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**HSANZ NG**
Haematology Society of Australia and New Zealand

## Inside:

**Plus much more…!**

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# HAA 2015

## 18 - 21 October 2015 Adelaide Convention Centre

You could come to Adelaide to explore the fabulous wine regions that surround Adelaide, you could come to explore the city of fine wining, dining and gastronomy, you could come to visit the home of the world renowned Haigh's chocolate factory, or you come to find out why Adelaide continues to make it in the worlds' most liveable city list. All of these are great reasons to come to Adelaide anytime of the year! However in October we really want to you to come to HAA in Adelaide to network with your colleagues, make new friends, share, learn and be challenged about your haematology nursing practice. The underlying theme of the nursing program for 2015 is the growth and development of Haematology nurses, their knowledge, careers and the profession.

The local organising team has put together a program that will appeal to nurses wherever they are in their career from early career haematology nurses to Clinical

# A word or two from the President…

I can't quite believe how fast this year is progressing. They say life speeds up as you age – don't comment on that please! Already program development for HAA 2015 is well underway and you'll hear more in the next edition or by following the HAA 2015 website - www.haa2015.com. Now is the time to be thinking of how best to present your great work at conference. Just 300 wise words and your abstract could be in contention for a prize – 3 X $1,000 winning abstracts presented as oral and 1 X $1,000 for best poster. Don't forget if you're presenting data, all work should be approved by a local ethics committee. For tips on how to write an abstract we've re-printed the 'How do I write an abstract article'.

This edition includes a wide range of interesting articles. Pamela Bousejean, a lady who's undertaken a transplant for Lymphoma tells us about her work and efforts in creating awareness of the low level of donors on the ABMDR from ethnically diverse groups. 'Ur The Cure' is her campaign and story. If you feel you are able to help or get involved or even just find out more – why not contact Pamela info@urthecure.com.au

A special feature from Jacqui Jagger tells us of a recent and exhausting sounding, trip to Taiwan to participate in a range of nurse education meetings on high risk MDS with a focus on advanced assessment in a nurse lead model. It's exciting to hear of local nurse members who have such energy to contribute to haematology nurse education elsewhere in Australasia and with such passion. Well done Jacqui and we look forward to perhaps welcoming some of the Taiwanese nurses to Australia and helping with their learning and visits to our units.

Our organisation is a product of the contribution and hard work of its members. I would encourage you all to get more involved and help our group evolve and grow. There are many ways you can do this.

- Attend local meetings
- Offer to help get involved with organising of events locally by contacting your local chair – details on back page
- Attend and contribute to HAA conference – submit an abstract
- Join an SPN of interest as they form
- Contribute an article to this newsletter – better still, offer to help produce this newsletter

***Ask not what my 'HSANZ NG' can do for me, but what I can do for HSANZ NG!***

Contact us & get involved via our new dedicated email – nurses@hsanz.org.au

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

Nurse Consultants. The invited speaker is Professor Daniel Kelly, from the University of Cardiff, Royal College of Nursing Chair of Nursing Research / Director of Research and Innovation. His initial nursing education was undertaken in Edinburgh and then at the Royal Marsden Hospital before engaging with academia and contributing to the development of innovative cancer and palliative care degree programmes. Several university posts later he was appointed to his current role. Professor Kelly has published on death dying and emotional labour, care and needs of young adults with cancer as well as in workforce issues, nursing of leadership, and nursing's' scope of practice. Professor Kelly will also conduct a Masterclass for those thinking about research on *How do you observe everyday work life to get to your research question?*

The nursing program reflects the diversity of clinical practice, with an update on Microbiology, evolutions of the Multidisciplinary team, hot issues in inpatient care, as well as looking at how new hospitals create new ways of practising nursing. Haematology nursing workforce issues are explored what is and is not the nurses' role, scope of practice and ensuring ongoing competence. The diversity of our practice is reflected in the nursing stream being asked to share sessions with a number of haematology societies. The shared session with HSANZ explores haematology care and indigenous health, with ANZSBT on apheresis and a shared session with BMTSAAA on stem cell collection reflecting the collaborative nature of our practice. We will continue with the *how to* sessions that remain one of the most popular sessions of the conference expanding the sessions to *how do you*?, a facilitated sharing to learn from each other. So for CNC's a chance to share and discuss topics like staffing ratios and what are the right key performance indicators. For early career nurses the chance to ask what is next and how do I get there?

We also want you to make friends and network. The welcome reception will have a dedicated meeting point for first timers and those on their own to meet colleague s and have friends to enjoy the conference and the conference dinner at Adelaide Oval where an amazing evening awaits

So hopefully now you are thinking you should come to HAA to learn, share, and grow as a nurse.

**Bev Quested,** Nurse Chair, LOC HAA 2015

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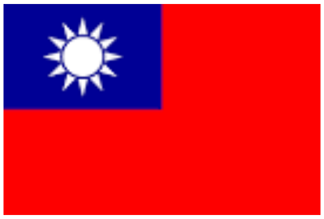
## HSANZ Nurses Group is seeking a motivated and capable nurse to take over production of the newsletter.

