerging themes will provide the framework for developing of a Model of Care for patients with AML and priority areas for development within the network. The themes include; *improved education regarding haematological illnesses disease processes for nurses and allied health staff, reducing the fragmentation of molecular and cytogenetic testing in NSW and support for a uniformed data collection process that will provide relevant and recent outcome measures.*

**Conclusion**: The NSW BMT Network has been highly successful and provides direction and support for the coordination of BMT planning and service delivery within a framework promoting access to, safety and efficiency of services in NSW. The success of a clinician led network for malignant haematology is reliant on clinician buy-in and engagement. Strategies for success are based on ensuring that clinicians feel their concerns relating to patient care are addressed and consultation is inclusive, transparent and collaborative and that discussions and activities are relevant and important to the clinicians.

# HSANZ NG Conference Attendance Grants: Recipient Report

**Recipient:** Cindy Bryant, Rural haematology nurse, VIC.

I was the very grateful recipient of a rural HSANZ-NG grant to attend the 2012 HAA in Melbourne at the end of October. I am a relative newcomer to both oncology and haematology, and work in a regional hospital in North East Victoria. We are a small rural unit with just 5 nurses, and limited resources mean we don't have dedicated nurses for specialty areas. Between us we try to cover as many specialties as possible, so our patients can benefit from our combined wide range of knowledge. After we had attended a Myeloma education session presented by the Peter MacCallum girls in a nearby town, they encouraged me to apply for this grant, and to my delight I was accepted.

I found the speakers in general were excellent, and especially enjoyed the discussions on palliative care, ethics, impact on caregivers, AYA's, and hearing stories from the lived experience perspective is always inspiring and challenges me personally to be the best oncology nurse I can be. I was particularly interested in the talk given by the guest speaker Karen Syrjala about the FHCRC Survivorship Program – "Exercise and Thrive", on the use of resistance training to overcome fatigue in survivors following their treatment. In our rural setting many people may not be able to access gyms due to cost or distance, and I would like to develop an exercise program that can be implemented at home involving simple resistance training to aid them in their recovery.

The conference opened many new doors for me. It has re-kindled an interest that began on my first ward as a staff nurse 25 years ago that was a haematology/oncology ward. I have made contacts and connections with people in bigger centre's, and have been inspired to apply for further study in this area. I have gained personally from attending the conference, I hope I have added something of value to our team, but mostly I hope our rural patients will benefit from the knowledge and inspiration I have gained from HAA 2012. Many thanks to the HSANZ – NG VIC for the opportunity.

# VIC Junior Haematology Nurse Grant Winner: Recipient Report.

**Recipient**: Lindsay Scudder, Peter MacCallum Cancer Centre

I was recently lucky enough to attend the HAA conference on a grant provided for a junior nurse by the HSANZ Nurse's Group. I have been nursing in haematology for just over 18 months and this was a perfect opportunity for me to further my knowledge and meet some of the amazing nurses working in the area. The conference was a great experience, one that I definitely plan to repeat.

Working on a haematology and autologus stem cell transplant ward I often do not see patients once they are discharged and their long term follow up is a bit of mystery to me. The topic of survivorship brought a fascinating insight into the long term difficulties that patients face and the work and research that is being done to support people through these issues. The exercise and thrive was particularly interesting as I can use this knowledge on the ward to encourage patients to incorporate strength building exercise into their recovery to help with fatigue.

One of the highlights was Marian Allison's How-to class on Integrating principles of palliative care into everyday practice. Marian's energy for the subject was infectious and her views on the way palliative care can work concurrently with the treating team from the beginning of the patient's journey really resonated with me. This is a practice that I would love to see introduced more widely as it would seem to provide a much more seamless transition of care.

Perhaps the most thought provoking sessions for me was Through the Eyes of the Beholder – Stories from the Frontline, a session from the patient's and carer's perspective. It was great to see our hard work being recognised but also to hear what was important to the patient throughout their treatment, as this often different what we as nurses' think it will be. The most thought provoking was the subject of hope raised by two of the speakers, specifically being the conflicting ideas of 'don't you dare take away my hope' and 'don't give us false hope'. For me this highlighted the fine line we tread as health professionals in providing specific care for each patient.

Overall I think that the best part was to meet so many knowledgeable and motivated nurses and listen to inspiring speakers talk about the work that they are doing. I have discovered a whole world of haematology nursing outside of the ward that I work on. I definitely walked away inspired about the places my career can take me.

# NSW Junior Haematology Nurse Grant Winner: Recipient Report

**Recipient**: Ellen Charalambous RPAH Sydney

Thanks to the generous support of Bayer Ltd, I was lucky enough to have been awarded the opportunity to attend HAA meeting this year. It was a fantastic experience and I came away from the conference with a new appreciation for haematology. Having had just over a years experience in haematology nursing I am still fairly new to the field and was excited yet a little daunted by the thought of attending a conference with so many knowledgeable and skilled clinicians. However after attending the conference I have come to realise that no matter where you are in your haematology career anybody who attends a conference like this will benefit from it on some level. I will attempt to highlight some of the areas and opportunities I found to be most interesting.

**Networking**: During conference I was able to speak to people from all areas of haematology, across Australia and New Zealand. I learnt, for example, that in certain parts of Australia Autologous transplants are being undertaken at home in the community setting, which is something I had never heard of before or considered as an option for our patients.

**Myeloma**: One of the talks presented by Tracy King, titled *'Supportive Care in Myeloma- a Challenge of Modern Myeloma Management'* offered an overview of the challenges facing us all, now but more importantly in the future, in providing optimal supportive care to those affected by myeloma. With the number of cases of myeloma due to increase by 57-75% over the next few decades due to an ageing of the population globally, we are only going to see more myeloma in our clinics. Despite outcomes improving, the 5 year survival rate is 40.3%. Those with myeloma live with a range of morbidities associated with their disease and the treatments given to treat myeloma as well as co-mordities associated with older age.

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Maximising quality of life (QOL) whilst improving survival are both equally important goals of care. The importance of measuring HRQOL and unmet supportive care needs is increasingly taking priority and we need to work together to find improved ways to meet these needs.

**Palliative Care**: One of the joint nurses and medical sessions covered the challenges of palliative care in haematology. We heard from a palliative care NP, a palliative care specialist and a psychologist who presented on the carers perspective. Challenges exist in delivering optimum palliative care for a variety of reasons including knowing when to involve the specialist palliative care team especially outside of the need for clear symptom support; when and how to transition management and care from one of active treatment to end of life care. The challenge of setting clear guidelines in this area exists due to the complex nature of haematological malignancies.

**Transfusion in trauma**: I found the symposium on Trauma and DIC presented by Herbert Schochl to be interesting as I learnt about how to effectively control bleeding in a trauma patient- something completely different to what I see and do on a haematology ward. I had assumed that blood was replaced with blood for a patient who is haemorrhaging but I now know that for a patient with trauma induced coagulopathy, a specific ratio of fresh frozen plasma, platelet concentrates and red blood cells should be administered to the patient, however the exact ratio of these products is still unknown and being investigated. Approximately 40% of all trauma related deaths result from coagulopathy caused from bleeding.

Overall I had a wonderful experience at the conference and would attend again without any hesitation. It was an excellent learning opportunity that allowed me to view haematology from a perspective other than ward nursing and it has inspired me to continue my haematology career. I cannot wait to see what is in store for the future of haematology.

# Study Spotlight: Survivorship and Haematology Patients

The Leukaemia Foundation of Queensland recently funded a major study examining the issues associated with survivorship for haematology patients. The research project, led by Associate Professor Pam McGrath, has provided a wealth of insights to inform the development of supportive care services. The findings challenge established ideas of survivorship through an enriched understanding of the meaning of the term survivorship, the importance to patients and their families of keeping the focus on life, and the development of an innovative concept of ‘receptivity’. Publications from the study address a diversity of topics such as the phenomenon of ‘chemo brain’, the impact of the disease and treatment on the individuals’ sexuality, concern with regards to re-entry to the work place post-treatment, and the integration of palliative care. Of particular importance for haematology health professionals are the findings on procedural care in relation to bone marrow aspiration and biopsy (BMAB) recently published in the international journal, Cancer Nursing.