- **Would you like to get more involved with your professional group?**
- **Do you have some time to collect articles and contributions from members with the support of the Council?**
- **3 editions per year - Help provided with design and publishing**
- **Great for your CV!**

**To find out more, please contact Tracy King**
**Tracy.king@sswahs.nsw.gov.au**



*'Ni Hao HSANZ colleagues'*

# Flying the MDS flag in Taiwan – sharing expertise ...and curious foods!

Just before Christmas I had an invitation to speak to nurses in Taiwan about my experience of caring for patients with higher risk MDS with a focus on advanced assessment within a nurse led model of care. The invitation excited me but the timing didn't. The week before Christmas would just put too much pressure on poor old Santa and his helpers! I managed to put the trip back to mid January so just had the 'what to do with the rugrats over the school holidays' to contend with. I arrived at night to a beautiful, action packed Taipei that makes Sydney look like a sleepy backwater!! The following day I was met by my hosts from Clegene, Ian and Christina Chang who took me to the high speed train station. This was my first real taste of Taipei's traffic, which was like India without the livestock!

It wasn't all work; I did get a chance to visit some beautiful and historic sites and eat some amazing food. Beef noodles are a speciality – unfortunately I'm vegetarian, which did cause a stir at first! The Grand Matsu Temple is a major religious and tourist site. Behind this first class historical monument is a tragic story of shattered ambitions, sacrifice and political resistance. It was built in 1680's as the Ming Palace by the resistance movement. When the Ming King committed suicide in 1683 rather than surrender, his 5 wives hung themselves from the palace bedroom (at the back of the now Matsu Temple). It's a stunning building hidden away down back streets

Anyway back to business! The first stop of the tour was the National Cheng Kung University Hospital in Tainan. The hospital boasts 1,320 beds and my hosts had kindly arranged a hospital visit around the Cancer Centre. The outpatient area has 30 beds & chairs and runs a 5 day service from 0700 – 2200 hrs. The majority of their patients come in after 4pm!

*My hosts, Christina Chang and Ian from Celgene Taiwan.*

The Cancer Centre took up the whole of the 5th floor and housed both adult and paediatric outpatient clinics. Annie, the NUM, was very friendly and showed us all around the unit. All the specialists consult rooms were housed within the Centre. The patients saw their doctor, picked up meds and waited for their number to be called to have treatment – very well organized. Their facilities were very similar to Australia with resource areas, computer and internet access to cancer related sites, clinical psychologists, social work etc. The extended hours ensured they were able to see the patients on the same day as consult.

"The *Outpatient Nursing Team" – The NUM (Annie) next to me gave us a tour of the whole floor. They have 2 shifts that cover from 7am – 10pm*

That evening a meeting was held at the Shangri-la Hotel in Tainan with 85 attendees. Chia-Ping Chang (pictured left with red scarf), the Director of Nursing of the National Cheng Kung University Hospital, moderated the session and assisted with translation. The session I gave focused on the role of the nurse in the management of higher-risk MDS patients particularly those receiving Azacitidine therapy. Tips on managing cytopenia's and reducing injection site reactions – introducing the delights of evening primrose oil to Taiwanese bellies! The remit of the trip was really to encourage nurse participation in advanced assessment and aggressively managing symptoms. Taiwan has in many parts a very medically driven model with nursing taking a much more supportive role rather than 'actively leading'. With a population similar to Australia, but a considerably smaller landmass, the prevalence of MDS is increasing in line with life expectancy, a problem we all experience worldwide.

*'Well wishes' board from past patients, which is a source of inspiration for many; and across the globe chemo trollies are just the same!*

Dr Ya-Ting Hsu followed on with a Cantonese overview of MDS, particularly the Taiwanese experience. With my extreme limits of literacy in Cantonese I sat and had yet more food. Question time was a bit of a challenge as Taiwanese sessions are apparently renowned for nurses not asking questions. It took some coaxing but eventually we managed to get a discourse going and a few interesting questions were discussed. At last it was time for home with 'a flight in a taxi' then the HSR back to Taipei – 2 ½ hrs later I flopped into bed.

The following day I participated in another evening meeting. Our moderator was Ms. Su-Huei Chien (Jane) a Professor and head of the Cancer Nursing Association of Taiwan.  Jane was a delight and proved to be a wonderful moderator. I would present a couple of slides in English which she would then summarise in Cantonese to ensure clarity and we'd take questions as we went along which made for a much more interactive and fruitful session. Jane was a fervent supporter of advanced nursing practice in Taiwan and nurtured innovation and practice development. Yi-Hua Su, a senior nurse with an interest in MDS at the Taipei Veterans General hospital presented on their local hospital experience caring for patients receiving azacitidine and some of the challenges they face. The evening was rounded off with a nice bottle of red (Australian) and a frank discussion around implementing and sustaining change…wine always helps with that topic I find!