The findings clearly demonstrate that for many of the haematology patients in the study, BMABs were a painful experience. Indeed, three quarters of the individuals diagnosed with PTSD reported traumatic experiences with BMABs. The results indicate that a major contributing factor to the pain and discomfort is the lack of effective procedural care. The findings emphasised the importance of the provision of choice with regards to anaesthesia or sedation as part of the procedural care for BMABs. The insights provide urgency to the call for further research to improve clinical practice and procedural care in relation to BMABs.

**For further details, including copies of publications from the study, contact Pam McGrath at p.mcgrath@griffith.edu.au.**

# HAA 2013: Save the date!

## Gold Coast, QLD, 20th – 23rd October 2013

### Calls for abstracts and registration will open in May 2013 and abstracts deadline 1st July 2013

As the QLD representative of HSANZ Nurses Group (NG) I would like to take this opportunity to invite you all to grab your sunscreen, pack your hat and bathers and come to the Sunny Gold Coast for next year's HAA 2013!! Calls for abstracts and registration will be in May 2013 with abstracts due 1st July 2013. There is already a fabulous range of invited and local speakers looking to participate in next year's program. We are very pleased to have Monica Fliedner attend as our international guest speaker for the Nursing program. Monica is and Adult Nurse Practitioner for Oncology at Berne University Hospital, Switzerland. She is an active member of the European Blood and Marrow Transplantation nurses group (EBMT NG) and past President. Monica has published widely and presented at many international conferences, with her most recent research focusing on understanding and meeting the challenges of compliance for oral cancer therapies, particularly TKIs in patients with CML.

I would also like to take the opportunity to encourage any QLD nurses willing and keen to be involved in helping to organise and showcase our local and interstate nursing talent in the three day nursing program at HAA 2013 to contact me directly. This is a great opportunity for you to shape and contribute to the nursing program and present your work to the wider haematology community. It's also FANTASTIC for your CV to be involved in your own professional group in this way, either as part of the organizing committee or as an invited local speaker.

We are calling for expressions of interest from haematology nurses keen to be involved in this exciting event to be a part of the Local Organising Committee (LOC). Please forward expressions of interest to:

**Catherine Kirk**
HSANZ NG QLD Nursing Representative
E: ckirk@hoca.com.au

## 2013 Survivorship Conference, 1-3 February South Australia

The inaugural national conference is bringing together clinicians, researchers and survivors to focus on understanding and addressing the issues facing cancer survivors and the priorities of survivorship care and research. For more information on the program and details on registration, see the conference website. Website: http://www.fcic.org.au/survivorship2013/

## 2013 BMT Tandem Meetings, 13-17 February, SLC, Utah

The CIBMTR Tandem Meeting 2013 is in Salt Lake City February 13-17th 2013. To review the program and find out how to register, please navigate via the CIBMTR website.
Website: http://www.cibmtr.org/Meetings/Tandem/Pages/index.aspx

## 2013 Culture of Care, 21-23 March, Dunedin, New Zealand

NZNO Cancer Nurses biennial Oncology / Haematology Conference 2013 in Dunedin NZ. Keynote invited speakers include Professor Nora Kearney, Professor Sanchia Aranda and Dr Fran Richardson. For more information and to find out how to register, see the conference website.

## 2013 39th Annual Meeting, EBMT, 7-10 April, London UK

Back in the UK after a gap of nearly 2 decades is EBMT – the 39th Annual Meeting. This conference has a strong and full nursing stream and although has a BMT focus has relevance to Haematology nurses with a broad area of focus. You can review their program online at the conference website.
Website: http://www.congrex.ch/ebmt2013

# NSW Sydney Support Groups

| Support Group | When | Where | Contact Details |
|---|---|---|---|
| Leukaemia Foundation Blood Cancer Information & Support Group | Last Friday of the month<br>10am - noon | Artarmon, Sydney | Madeleine Thompson<br>02 9902 2208/ 0421 582 758<br>mthompson@leukaemia.org.au |
| Leukaemia Foundation Blood Cancer Information & Support Group | Second Friday of the month<br>10am - noon | Concord, Sydney | Madeleine Thompson<br>02 9902 2208/ 0421 582 758<br>mthompson@leukaemia.org.au |
| Leukaemia Foundation Multiple Myeloma Information & Support Group | First Friday of the month 10am - noon | Artarmon, Sydney | Emily Schneider<br>02 9902 2207/ 0421 610 998<br>eschneider@leukaemia.org.au<br>mthompson@leukaemia.org.au |

# International Conference Report

**Written by**: Claire Dowsing, Apheresis & Donor BMT CNC Royal Melbourne Hospital. E: Claire.Dowsing@mh.org.au

I was very fortunate to be able to attend this year's AABB Conference in Boston, Massachusetts, thanks to sponsorship from Fresenius Kabi Pty Ltd. The conference held over four days provided the opportunity for the 5000 or so attendees to network, learn about new developments in transfusion medicine and related biological therapies including apheresis. This meeting was not just about transfusion! Formerly the American Association of Blood Banks its name was changed in 2005 to AABB to reflect the broader scope of cellular therapies that the association now encompasses, including haemopoietic progenitor cells. Whilst it is not possible to cover all aspects of the conference I attended, a snapshot is presented below.

My particular area of interest is sickle cell disease (SCD) and there were several interesting and thought provoking sessions presented relating to the pathophysiology and treatment of SCD, issues relating to the chronically transfused patient (including phenotyping of blood – how much is required?) and potential new therapies. As one would expect this is an area of much interest in the United States with an estimated 100, 000 Americans being affected by SCD and 1 in 400 African-American new-borns diagnosed[1].

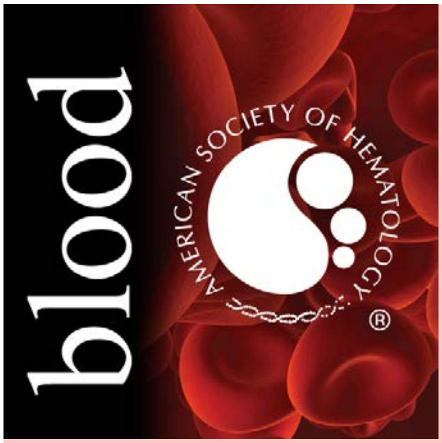
One speaker likened the pathophysiology of chronic inflammatory vasculopathy in SCD to atherosclerosis without the fatty streak! Describing how microvascular occlusion leads to macrovascular vasculopathy via a pathway of endothelial damage, decreased nitric oxide (NO) bioavailability and aggravated by activated adhesion biology - platelet and coagulation activation. Endothelial dysfunction is central to this inflammatory process with the dominant mechanisms differing in different vascular beds, but characterised by intimal hyperplasia and disruption to the internal lamina of blood vessels. Future therapies are needed to switch off this systemic inflammatory process and target ischaemia and reperfusion. The use of statins (referencing the athersoclerosis analogy) and cannabinoids were postulated although the mechanisms were unclear.

In the area of transfusion medicine the vascular effects of the red blood cell storage lesion, and the optimal age of transfused blood were discussed. The FDA gold standard in transfusion is that 75% of transfused cells will remain in circulation after 24 hours, with less than 1% haemolysis in storage bags. Stored blood is associated with increased cell free haemoglobin, which is a potent nitric oxide scavenger. Decreased NO contributes to vascular thrombosis by causing vasoconstriction, platelet activation and the release of procoagulants and inflammatory cytokines. Although over 20 clinical trials were quoted as investigating the link between the age of transfused blood and adverse effects, the small numbers of patients in these studies and the dearth of randomised controlled trials meant that no firm conclusions could be extrapolated. The debate continues. Ongoing trials to further investigate the use of older versus younger blood were discussed and included the Informing Fresh versus Old Red Cell Management (INFORM) study, the Age of Blood Evaluation (ABLE) trial and the Red Cell Storage Duration Study (RECESS) – watch this space!