The final presentation of the trip I was the most excited about as it was in the education room on the Haematology ward at the China Medical University Hospital. I was met by Jennifer the NUM of the Haem/BMT Unit (right) who was a perfect host, taking me around everywhere and was very keen to share practice. We also shared our feelings of being overwhelmed as Jennifer had just finished her Master of Nursing and I'm in the last year of mine!

The unit would have been a special interest for my BMT colleagues as ALL neutropenic patients are isolated on an 'extreme scale'.

The large metal doors on the left are the doors to the isolation rooms – big sliding doors like the entry to a vault. There is a 'lobby' to each room for handwashing & gowning. Neutropenic patients are not allowed **any** visitors. There is a visitor's room which is a row of screens where the relatives can talk to the patient via video. The ward was a 40 bedded unit with another 50 Haem / Onc beds on the floor above.

Jennifer's jaw almost dropped to the floor when I explained about outpatient transplants in Australia! I almost needed to call a rapid response when discussing outpatient management of low risk neutropenic sepsis!

**China Medical University Hospital Taichung**

The afternoon presentation was well attended by 32 nurses and hosted by Dr Su-Huei Hsieh, the Department Head of Haematology and BMT. The doctor was extremely enthusiastic and I think the motivator behind the educational tour in the first place. After his lengthy introduction of my CV he rather embarrassingly got very excited describing me as an 'excellent example of lifelong learning' and how I started my nursing career in 1987 and was still studying some 25+ years later (bringing gasps from the audience!). At this point I was feeling positively ancient in front of a crowd of, primarily, fresh faced, wrinkle free nurses. Thank goodness for Jennifer the NUM seated beside me.

*The Nurses Station*

We had a great session with a strong focus and discussion on advanced nursing assessment, patient-focused care and aggressive symptom management. The nursing team and Dr Su-Huei Hsieh were particularly interested in development of nurse led models of care. Once again evening primrose oil on injection sites, supported by research evidence received an instant response with one of the senior nurses ordering a bottle to be picked up the next day.

There was a healthy debate about access to specialist education, which is very limited in Taiwan. Jennifer could only do a general nursing Masters degree as there isn't a specialist oncology/haematology one available in Taiwan. 2 senior nurses were looking into the possibility of travelling overseas (one Australia, one USA) to undertake Master of Cancer Nursing. Contact details were shared and hopefully we can assist with support certainly for the girl travelling through to Australia.

It was great to see such interest from the medical fraternity in 'nursing business', which hopefully extolls a collaborative team approach to patient care. The medical staff were busy taking notes particularly regarding developing nurse led models that focus on advanced, comprehensive patient assessment and the promotion of a self-care philosophy incorporating the family. This is particularly important in Taiwan if they are to achieve a more outpatient focused program as generally the male offspring are still expected to be the providers of support and care for their aged parents although this is changing.

The final education session complete Ian and I headed for dinner before my HSR back to Taipei. He took me to a fantastic vegetarian restaurant where we had 10 courses of beautiful food for about A$15. Of course I took some photos of that too!

I spent the following morning on a final sightseeing trip before heading back to Australia. I took a photo for our Chief Exec as a solution to our parking problem, not sure if there was much enthusiasm! And of course the must do 101 Tower for a selfie!

*'Xie Xie to my new Taiwanese friends and thank you for your hospitality'*

**Jacqui Jagger**
Haematology Care Coordinator
Gosford NSW

# Leukaemia Foundation advocates for greater drug access

***As Australia's leading advocacy group for people affected by blood cancer, the Leukaemia Foundation is advocating for greater access to new therapies and recently made two major drug-related submissions.***

In February, the Foundation made 12 key recommendations to the Senate inquiry into the *Availability of New, Innovative and Specialist Cancer Drugs in Australia*. These were based on the results of a Leukaemia Foundation survey in which 675 people detailed their experiences and difficulties in getting access to and paying for drugs to treat their leukaemia, lymphoma, myeloma, MDS, MPN, or a related blood disorder. The issues they faced included timing, affordability, therapies not being available through the PBS system, inability to access clinical trials and the need to relocate to access a drug.

Anthony Steele, the Foundation's Head of Blood Cancer Support, said the survey results revealed only 1 in 5 respondents had successfully accessed new drugs and 60% of them had to take part in a clinical trial to get the drug.

"In total, 42% of people had actively tried to access new treatments and only 21% were successful," Mr Steele said.

"The Foundation does not believe this is acceptable, especially when 76% of people taking a new drug experienced a life extension and 50% were either in remission or disease-free according to the survey. And more than a third of people had to pay for the drug either by drawing on their savings, selling assets, taking out loans and/or community fundraising."

The Foundation's key recommendations to the Senate inquiry were to:

- **Fast-track approval** – introduce a FDA-style assessment for the TGA and the PBAC to fast-track conditional approval and PBS listing of promising drugs from Phase II trials onwards.
- **Improve Shared Risk program** – to encourage pharmaceutical companies' willingness to use this program to submit drugs via the Managed Entry Scheme.
- **Improve Managed Entry Scheme** – a less restrictive scheme is essential.
- **Decrease lag time in approving other disease indications** – encourage drug data submissions from other groups other than the drug sponsor.
- **Extend PBS listings to include drug target** not just the disease indication.
- **Include quality of life measures** in the health technology assessment and give it a formal weighting in the assessment process.
- **Improve the general public's understanding** of TGA and PBAC decisions.
- **Increase clinical trials** by implementing HoMER and other CTAG recommendations.
- **Extend PATS** to include patient participation in clinical trials.

And, should an additional budget allocation be available, the following recommendations would improve the system:

- **Increase PBAC resources** to reduce approval delays and fast-track price negotiations.
- Establish a **national cancer clinical database** to increase data available for PBAC to assess new and innovative drugs.
- **Educate Australians** about the role of the TGA, the PBAC and the PBS to improve understanding about the cost and value of medicines to the Australian community.

In March, the Foundation made another submission, commenting on the TGA's review of its orphan drugs program regarding suggested changes to improve Australian's access to orphan drugs and identifying areas of cost savings. It outlined four recommendations:

- Allow orphan drug registration for drugs commercially viable in other diseases
- Introduce a mechanism for stakeholder feedback on listing limitations.
- Piggy-back off FDA and European regulatory approval for orphan drugs.
- Delayed payment of high cost orphan drug listings.

As well, the following operational changes were put forward:

- Fast-track approval for orphan drugs still in clinical trials
- Make it easier to collect data on new drugs through a national clinical cancer database

**The Leukaemia Foundation's full submission to the Senate inquiry can be viewed at www.leukaemia.org.au.**

# Another $4 million invested in 'hottest areas' of research

**This year, the Leukaemia Foundation is investing almost $4 million in 14 promising blood cancer research projects in 'the hottest areas of research in haematology at the moment'.**

Announcement of the 2015 round of grants means the Foundation's National Research Program now has 49 research projects underway at leading research institutes in Melbourne, Sydney, Brisbane and Adelaide. The Foundation's Head of Research and Advocacy, Dr Anna Williamson, said this new funding allocation was across the whole blood spectrum – lymphoma, myeloma and the chronic and acute leukaemias, including a CLL clinical trial grant.

"There are studies in some of the most important and influential areas of research – epigenetics (the non-DNA component of the cell), CAR T-cells and immunotherapeutic mechanisms," said Dr Williamson.

Leukaemia Foundation®
VISION TO CURE
MISSION TO CARE

"This means our researchers are working at the frontiers of medicine and puts us right on the mark with what's happening internationally, as highlighted at last year's ASH conference. "

Three key projects, which the Leukaemia Foundation had previously seed funded, announced significant achievements in 2014.

These new therapies are:

- ABT-199 (for acute myeloid leukaemia [AML], myeloma, non-Hodgkin lymphoma and chronic lymphocytic leukaemia [CLL]);
- CX5461 (for AML and myeloma); and
- CSL362 (for AML).

"We had provided vital seed funding for the basic biology that saw these important new therapies emerge, and we anticipate similar results to eventuate from our 2015 round of new research awards," Dr Williamson said.

**For more information and the list of 2015 grant recipients: www.leukaemia.org.au.**

# ‘Push the posa’

## First-time conference attendee, Linley Edwards, reflects on one of the sessions from the recent HAA conference in Perth.

After recently attending the 2014 HAA conference in Perth, my first conference, I came away with a new focus on improving my own practice and a better understanding of nursing issues surrounding the patients in the bone marrow transplant setting. One particular session at the conference very relevant to the acute transplant setting I work in was a discussion on posaconazole presented by Peter Hayward on "Patterns of initiation of broad spectrum anti fungal prophylaxis in newly diagnosed acute myeloid leukaemia undergoing induction".

According to Peter Hayward, 1:3 patients will die if they develop an aspergillas infection. Posaconazole is recognised as one of the most effective prophylactic drugs used in reducing the risk of developing invasive fungal infections such as aspergillas. Posaconazole therefore is very important to the well-being of our transplant recipients, However as a ward nurse I know there are significant barriers with respect to patient compliance regarding pozaconazole, particularly as it is only available as an oral suspension and must be taken with fatty food.