A summary from the National Marrow Donor Program (NMDP) reported on donor experiences in haemopoietic progenitor cell apheresis (HPC-A) and marrow collections. As well as the common reported side effects the observation was made that bone marrow donors, whilst taking longer to recover (an average of 21 days compared to 6 days for HPC-A donors) and experiencing more intense pain reported feeling more prepared and greater psychological benefit from their donation. Whereas donors who failed to fully recover reported feeling less prepared for their donation. This is an area which warrants more study. The incidence of leukaemia in GCSF stimulated donors was also reported and showed no greater incidence of leukaemia in this population than would be found for age matched cohorts in the general populace.

In addition to attending these interesting topics and hearing many famous presenters speak so eloquently it was also great to have the opportunity to network with our American colleagues, hear their stories and share common experiences. This may not be a conference that springs to mind when considering the many conferences available to haematology nurses but one I would recommend for anyone with an interest in transfusion, apheresis, and BMT.

1. www.cdc.gov, accessed 28th November 2012



# Keeping up to date: *This is how I treat…*

Every now and then we come across a patient in our wards or clinics that has an unusual haematological condition or you haven't come across for a while. You may need to quickly remind or update yourself to the disease and its management. An invaluable resource that can be both informative and up to date is a regular series in the journal '***Blood'*** commonly referred to as ***'How I treat…'.*** Although published within a medical journal, these articles are relatively easy to understand and provide a concise and summary of the disease and how to manage it.

*Blood* is a weekly medical journal published by the American Society of Hematology and is the most cited peer-reviewed publication in the field of haematology. The journal covers all aspects of haematology, including both malignant and non-malignant disorders in both pediatric and adult populations – so it is valuable resource for us all.

Recent articles include:
'How I treat………..'

- Plasma cell leukemia
- Oral chronic GVHD
- POEMs syndrome
- Thalassemia
- Paediatric AML
- Patients who mobilise haematopoietic stem cells poorly
- How I chose factor VIII to treat haemophilia
- Amyloidosis
- Haemolytic anaemias in adults
- Relapsed childhood ALL

Although a subscription is required to receive full access to the journal, *Blood Online* provides a large amount of free content to the public. Five articles from each issue of Blood are made publicly available. Additionally, all articles are made publicly available 12 months after publication. You may of course be fortunate enough to work in an institution that provides access to *Blood* or for those of you currently undertaking some study; you will be able to access it via your educational provider's libraries.

Why not look up one of the recent summary articles and share it with your colleagues, display in your tea rooms or use it to provide an in-service or present at your journal club?

Written by:
**Julija Sipavicius,**
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# Rating Cancer Care Excellence

**David Joske**
Haematologist
Sir Charles Gairdner Hospital,
Nedlands, WA

Cancer services in Western Australia are undergoing major expansion and revision, partly as an outcome of the Reid Report (*WA Health Clinical Services Framework Report*), and partly in response to the geographic reconfiguration exemplified by the Fiona Stanley Hospital building. Estimates available to the WA Cancer and Palliative Care Network (through personal communication with WACPCN Co-Lead Rhonda Coleman) suggest the number of prevalent cases of people living with cancer in WA will double between 2001 and 2017, and so there will be a huge drain on cancer services.

The Reid Report, and the subsequent Barton Report (*Overview of Cancer Treatment Services in WA*), have also been a stimulus for installing radiotherapy bunkers housing the treatment machines in several new locations across WA, such as Joondalup and Bunbury. Other outcomes include the building of the new Comprehensive Cancer Centre on the QEII site (wherein SolarisCare will have a new facility with four separate treatment rooms), and recognition of the need to concentrate and develop expertise in rare cancers. Looking at outcomes, some data available suggest that in WA our results have improved for breast cancer in recent years with better screening and earlier detection. With this focus on new services it is timely to ask how we judge the quality of cancer services. Do we look at survival rates? For example, two reports published by the NSW Cancer Institute a few years apart have enabled health workers in that state to identify areas of high need for improvement, such as in lung cancer. Do we look at waiting times, or time to the start of treatment following diagnosis? Undoubtedly, all these are important markers of a good cancer service. But there is another side to this story that came to light with the publication of the now-infamous *MacMillan Hospital League Tables* in April 2011.

This story centres around Dr Jane Maher, a personal friend and a strong supporter of SolarisCare from the outset. Jane came to Perth in 1999 as the John Nott Fellow funded by the (now) Cancer Council, and spoke passionately about the need for cancer support, and in fact gave me the seed of the idea for a cancer support centre in my hospital - which became SolarisCare. Jane is the Chief Medical Officer of the MacMillan Cancer Support charity in the UK. She came to Perth again last year to speak at the Inaugural SolarisCare Symposium, and part of her talk included an outline of what follows here.

MacMillan were asked by one prominent London Hospital Trust to survey their patients and have their cancer experience assessed. They knew that their "hard" cancer outcomes were good; what they wanted to know was how the patients felt about the service. The result was a big reality check – their patients voiced a large number of problems and causes of distress throughout the service. MacMillan subsequently surveyed cancer Hospital Trusts across the UK, rating and crucially, comparing the patients' cancer experience.

When the results were published in April last year, the press had a field day: the headlines screamed "London hospitals the worst – Cancer report" and "Yorkshire cancer hospitals rated the best in the UK". (The full table can be seen at http://www.ncin.org.uk/cancer_information_tools/cancer_patient_experience.aspx. ) Suddenly, UK Hospital Trust managers realised that the delivery of their services – as perceived by their consumers – was important to their institutions' reputations, and administrators galvanised to examine many aspects of their service. MacMillan had, in a very tangible way, put patient care experience well on the agenda and the focus widened beyond just the numbers.

How do we rate here in the cancer experience? I attended one cancer unit's planning day recently and told them this story. To their credit, they had patient surveys "on the table" as they put aside a day to look objectively at what they do and how they could do it better – surely a good exercise for many health delivery units to pursue. Overall, though, I don't think we know – I am not aware of any formal surveys. As we set about reconfiguring our mainstream cancer services, surveying our consumers would seem a wise move, so that we can not only factor in the costs, and need for multidisciplinary review of individual cancer patients' care plans, but also the things that affect the experience that cancer patients go through. It is never an easy road, and anything we can do to assist, or relieve symptoms, or reduce side effects, or to promote understanding of what is happening and why, is surely to the good.

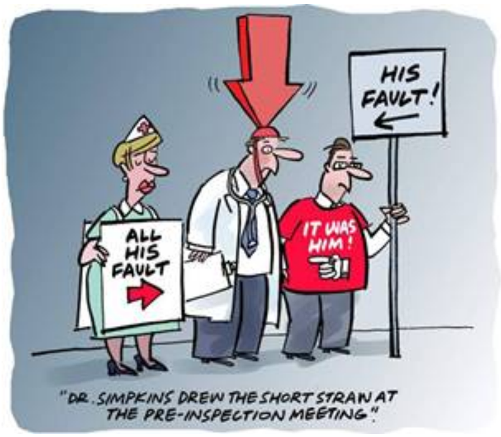
Which is exactly why, for all these reasons, I started the first Peters & Brownes support centre 11 years ago. With two metropolitan centres, two regional, the Chemo Club exercise program at the Aspire Gym in Claremont, the carer's courses, the Men In The Kitchen program for recently bereaved men and our recent first survivorship course, SolarisCare is now a huge undertaking that reaches and helps many thousands of Western Australians with cancer. From the avalanche of anecdotal feedback I receive personally, and from our own surveys and audits, I know that we do a lot of good for a lot of people. SolarisCare greatly improves the cancer experience for those that take up the offer.

The MacMillan Trust Hospitals League Table concept requires a shift in mindset from bricks, mortar, dollars, waiting times, survival curves and relapse rates, to an awareness that we are dealing with people at a vulnerable and distressing time that requires great humanity and compassion. We should learn from the League Table and strive to humanise cancer services in Western Australia as best we can.

# Trials Corner

**Written by:** Rebecca Meti, Clinical Trial Nurse, RPAH Institute of Haematology, E: Rebecca.meti@sswahs.nsw,gov.au

Welcome to the last trials corner for 2012. In this final edition we will take a look at the *"Trials of a Trials Nurse"* in the hope that it may dispel some common misconceptions about trials nurses. Recently a colleague of mine asked if I would still receive nursing accreditation given that my job was not really clinical and mostly office based! Once I had retrieved my jaw from the floor I thought that perhaps the best way to address this was to shed some light on the role of a (clinical) trials nurse.



## So what do trials nurses do?

This role is varied and requires a mixed bag of skills ranging from being a counselor to an accountant. Whilst the ultimate responsibility for a clinical trial rests with the principal investigator (PI), the trials nurse's role is vital for ensuring the smooth running of the clinical trial and the coordination of patients enrolled.

***"Staff in the Phase 1 unit could tell the High St economy was still suffering…but at least volunteer recruitment was up"***

Successful patient recruitment is key to the success of any clinical trial, and central to this is the informed consenting process. The role of the trials nurse is to ensure this process runs smoothly and to give as much time to the patient as they need to completely understand what their participation within the trial involves. We need to draw on our experience in order to explain and compare the trial with standard care to help the patient make a fully informed decision. Importantly patient must know that the trial is not compulsory, the needs and concerns of the patient always outweigh the need to enroll.

The research nurse must have an in-depth understanding of the trial protocol, underlying disease and any study treatments or investigations. We do not necessarily treat patients in the traditional settings of the ward or clinic, however we are there

Trials Corner continued from page 14

to counsel educate and support them through their treatment and follow up. We are at the other end of a phone/email and pager if the patient needs advice. We develop strong links with allied health and ensure that our patients are referred onto these services as appropriate. Practices may vary from centre to centre however at RPAH haematology trials nurses are present at trial visits with the staff specialists to ensure that the trial boxes are ticked and importantly provide support and care co ordination. A typical clinical visit may include consulting with the patient to discuss treatment and side effects and any interventions required. We take trial specific bloods, centrifuge then freeze them or prepare them for shipping. We book scans, biopsies and generally coordinate the patient through the complex health system as smoothly as possible. A trials nurse would generally have a portfolio of trials with (hopefully) lots of patients on each one so our workload can be considerable, varied and requires keen coordination, tracking and documentation skills.

In addition to this there is the day to day management of the trial which may be a new and daunting prospect to a nurse who hasn't dealt with this particularly when coming from a ward nursing background. I often tell people it's like taking on a whole new career it is so far removed from what a traditionally seen as the nursing role. You are required to liaise with ethics and hospital governance departments to resolve often complex issues. You may also need to be involved in budget negotiations between the hospital and the industry sponsor.

Then there is the data entry, vital to the study. It goes without saying that this needs to be accurate therefore good attention to detail is a must. The research must be conducted according to strict guidelines and clinical trial sites are open to industry and regulatory inspections. Therefore it is imperative that the research nurses ensure all documentation is correct and up to date. Lets not forget the trial needs participants and it often falls to the trials nurse to devise ways to increase recruitment and raise the profile of clinical trials.

## Why do we do it?

I asked Beth Thomas, a Clinical Trials Nurse at RPAH this very question. Beth has been in this role for 3 months having previously working in a Chemotherapy daycare unit;

> *'I have been interested in evidence based care and finding new and more effective ways to treat our patients since I started studying nursing. As a new graduate nurse I cared for patients undergoing a clinical trial and found this extremely interesting. A few years later while completing my postgraduate certificate in oncology/haematology nursing I decided this was an area I was very interested in and decided to find myself a clinical trials job. I have been in the job for a few months now and am really enjoying it. I am able to use my nursing skills and clinical knowledge daily to assist with my patients on trial. In addition to this I am learning about the other aspects of the job such as ethics and governance submissions, ensuring accurate data collection and storage and establish relationships with haematologists, laboratory staff and other staff involved the complex business of clinical trials. I love that education is strongly valued and I attend education sessions often and attendance of external conferences is strongly encouraged.'*

Working in a dynamic field providing cutting edge treatment that may otherwise be unavailable is challenging, sometimes daunting but overall extremely rewarding. I would encourage nurses who are interested in Research to speak with their trials team to gain a further understanding of the role, its not all paperwork and cups of tea!

## Spotlight on a trial - CHUMP

During the season of overindulgence I thought I'd end the year with this spotlight on a trial, the CHUMP (Chocolate Happiness Undergoing More Pleasantness) study. What variety of chocolate should we choose for maximum pleasure milk, dark or none at all? This trial was fraught with problems from the start, the group randomized to chocolate were crossing between milk and dark, and the group randomized to no chocolate were turning to it for comfort and researchers didn't take into account the pleasure gained from chocolate based food such as a giant slab of cake. Overall the results were inconclusive…anyone out there interested in a research project?

# Paediatric News:

## 'Accuvein' a new tool for establishing venous access

Accuvein is a new Australian manufactured device that displays veins beneath the surface of the skin. Accuvein's manufacturer states the following about the device:

- Point and click – Simply aim the portable vein finder at an area of skin and click to locate the veins beneath the skin's surface.
- Small size – The device weighs only 10 ounces and is easily handheld. When not in use, it's small enough to carry in the pocket of scrubs or uniforms.
- Hands-free option – In situations that require hands-free use, the device quickly attaches to a chair or bedrail.
- Non-contact – Because the device has been designed not to come into contact with the patient, the device may not require sterilization between uses.
- Works in light or dark – The device effectively locates veins under light or dark lighting conditions.
- Rechargeable battery – The device doesn't need to be plugged into an electrical outlet.
- Real world ruggedness – Designed to take the wear and tear of hospital and field applications.
- Movement tolerant – Because the device shows the veins in real time, the device can accommodate patient movement, when operated properly, a critical feature for venous access procedures performed on children and restless or combative patients. http://www.accuvein.com/accuvein-for/nurses/

**Why use Accuvein for IV access?**
In paediatrics particularly with younger chubbier children obtaining IV access can be particularly problematic. Obtaining venous access and limiting the trauma associated with difficult IV access is a goal of all paediatric nurses. Avoiding the development of needle phobia is particularly important in the child who requires regular venepuncture or IV access. Accuvein is helpful in establishing the location of patient's veins and their direction, as unfortunately not everyone's veins follow text book pathways.

The paediatric service at our hospital has used a variety of vein finding tools in the past to assist in obtaining venous access including the Wee Sight™ and Venoscope™. In children with particularly difficult venous access we call upon our anaesthetic colleagues and their ultrasound machine to assist us in obtaining IV access.

The Paediatric outpatient service at Royal Hobart Hospital purchased the Accuvein approximate two months ago with the use of donated money. Cost is an issue as the Accuvein is more expensive than other devices on the market. However it has some advantages over other devices which are not limited to but include e.g. the device does not have to touch the skin to be used, the veins can be illuminated better than with some other devices. Overall our experience has been positive and we find the Accuvein a useful tool.