Patients considered being ‘high risk’ of fungal infections

- Patients receiving induction & consolidation therapy for AML
- Any acute leukaemia with previous invasive fungal infection
- High risk allograft recipients such as MUD or cord transplants
- Grade 2 or above acute GVHD or extensive chronic GVHD

***Editor***

**Push the POSA. Is this the new ward slogan?**

As nurses we encourage and educate our patients regarding the importance of taking their medications. However haematological nursing has a high acuity and is often busy, and frequently we may find ourselves leaving the matter of patients actually taking tablets as a low priority. Furthermore the multitude of tablets including prophylactic oral antivirals, anti-fungals and antibiotics mixed in with their analgesics, anti-rejection, anti-nausea, vitamins and electrolytes to name a few, it's no wonder the patients boggle at their medications, with many struggling to take all their tablets.

Additionally for some patients the large numbers of essential medications that need to be taken are not well tolerated for a number of reasons including, but not limited to, nausea, dislike taste of medications or inability to tolerate fatty foods – an important component of taking posaconazole to ensure its correct absorption occurs. Too often I've seen these and probably a few other reasons played out literally on a daily basis at work.

The conversation between patient and nurse about refusing to take tablets is played out often and it is commonly too easy in a busy ward setting to overlook patient medication compliance issues. It is much easier as busy nurses to document "patient refused medication" than to deal with issues surrounding the 5ml of posaconazole still sitting on the patient side table at the end of a meal. Considering it happens so regularly it is easy for nursing staff to become complacent.

**For further information about adherence to oral therapies – see EBMT nurses group guide, available as free download. Although written with oral cancer therapies in mind, much of the information is applicable to any oral therapy including anti-fungal medication**.
http://www.ebmt.org/Contents/Resources/Library/Resourcesfornurses/Documents/Adherence_to_Oral_Anti-tumour_Therapies_EBMT_Swiss_Nurses_Working_Group_2011.pdf.pdf

*We need a posaconazole action plan for nurses*

Education is paramount to ensure patients understand the importance of taking pozaconazole and its role in reducing the risk of developing invasive fungal infections. But nurses need to go further by assessing ‘at risk’ patients for symptoms that are preventing them taking their posaconazole and developing strategies to manage adherence such as education, and anti-emetics for nausea. We also need to inform the medical team of patients struggling to take their posaconazole so that patients are getting the same message from all members of there treating team re the importance of compliance. Clinical psychologists and pharmacists can also play an important role in assisting with patient compliance before and after discharge for at risk patients to develop strategies for adherence at home.

In the acute transplant setting and after hospital discharge there are a multitude of complex reasons why patients refuse or are unable to tolerate oral posaconazole. Commonly nurses struggle to ensure compliance with taking posaconazole, often resulting in poor compliance with an essential and potentially lifesaving drug. Nurses play an important role in ensuring and assisting patients to better understand the importance of compliance with pozaconazole. The creation of a posaconazole action plan is needed that includes nursing education, timely assessment and the development of individualised strategies to assist patients to tolerate their posaconazole. We as nurses need to push the POSA.

**For more information regarding the importance of anti-fungal therapies and the various agents currently in use please refer to eviQ.org.au.**

**Linley Edwards**,
RN, Ward C6 (Haematology/Oncology/Bone Marrow Transplant),
Royal Adelaide Hospital.

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# Updated Patient Resources

**Understanding Acute Leukaemia** - This booklet has recently been clinically reviewed and updated. Key changes include: more detailed information on the allogeneic stem cell transplant process as it is more commonly used in the treatment of acute leukaemia; definition of autologous stem cell transplant has been included to highlight the difference between the procedures, but not expanded upon, as it is rarely used; inclusion of the factors that will help determine the type of transplant chosen for a particular patient; additional detail about what happens during an allogeneic stem cell transplant; and expansion of the 'Chemotherapy side effects' section to include hair loss.

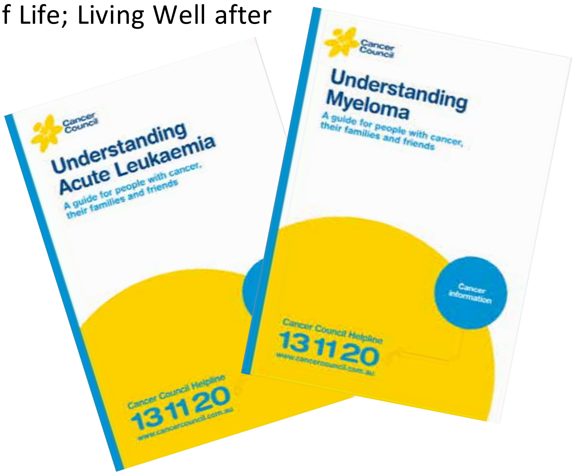
**Understanding Myeloma** - This edition has been clinically revised and updated. Key changes include: updating of the risk factors and removal of the link to obesity; stronger emphasis on the need to let the person conducting the CT scan know that if the patient is suspected of having myeloma, the contrast medium used during CT scans could damage the kidneys;; and an emphasis throughout the book that new treatments are being developed all the time, so treatment for myeloma, especially recurrent myeloma, is being improved constantly.