Accuvein continued from page 16

## Comments from staff and patients who have used Accuvein include:

- Accuvein can be useful in supporting the nurse's decision making process in venous access by confirming the position of the vein.
- Patients have commented that they feel reassured when they see staff using the Accuvein.
- Children and parents who do venous access at home find using Accuvein reassuring as part of their venous access teaching process.
- Some staff have reported difficulty assessing when venous flash back has occurred when using Accuvein, turning off the Accuvein is recommended at this point or immediately prior.
- Remember to be careful with the laser light.
- Accuvein wasn't helpful however perhaps it was used on an inappropriate patient e.g. is the child too chubby to use the device on, veins too deep?
- In my practice I communicate with nurses in a variety of clinical settings. I had emailed the Accuvein link to a clinical nurse at King Island Hospital. King Island Hospital serves an isolated population of 1700 people and medical care is provided by a number of GP's. The nurse showed the Accuvein link to their GP team and 1 GP was so impressed with the concept she bought her own. They had the opportunity to use it successfully on a 13 year old patient to obtain IV access.

Accuvein is an excellent clinical tool however it is not 100% effective as patients and their veins are not always text book. Users should be patient when using Accuvein as you have to move the device over the patient's veins and also decide which setting S1 or S3 is more appropriate in displaying the veins. Accuvein can be beneficial in patients of all age groups.

Overall Accuvein is a valuable tool for the venous access tool belt!

Written by:

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# Building a Youth Cancer Service Network to improve cancer outcomes for adolescents and young adults in NSW and the ACT: Phase 1

Authors: Cath O'Dwyer and Fiona Maguire, Clinical Nurse Consultants, Youth Cancer Services, Sydney, NSW.

**Background:** Although cancer in adolescents and young adults is rare, the related burden of disease can be substantial[1]. The Commonwealth recognised a need for greater attention for this age group through the commitment of $15 million given to CanTeen to deliver the *Youth Cancer Networks Project* to develop a better model of care for young people with cancer. The Cancer Institute NSW was contracted to deliver the *Youth Cancer Networks Project, Phase 1* in NSW and the ACT in conjunction with the NSW Local Health Districts, the Capital Region Cancer Service and other key stakeholders. The pattern of cancer diagnoses in adolescents and young adults is distinct indicating a need for targeted service delivery. This age group have unique medical, psychosocial and information needs which are not being met by paediatric and adult cancer services[1]. Important factors affecting the care of adolescents and young adults include:

- Delays in diagnosis and referral due to low suspicion of cancer in young people
- Lack of awareness of cancer symptoms amongst health professionals and consumers
- Treatment availability across multiple paediatric and adult cancer services
- Low recruitment and participation rates in clinical trials
- Lack of clinical data to inform evidence based treatment protocols and guidelines
- Lack of age appropriate supportive care services [1]

**Methods:** As part of the *Youth Cancer Networks Project*, five Youth Cancer Services (YCS) were established to provide age appropriate multidisciplinary care, support services and care coordination for 15-24 year olds diagnosed with cancer in NSW and the ACT. For the purpose establishing services it was agreed that as a minimum Youth Cancer Services NSW agreed to provide:

- Provide high quality evidence based care
- Be multidisciplinary and collaborative
- Be patient focused, provide holistic care for patient and family
- Facilitate participation in clinical trials and integrate research to support innovation;
- Support ongoing care and survivorship needs of patients.

To ensure equitable accessible for young adults, each YCS is the contact point for several Local Health Districts.

**Results:** Between January 2011 and June 2012, a total of 342 adolescent and young adults were referred to one of the five YCS's. This included:

- 31 newly diagnosed patients
- 17 relapsing patients
- 183 patients on ongoing treatment
- 9 palliative care patients
- 2 deceased patients

Of the patients referred to a Youth Cancer Service team in NSW and the ACT:

- 100% were assigned a Clinical Nurse Consultant to assist in care navigation
- 100% were discussed by a adolescent and young adult multidisciplinary team and/or specific tumour multidisciplinary team
- The majority were discussed by a YCS psychosocial MDT (not currently available at every service)
- There was an increase in proportion of patients screened using the age specific Psychosocial Assessment Screening Tool
- There has been an increase in the number of patients being referred to supportive care services including fertility preservation.

Preliminary evaluation data indicates increased referrals to Youth Cancer Services as well as requests for secondary consultation. A formal evaluation is being conducted; at this time there is no data available to measure the impact of the services on patient outcomes.

***Achievements:*** In Phase 1, key achievements that improved service delivery include:

- Increased access to age appropriate services by establishing dedicated services
- Establishment of initial referral relationships and the inclusion of referral information on Canrefer website [iv]
- Increased workforce capacity and clinical expertise through clinical placements
- Provision of formal training through an AYA Clinical Fellowship Program, Graduate Certificate in Adolescent Oncology, University of Melbourne, in-service and education days
- Consolidation of point-of-care resources for health professionals on the eviQ website[v]
- Established links with rural centres.

Phase 2 of the project is about to commence in January 2013, the key objectives of the service are to be announced but they will include:

- The development of minimum service requirements and key performance indicators
- The development of a national data base for young adults with cancers
- Quality accreditation processes
- Establishing a national research network.
- Increased use of telehealth systems to improve services and accessibility for patients in rural and remote locations.

**Conclusion:** The Youth Cancer Services established under the *Youth Cancer Networks Project* have adopted an innovative model of care to better meet the needs of the adolescents and young adults living with cancer in NSW and the ACT. Preliminary evaluation indicates that the service delivery model has resulted in increased referral to Youth Cancer Service thereby improving access for young people to age appropriate cancer services. The established services are at varying degrees of maturity based on resources available. Further investment is required to ensure equitable access through a comprehensive state wide network.

Acknowledgments: The Youth Cancer Project, NSW

[1] Australian Institute of health and Welfare 2011. Cancer in adolescents and young adults in Australia. Cancer series no. 62. Cat. No. CAN 59. Canberra: AIHW.

[1] Dr Palmer S & Assoc Prof Thompson D. 2008. On Trac@PeterMac. A Practice Framework for working with 15-25 year old cancer patients treated in the adult sector. Citied on 7/08/212 at http://www1.petermca.org/ontract/pdf/AYA-Practice-Framework.pdf.

[iii] [1] C. Bullivant, E. Tracey, T. O'Brien, S. Sinclair, J. Bishop. Adolescent and Young Adult (AYA) Cancer in NSW. Accessed online 07/02/12 at http://www.cancerinstitute.org.au/publications/i/adolescent-and-young-adult-cancer-in-nsw

[iv] www.conrefer.org.au

[v] www. eviQ.org.au

# Haematology Nurses Finalists for Leadership Award

We proudly report that 2 Haematology nurses were finalists in this year's Leadership in Nursing and Midwifery Awards from Deakin University and Health Super. Bianca Hopkins Haematology nurse coordinator for the Alfred in Melbourne was nominated by her team for her work that includes implementing an effective care coordination model, developing a modified living with blood cancer program and the introduction of a supportive care plan for patients in the terminal phase of their illness. Tracy King from RPAH & CNRU Sydney Nursing School was nominated by her research team for her work that includes contributions to the development of knowledge, skills and expertise in myeloma for nurses, both nationally and internationally and better educational and supportive care services for myeloma patients and their families. Although Bianca and Tracy didn't win the leadership award it was a great achievement that 2 haematology nurses were recognised within a shortlist of 15 finalists. HSANZ NG would like to congratulate them both for their leadership within Haematology nursing.

Editor

# Who are you calling a TWIT?

## *How to make TWITTER your friend*

**Written by:** Louise Acret, Research Officer, CNRU, Sydney Nursing School, University of Sydney

### What is Twitter?

Twitter is a micro-blogging social media platform that allows users to post messages, called Tweets, up to 140 characters in length. By including a URL link it is possible to link to blog posts, journal articles, reports, media articles and more.

### Why use Twitter?

There are many professional benefits that can be gained by using Twitter. An increasing number of health professionals, academics and organisations are using Twitter as a communication and collaboration tool. As a result Twitter is becoming ever more useful for accessing research knowledge, expert opinion and commentary by others with similar professional interests.By following individuals and organisations you can effectively establish a personalised news service that not only delivers information but provides opportunities for you to engage with other people in your field.

Twitter allows you to;

- tap into research knowledge, expertise and ideas in areas as broad or as narrow as you choose
- connect with people with similar professional interests
- strengthen professional relationships
- join discussions and debates
- ask questions
- share your knowledge and expertise with others
- promote your own research
- follow and participate in conference discussions without actually being there

## Getting started

For information on getting started with Twitter and to learn about the language of Twitter have a look at : **http://www.wikihow.com/Use-Twitter**

## Who to follow?

Start with people you know or organisations you are involved with or belong to. Look at who else follows them and who they follow. In this way you are directed to other Twitter feeds in your area of interest. Using the Twitter search function you can search for a subject, a person or an organisation. Alternatively you can search using a hashtag (#). Hashtags are used to categorise Tweets to make it easier to search for Tweets relating to a specific topic. For example #ASH12 was used to categorise Tweets that related to the American Society of Hematology conference. By entering #ASH12 in the search field you will find all Tweets relating to this event.

## Some suggestions to get you started:

| | |
|---|---|
| **HematologyTimes.com** | @HematologyTimes |
| **The European Hematology Association** | @EHA_Hematology |
| **American Society of Hematology** | @ASH_Hematology |
| **Leukaemia Foundation** | @LeukaemiaAus |
| **Cancer Council Australia** | @CancerCouncilOz |
| **European Bone Marrow Transplant (UK) Nurses and Allied Professions Group** | @ebmtuknap |
| **Australian Red Cross** | @RedCrossAU |
| **Moira Stephens** | @Teacher_Mo |
| **Jeff Szer** | @marrow |
| **Australian College of Nursing** | @rcna_tweet |
| **Cancer Nursing Research Unit** | @CNRU_Syd |

**Further reading:**

- RCNA Social Media Guidelines for Nurse: http://www.rcna.org.au/WCM/Images/RCNA_website/Files%20for%20upload%20and%20link/rcna_social_media_guidelines_for_nurses.pdf
- WeNurses – Welcome to Twitterversity http://www.wenurses.co.uk/Resources/twitterversity.php
- Impacted Nurse – Why I was wrong about Twitter: http://www.impactednurse.com/?p=3888

# 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 has had another successful year running education evenings for nurses interested in haematology. As at the 28th November 2012, we will have run six sessions over the year split between Wellington and Palmerston North. There has been an enthusiastic response to these meetings. Topics covered in 2012 include: new oral anticoagulants, lymphoma, women and bleeding disorders, multiple myeloma, myelodysplasia and acute lymphoblastic leukaemia. The education evenings have become sought after events. They would not be possible without our sponsors. We have had very generous support this year from Roche, Gilead, Bayer and Janssen Cilag.

There are another six education evenings planned for 2013. Session dates, locations and topics have yet to be finalised. If anyone has any suggestions for topics for next year's sessions, please get in touch with me at the email address below. Likewise, if anyone has further suggestions for education initiatives then also please get in touch with me. I can be emailed at Catherine.Wood@ccdhb.org.nz

## New South Wales

**Tracy King**

NSW is working hard to improve the quality of its educational meetings by changing to a more targeted approach to the provision of our educational events. In an effort to add value and relevance to our meetings, we are now aiming for a smaller meeting with a more targeted invitation to nurses working within related areas. Noting that HSANZ NG aims to host and promote educational events for all tribes within Haematology (adult, paed, malignant, BMT, thrombophylic etc) we recognise that most of us only have a role and scope of practice within 1 tribe. With that in mind NSW held its last educational supper meeting on November 15th in Sydney. Prof Ken Bradstock joined us to present to a group of transplant specific nurses on the hot topic of 'Haploidentical transplants – now everyone has a donor'. Prof Bradstock and his team are leading the way in Haploidentical transplantation in Australia and it was an invaluable opportunity to not only learn more about the process and rationale, but also to hear feedback from a cohort of transplants undertaken to date within his unit. In addition to the educational component much business and networking was apparent alongside a lighter, social catch up with old and new friends. We feel this approach to our meetings is the way forward and look forward to delivering this targeted approach to our meetings as we move ahead into 2013.

NSW Meetings for 2013. *(Venue and topic to be confirmed nearer the time)*

- Feb 7th (Sydney)
- April 11th (Gosford)
- June 13th (Sydney)
- August 15th (Wollongong)
- Nov 14th (Sydney)

We are keen to host meetings in Dubbo (and area) and ACT during 2013 and are working hard to secure them. We would love to hear from you if you are working in these regions and have opinions, thoughts, and contributions to make.

## Tasmania

**Gillian Sheldon-Collins**

On Friday 30th November several nurses attended a dinner meeting convened by THING (Tasmanian Haematology Immunology Neoplasia Group). THING has a long tradition of supporting local professionals by providing educational and social events throughout Tasmania. THING very generously enabled this to be a collaboration between medicine and nursing by providing a program with both medical speakers and a nursing speaker. The three topics covered were CLL, brain tumours and bone marrow transplantation. This dinner meeting was a great success with a broad medical, scientific and nursing audience. Several attendees had travelled from the north of the state, including 3 nurses. We all enjoyed a pleasant meal and the opportunity to enjoy each other's company and the program. As the Statewide Bone Marrow Transplant Coordinator I personally enjoyed a conversation with a General Practitioner from Launceston who cared for one of our autologous transplant patients. This was a wonderful opportunity to be able to meet each other as part of the broad medical community involved in his care. We look forward to THING's program for 2013 and opportunities for nurses through both the HSANZ Nurses Group and future collaborations with all our colleagues.

## Western Australia

**Cassi Lawrence**

This years education sessions are coming to an end. Our final session is titled "What's HOT in lymphoma". We have 2 presenters; Matt Wright,a haematologist discussing lymphoma. We also have a training registrar Paul Kruger presenting on HOT Mabthera. He has recently presented at HAA in Melbourne and has had his research in this specialised area published. This session will be held at Sir Charles Gairdner hospital in the Haematology Care Centre on Tuesday 27th November @ 6pm. Everyone is welcome. The amazing support we receive from pharmaceutical companies enables us to provide these sessions free of charge. Next year I will be sending out a "Save the Date" email so nurses working with rosters can organise in advance! Thank you all & Merry Christmas

E: cassi.lawrence@health.wa.gov.au

## South Australia/Northern Territory

**Allan Hayward**

The SA/NT chapter is looking forward to a reinvigorated education program in 2013. If you would like to become more involved in planning / organising these events please contact me at E: allan.hayward@health.sa.gov.au

Best wishes for the festive season!

## QLD

**Cathering Kirk**

SAVE THE DATE – Saturday 23rd March 2013.

HSANZ NG Queensland has partnered with Celgene to host a Multiple Myeloma Education day in Brisbane on Saturday 23rd March 2013. This comprehensive nursing education day will cover disease biology, induction therapies, indications for treatment, treatment options, Autologous & Allogeniec Stem Transplant, supportive care, patient education and self care management strategies for patients and their families. The program is shaping up nicely and will undoubtedly have many wonderful and informative speakers…including our very own HSANZ NG President Tracy King. Boy that women will go anywhere to talk about myeloma! Stay tuned for more information regarding this event and circulation of program and poster nearer to the time.

E: ckirk@hoca.com.au

# Thalassaemia Society of NSW & Thalassaemia Australia 2nd Annual Thalassaemia Nurses Workshop

## 3rd August 2012,Prince of Wales Hospital, Randwick, NSW

The Thalassaemia Nurses Workshop was run in Melbourne for the first time in 2011. It was attended by 18 nurses from around Australia and provided participants with an opportunity to collaborate and share knowledge to improve clinical services for patients with Thalassaemia. With ongoing support from Novartis Oncology and Aspen we have been able to build on this great work and it was a wonderful honour to be asked to be involved in setting up the programme for this year's workshop in Sydney.