Quantities of both booklets can be ordered by health professionals via our Publications order form of the Cancer Council website. Many other relevant titles are also available via the order form (eg Emotions and Cancer; Nutrition and Cancer; Living with Advanced Cancer; Understanding Palliative Care; Facing End of Life; Living Well after Cancer; etc).

Patients can pick up booklets from a Cancer Council Information Centre, call 13 11 20 to have one posted to them, or download a PDF from the Cancer Council website:

http://www.cancercouncil.com.au/publications/understanding-cancer-book/

All patient information resources are available free of charge.



# Educational Resources

Learning programmes

Lymphoma Learning Programme

You must register to get your personal download link for the Lymphoma Programme. The download is free of charge: this registration will not generate any costs for you! Please click on the link below:

http://www.ebmt-swiss-ng.org/lymphoma-programme.html

VOD Learning Programme

Trainee opportunity in Immunology/Infectious Diseases/Bone Marrow Transplantation
01/04/2015
Great Ormond Street Hospital for Children NHS Trust... Read more >>

EBMT Newsletter - March 2015
13/03/2015
http://ebmtnewsletter.org/bulletin/march-2015/volume-46-issue-1... Read more

A wide range of resources are available from various organisations relating to haematology or cancer nursing. In this edition we showcase those available from EBMT nurses group. https://www.ebmt.org/Contents/Nursing/Materials/LearningProgrammes/Pages/default.aspx

- Lymphoma Learning Programme
- VOD Learning Programme
- ITP Learning Programme
- CML Learning Programme
- Practice Guides
- Videos
- Slide Bank
- Current Strategies for the Management of MDS

EBMT was also involved in the development of Myeloma UK's Myeloma Nurse Learning Programme available via Myeloma Academy http://www.myeloma-academy.org.uk/nurse/

These resources are available free to download or participate in, via the above web links. Why not review them for yourself and undertake those that are of interest / relevance. Don't forget to let your colleagues know so they can benefit too.

If you've come across a useful educational resource that you feel may be of interest to other haematology nurses – let us know and we'll print them in the next edition.
nurses@hsanz.org.au

**The Editor**

eviQ
Cancer Treatments Online

## eviQ Program Rebuild

The eviQ website is currently being rebuilt; this will provide additional functionality and improved integration between other information systems. Work with the development team commenced in February 2015 with the final delivery of the new eviQ system complete with all migrated content, planned for March **2016.**

## eviQ Patient Information

eviQ is in the process of a review of all patient information as we prepare to translate selected information into multiple languages; thankyou to the sites that have provided feedback and reviewed this information for us. These will become available over the next few months.

## eviQ Professional Education

eviQ Professional Education resources, primarily the adult Antineoplastic Drug Administration Course (ADAC) is being used in over 250 cancer centres nationally. These education resources have assisted with the uptake of eviQ across Australia, as the eviQ content supports these education resources.

**Current modules:**

- Adult and Paediatric ADAC
- Reassessment of Clinical Competency module- *implemented October 2014*
- Introduction to Radiation Oncology modules
- Malnutrition in Cancer – result of a collaborative funded by the Department of health (Victoria)

**In development**

- Community Pharmacy – online education for community pharmacists who dispense oral antineoplastic drugs and supportive medications
- Advanced Radiation Oncology modules
- Community Nursing Project (*to provide education modules to generalist community nurses caring for patients having cancer treatment*)

# 24 hour snapshot of the symptom profile of patients admitted to an acute oncology setting

***Dr Emma Cohen RN PhD***

*NUM, oncology/haematology/BMT (7 South), Olivia-Newton-John Cancer and Wellness Centre, Austin Health.*

The clinical sequelae of symptoms and the methods for the assessment and treatment of symptoms in the acute cancer care context provides unique challenges for both cancer patients and clinicians. The clinical reality is that patients with cancer experience a high incidence of both physical and psychological symptoms that are sometimes not detected or alleviated. The reasons behind suboptimal symptom management in the acute care setting are varied and multifactorial.

The data presented in this article originated from a large multi-method research program exploring patient participation in symptom management in an acute oncology setting [1,2]. Methods included: patient survey, focus groups with nurses, medical record audit (documentation and medication) and naturalistic participant observation. The purpose of this article is to present a snapshot of patients' symptom profile in a 24 hour period during an episode of admission and potential barriers to symptom assessment and management.

One hundred and seventy-one cancer inpatients from one institution consented and completed an interview-administered questionnaire.

Symptom profile data were collected using the Memorial Symptom Assessment Scale (MSAS)[3]. The MSAS is a patent rated instrument that measures symptom presence across three dimensions: frequency (how often a patient experiences symptoms in a 24 hour period), severity and distress/bother. Nurses perceptions of symptom management and the role of the patient were explored in three focus groups.