The workshop began with an overview of Thalassaemia, the effects of iron overload and the role of the different chelation options currently available to patients. This then set the scene for a host of other topics including; the role of the geneticist, early diagnosis and management including treatment with allogeneic stem cell transplant, preparing patients for pregnancy, management of pregnancy and management of patients pre and post splenectomy.

There was also a breakout session where the participants were able to share challenges faced in caring for this chronic group of patients and to discuss various management strategies to combat these issues. Challenges discussed included transition from a child to an adult centre and compliance with medications and appointments.

The workshop generated extremely positive feedback from the delegates. On this basis we will be hosting another similar workshop next year. If you are interested in attending next year's workshop or would like to be added to the contact database, please contact:

**Nancy Lucich**
M: 0400 116 393 or
E: coordinator@thalnsw.org.au

The afternoon concluded with a panel discussion consisting of 3 patients and 2 parents who spoke of their experiences of living with Thalassaemia and their health care needs. This session was warmly welcomed by the delegates who developed a further understanding of the need to take a coordinated approach in caring for these patients as they face complex issues.

This year saw increased numbers in participants and once again we had nursing representation from Victoria, Queensland and New South Wales and we welcomed social workers to our delegate list. As a result of the workshops a contact database has been established with the aim of a creating a forum for nurses and allied health to share knowledge and seek assistance in providing the optimal care for these patients as well as communicate education dates.

This workshop would not have been made possible if was not for the wonderful guest speakers, Thalassaemia Society of NSW, Thalassaemia Australia and the ongoing support from our sponsors, thank you.

**Written by:**
Elizabeth McGill
A/CNC Thalassaemia, POWH

NSW GOVERNMENT Health
South Eastern Sydney
Local Health District

Thalassaemia Society of NSW

# Educational Resources

## Tools and Resources: What if I can’t go to the conference?

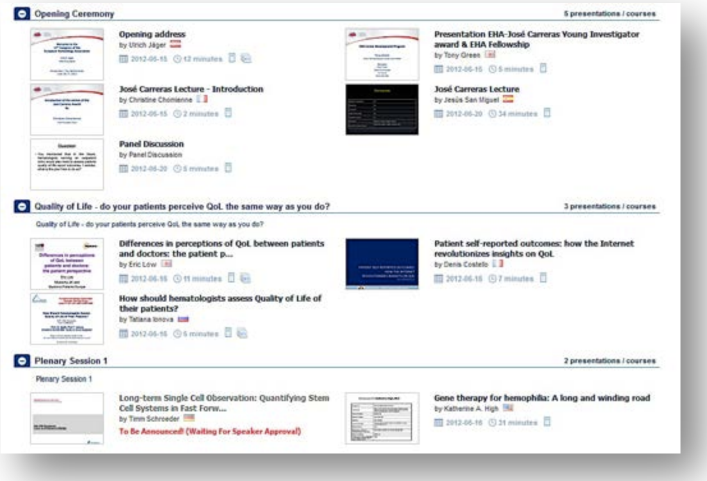
**Written by:** Jessica Roydhouse, Senior Research Officer, Cancer Nursing Research Unit, Sydney Nursing School

The good news is that there’s a way to access some or most of the material presented at a conference online, from the abstract book to podcasts of key sessions. While this doesn’t give you the same experience as discussions with speakers and networking, it’s still a good option for getting up to date information if you can’t attend the conference. The list below looks at the accessibility of some of the major nursing and haematology conferences. If you know of other resources please contact the newsletter to spread the word.

### European Hematology Association (EHA):

http://www.ehaweb.org
Twitter (https://twitter.com/EHA_Hematology),
Facebook (http://www.facebook.com/EuropeanHematologyAssociation)
Webcasts can be accessed from
http://www.multiwebcast.com/eha

EHA’s website features video webcasts of all educational and plenary sessions from EHA’s annual conferences from 2007 – present. For the first four months after a conference, access is restricted to EHA members and conference attendees, but after that non-members can access the site following registration. EHA also provides free access to pdf versions of conference education and abstract books from 2006 – present. The abstract books contain all accepted abstracts for that year’s conference, and the education books are written by speakers from the conference’s education sessions and cover important topics in haematology. Other educational materials are also available for free on the website. Podcasts of brief interviews with expert haematologists on a range of topics, undertaken at EHA and other conferences over the years, are also accessible and do not require registration.



Opening Ceremony 5 presentations / courses

Opening address
by Ulrich Jäger
2012-06-15 12 minutes

Presentation EHA-José Carreras Young Investigator award & EHA Fellowship
by Tony Green
2012-06-15 5 minutes

José Carreras Lecture - Introduction
by Christine Chomienne
2012-06-15 2 minutes

José Carreras Lecture
by Jesús San Miguel
2012-06-20 34 minutes

Panel Discussion
by Panel Discussion
2012-06-20 5 minutes

Quality of Life - do your patients perceive QoL the same way as you do? 3 presentations / courses

Quality of Life - do your patients perceive QoL the same way as you do?

Differences in perceptions of QoL between patients and doctors: the patient p...
by Eric Low
2012-06-15 11 minutes

Patient self-reported outcomes: how the Internet revolutionizes insights on QoL
by Denis Costello
2012-06-16 7 minutes

How should hematologists assess Quality of Life of their patients?
by Tatiana Ionova
2012-06-16 6 minutes

Plenary Session 1 2 presentations / courses

Plenary Session 1

Long-term Single Cell Observation: Quantifying Stem Cell Systems in Fast Forw...
by Timm Schroeder
To Be Announced! (Waiting For Speaker Approval)

Gene therapy for hemophilia: A long and winding road
by Katherine A. High
2012-06-16 31 minutes

- Abstract books: http://www.ehaweb.org/congress-and-events/annual-congress/previous-congresses/abstract-book/
- Education books: http://www.ehaweb.org/congress-and-events/annual-congress/previous-congresses/education-book/
- Podcasts: http://www.ehaweb.org/education-science/online-learning-tools/podcasts/

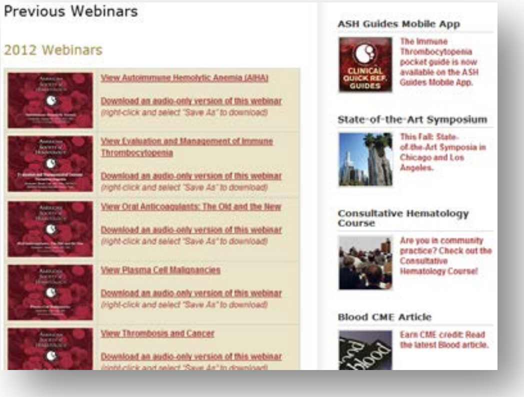
### American Society of Hematology:

**http://www.hematology.org**
Twitter (https://twitter.com/ASH_hematology),
YouTube channel (http://www.youtube.com/user/ASHWebmaster)

Webcasts of the ASH conferences are not freely available online but DVDs of meetings from 2008 – present can be ordered from the ASH site. The webcast of the 2011 conference can be purchased online until December 2012. ASH’s abstract and educational books are available online for free for institutional or individual subscribers to the journals (*Blood* and *Hematology*, respectively). Print versions of the relevant journal editions can be ordered from the ASH site. ASH also publishes Hematology Web Focus, a quarterly collection of current articles on important haematology topics selected by an expert. The articles referenced in Hematology Web Focus are available online to the reader. Access to Hematology Web Focus is free for ASH members and subscribers (either institutional or individual) to *Blood*.

Educational webinars are available at no cost on the website. Webinars are from 2010 – present and feature discussion of relevant topics in haematology.

Webinars can be accessed from:
[http://www.hematology.org/Meetings/Webinars/5559.aspx](http://www.hematology.org/Meetings/Webinars/5559.aspx)



Previous Webinars

2012 Webinars

View Autoimmune Hemolytic Anemia (AIHA)
Download an audio-only version of this webinar
(right-click and select "Save As" to download)

View Evaluation and Management of Immune Thrombocytopenia
Download an audio-only version of this webinar
(right-click and select "Save As" to download)

View Oral Anticoagulants: The Old and the New
Download an audio-only version of this webinar
(right-click and select "Save As" to download)

View Plasma Cell Malignancies
Download an audio-only version of this webinar
(right-click and select "Save As" to download)

View Thrombosis and Cancer
Download an audio-only version of this webinar
(right-click and select "Save As" to download)

ASH Guides Mobile App
The Immune Thrombocytopenia pocket guide is now available on the ASH Guides Mobile App.

State-of-the-Art Symposium
This Fall: State-of-the-Art Symposia in Chicago and Los Angeles.

Consultative Hematology Course
Are you in community practice? Check out the Consultative Hematology Course!

Blood CME Article
Earn CME credit: Read the latest Blood article.

## International Society of Nurses in Cancer Care

## http://www.isncc.org

*Twitter (<https://twitter.com/ISNCC>),*
*Facebook (<http://www.facebook.com/pages/ISNCC-International-Society-of-Nurses-in-Cancer-Care/192086774173053>)*

The abstract and program books from the 16th (2010) and 17th (2012) ISNCC conferences are available online. The books from the 17th conference can also be downloaded onto mobile devices using QR codes. Program books from the 15th and 14th conferences are available online.

Abstract and/or program books for the 14th – 16th conferences can be accessed from <http://www.isncc.org/conference/>

Abstract and program books for the 17th conference can be accessed from:
<http://www.isncc.org/conference/17th_ICCN/Program_and_Abstract_Book.aspx>

Presentations from the 16th ISNCC conference are available online but access is restricted to members. Presentations from the recently completed 17th ISNCC will be available online shortly.

17TH INTERNATIONAL CONFERENCE ON CANCER NURSING
Hilton Prague Hotel, Prague, Czech Republic
Enhancing Patient Safety through Quality Cancer Nursing Practice
SEPTEMBER 9-13TH, 2012

Home > Conference > 17th ICCN

ISNCC Hosted a Successful 17th ICCN!

## Clinical Care Options Oncology (CCO)

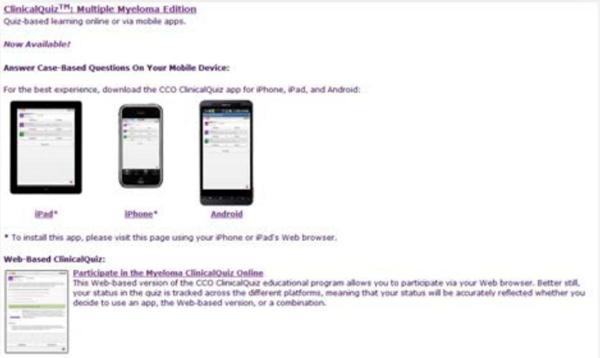
## http://www.clinicaloptions.com/Oncology.aspx

RSS feeds (<http://corp.clinicaloptions.com/RSS.aspx>)

CCO features conference reports, podcasts, and other educational tools and resources related to oncology and haematology on their site. Resources can be accessed through free web registration.

The podcast library contains CCO coverage of relevant conferences as well as discussions with expert CCO faculty on key topics. Video and/or audio podcasts are available.

The podcast library can be accessed from :



ClinicalQuiz™: Multiple Myeloma Edition
Quiz-based learning online or via mobile apps.

*Now Available!*

**Answer Case-Based Questions On Your Mobile Device:**

For the best experience, download the CCO ClinicalQuiz app for iPhone, iPad, and Android:

iPad*
iPhone*
Android

* To install this app, please visit this page using your iPhone or iPad's Web browser.

**Web-Based ClinicalQuiz:**

Participate in the Myeloma ClinicalQuiz Online
This Web-based version of the CCO ClinicalQuiz educational program allows you to participate via your Web browser. Better still, your status in the quiz is tracked across the different platforms, meaning that your status will be accurately reflected whether you decide to use an app, the Web-based version, or a combination.

http://www.clinicaloptions.com/Oncology/Resources/Podcasts.aspx

The conference coverage library has reports by CCO on topics covered at major international conferences on a range of malignancies. Reports are available from 2003 – present and include summaries of sessions and slideshows. Conference reports: http://www.clinicaloptions.com/Oncology/Conference%20Coverage.aspx

The Treatment Updates section includes slideshows, case modules, quizzes and interactive presentations on treatment-related topics for malignancies. Treatment Updates:
http://www.clinicaloptions.com/Oncology/Treatment%20Updates.aspx

CCO also has a nursing resource section aimed at cancer nurses. The section has links to nursing-specific conference reports or other conference reports which may be of interest, as well as slideshows on cancer nursing topics and free access to online textbook chapters.The nursing resource section:
http://www.clinicaloptions.com/Oncology/Topics/Oncology%20Nursing.aspx

The slideshows:
:http://www.clinicaloptions.com/Oncology/Topics/Oncology%20Nursing/Selected%20Assets.aspx?template=slidesets

## Social Media Glossary

- **Facebook**: Social networking site where users can share information and links via pages. Followers of individual or organisational pages can see updates and publicly comment on the pages.
- **RSS feeds:** Compilation of news or other updates from organisations, allowing for quick updates without manual searching.
- **Twitter:** Social networking and microblogging site where users can share information and links via short messages. Followers can re-send information to others through their own accounts or reply to posts by other users.
- **YouTube:** Video sharing site which allows for the dissemination of user-created videos. Many organisations have YouTube channels. Followers will be notified of new video updates and can publicly comment on videos.

# New easy guide for irradiated products

The National Medical Education Unit at the Australian Red Cross Blood Service has created a simple click or search guide to determine whether irradiated blood products are required. Transfusion associated graft versus host disease (TA-GvHD) is a rare and life threatening transfusion reaction that may occur in immunocompromised patients following the transfusion of cellular components. This complication can also occur in immunocompetent patients if HLA homology is present between recipient and donor. The outcome is nearly always fatal. The use of irradiated components has been proven to reduce the incidence of TA-GvHD, however, they are not appropriate in every circumstance. This tool provides health professionals with guidance on situations when the use of irradiated cellular components is appropriate.

You can find the page on the Blood Service website for health professionals www.transfusion.com.au and http://www.transfusion.com.au/indications_irradiated_components

# The Australian Red Cross Blood Service wants to hear your opinion on the use of CMV negative blood components

Click here to participate in a short on-line survey: http://www.surveymonkey.com/s/CMVNegative

In March 2012, the UK Department of Health's Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO) released a report and position statement, concluding that the range of patients provided with cytomegalovirus (CMV) screened blood components should be reduced. This has created significant interest in the international transfusion community.

The Blood Service is conducting a short online survey of current policies and clinical practices regarding the use of CMV negative blood components. The survey is now open at this link.

The survey aims to:

- Identify existing policies and clinical practices for the use of CMV negative blood components by our health providers
- Inform decision-making regarding the range of patients who should be provided with CMV negative blood components
- Contribute to the development of future inventory planning models for CMV negative blood components
- Assist with the Blood Service response to the international survey

To read more about CMV tested blood components click here:

http://www.transfusion.com.au/blood_products/components/modified_blood/cmv-seronegative

To read the SaBTO guidelines click here

We have also recently launched a CMV Forum on our website where you can discuss the use of CMV negative products with your peers. See the links below.

Transfusion Forum Topic Page: https://itransfuseonline.transfusion.com.au/course/view.php?id=29

CMV forum thread: https://itransfuseonline.transfusion.com.au/mod/forum/view.php?id=323

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