Table 1: Demographic and illness related characteristics of participants (N=171)

| **Sample Characteristics** | **N** | **%** |
|---|---|---|
| Age (mean 53.7 years, SD 15.4) | | |
| Sex | | |
| Male | 113 | 66.1 |
| Diagnosis | | |
| Haematological malignancy | 115 | 67.3 |
| Solid tumour | 56 | 32.7 |
| Months since diagnosis | | |
| ≤6 months | 81 | 47.4 |
| 7-12 months | 28 | 16.4 |
| >12 months | 62 | 36.3 |
| Reason for admission | | |
| Symptom management | 94 | 55 |
| Treatment | 77 | 45 |

Patients who participated in this research were diverse in terms of age, ethnicity, diagnosis, time since diagnosis and current treatment (see Table 1). Previous research into symptom management has often been limited to patients with a single disease; patients with haematological malignancies are under-represented in cancer symptom research. While single disease-focussed research has yielded important findings, a strength of including disease heterogeneity is that it more accurately reflects clinical, real-world practice.

Patients experienced a high symptom burden, having experienced a mean of 12.1 (SD 4.9) symptoms in the 24 hours prior to interview (minimum 1, maximum 27) (see Figure 1). There was variability in symptom dimensions i.e. a symptom that was rated as severe/very severe did not always correspond with how frequently a symptom was experienced in the previous 24-hours or how much distress or bother it caused. Numbness/tingling in hands/feet was the most frequent symptom, difficulty sleeping was the most severe and fever was the most distressing. Large, positive correlations were noted between each symptom dimension suggesting that in general as the scores in one dimension increase, the higher the rating in other dimensions.

Nurses recognised that patients did not always volunteer symptoms and also described asking specific questions to elicit patient symptoms. They did not, however, describe a systematic method for asking patients specific symptom questions and the type of symptoms assessed tended to be based on what the nurses perceived to be either potential or actual problems for the patient. Lack of time was most commonly the barrier to comprehensive symptom assessment.

The complexity of patients' symptom profile coupled with the busyness of nurses mean that methods for symptom assessment which rely on patients volunteering symptoms or questioning based on clinician judgement are unlikely to result in an accurate understanding of patients' symptom burden. If optimal symptom management is to be achieved in acute care settings then symptom assessment, documentation and management processes should be consistent and systematic and include processes for collaboration between clinicians and patients. When using symptom assessment tools, symptoms are elicited by asking patients whether a symptom is present or not; this question therefore, acts as a prompt for both patients and clinicians. The findings of this research suggest that multi-symptom assessment tools may have a place in the clinical assessment of patient symptoms provided the tool used is easily applied, interpreted and lead to an appropriate management strategy.

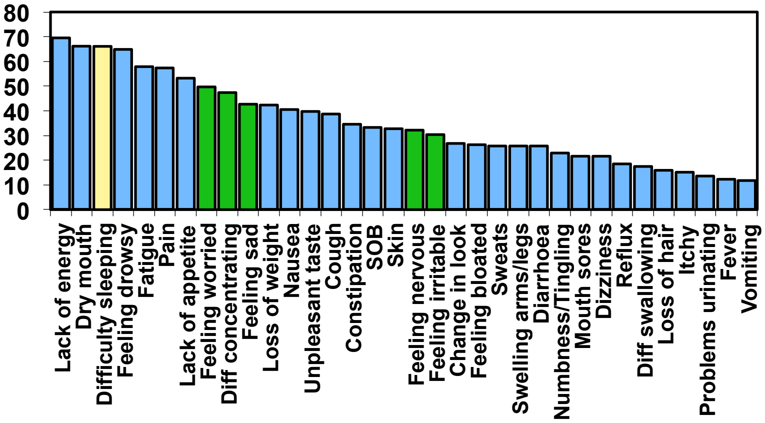


Figure 1: Prevalence of physical and psychological symptoms

*I would like to acknowledge Deakin University, the Alfred Hospital and my supervisors Alfred-Deakin Professor Mari Botti, Chair of Nursing at the Epworth-Deakin Centre for Clinical Nursing Research and Professor Maxine Duke, Head of School at Deakin University for their support in my PhD program.*

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# An update from CNSA

In January 2015, the Cancer Nurses Society of Australia (CNSA) welcomes its new President, Dr Raymond Chan and acknowledges the significant contribution of Sandy McKeirnan to the Society and cancer nursing as a profession. Dr Raymond Chan holds a joint appointment as the Director of Research and Innovation, West Moreton Hospital and Health District and NHMRC Health Professional Research Fellow, Queensland University of Technology. Sandy will remain on the National Executive Committee till the end of 2015 as immediate Past President. CNSA is absolutely growing from strength to strength; the Society is now representing over 1100 cancer nurses across Australia (which reflects >200% of membership growth over the past 3 years). With excitement, CNSA also announces the establishment of the *Queensland Group*, the *Cancer Nurse Practitioner Specialist Practice Network* and the *Venous Access Device Management Specialist Practice Network*. The vibrancy of the Society is so palpable and is absolutely reflected in the growth of membership and establishment of new groups.

In June, CNSA will be holding their 18th Winter Congress in Perth (14-16th June 2015). The Local Organising Committee led by Dr Ruth McConigley is delighted to announce three international key note speakers Dr Carrie Tompkins Stricker, Professor Alex Molasiotis and Professor Lesley Fallowfield will join a diverse range of Australian cancer experts to present a program based on the Congress theme of "Expanding the Possibilities". Congress 2015 will focus on areas that cancer nurses can look to further their career choices, including specialist breast cancer care, radiation oncology and advanced practice. For more information please visit the congress website - http://www.cnsawintercongress.com.au/. '

# Identifying and meeting the needs of carers of haematology patients in New Zealand

**Amanda Foster**

*Support Services Coordinator, Leukaemia & Blood Cancer New Zealand*

## Who are carers?

The term 'carer' is used broadly to describe someone offering unpaid support to a friend or family member. Generally, carers are close family members who assume the role because they feel they are doing what anyone else would do or that the patient would not cope without them. Carers come from all walks of life and often have no experience in providing care (Carers New Zealand, 2015). The 'care' they are required to provide will vary depending on the individual needs of the patient and these will change in throughout treatment, recovery or disease progression.

Extensive literature demonstrates that carers of cancer patients may experience high levels of depression, anxiety and stress and have poor overall wellbeing. In some cases carers have more unmet psychosocial needs than the patient (Soothill *et al.*2001). Carers may experience feelings of guilt, anger, sadness, uncertainty, loss of control, changes to their own identity and social self, inability to balance their own needs, unmet information needs and fatigue and stress due to the strain of caring.

## Why a support group?

Research has shown that a support group can be an effective intervention for carers in a general oncology or palliative care setting (McGrath 2000). There is currently little evidence specifically identifying the needs of, or recommending interventions for carers in a haematology setting. However the support needs to differ from psychosocial care offered to patients, needs to be set in the context of the carer and needs to offer strategies to manage the demands of the role (Chambers *et al*., 2011). Support groups have been well researched and have proven to help improve emotional and physical functioning, relationships, role adjustment and quality of life (Olsen 2014). People can offer mutual support which increases feelings of equality, social usefulness and social value (Moore *et al., 2008*).

Leukaemia & Blood Cancer New Zealand (LBC) is a national non-government organisation which offers individualised psychosocial care to support patients and family members to adapt to and cope with the impact of disease and treatment. It is well recognised that a patient is more likely to cope better when they have an effective support network around them and LBC is ideally placed to offer support for carers.

## Setting up a support group for carers

A pilot support group specifically for carers of people living with or beyond a blood cancer diagnosis was held at the LBC Midland Office (Hamilton, NewZealand). The group was facilitated by an LBC Support Services Coordinator and a counsellor specialising in stress management and relationship counselling. Participants were asked to complete a self administrated questionnaire at the completion of the support group to assess the effectiveness of the meeting.

From the nine questionaries sent out six were returned, all feedback was positive with comments including "it felt like a weight had been lifted off my shoulders when I left the meeting", "so nice to talk about what is happening to me", "I'm normal, so good to hear others feel the same as I do".

***One very common theme that arose during the group was how all interactions with health professionals, friends and family were concentrated on the patient, specifically their physical well-being.***

The responses from the questionnaires reflect the literature, demonstrating that the act of sharing experience with others in a similar situation reduces feelings of isolation and alienation (McGrath, 2000). Facilitated support groups provide a safe environment for problem sharing and solving.

## 'Star Supporters' – a new group for carers.

During the group, one carer described herself as a 'Star Supporter'. Other group members agreed this was the perfect name for their group. Star Supporters now runs every 3 months in Hamilton, with people traveling long distance to attend. The group has also been commenced in Auckland to help meet needs of carers in that area of New Zealand.

Following the work I have done researching and piloting support for carers, I have reflected on my own practice. I often focused my assessment and care interventions solely on the patient. I have learnt that carers are not an extension of the patient and I now always ask them, how they are doing today.

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15th International
Myeloma Workshop
Rome, September 23-26, 2015

## 15th INTERNATIONAL MYELOMA WORKSHOP

*Rome, Auditorium Parco della Musica*
*September 23-26, 2015*

# 2nd MYELOMA NURSING SYMPOSIUM
# Wednesday, September 23, 2015

Are you a myeloma nurse? Would you like to meet, learn and share best practice with your international nursing colleagues? We are delighted to announce that a full-day nursing symposium will be held within the 15th International Myeloma Workshop in Rome. The aims of this nursing symposium are to:

- Educate nurses on issues specific to the care of the myeloma patient and their family
- Disseminate the latest nursing research in the field of myeloma
- Provide a forum for nurses working in myeloma to network and share practice initiatives.

Nurses will be able to register for IMW at a special nurses' rate of €200 and in addition to attending the man workshop program of presentations and debates, can also attend a full day nursing symposium on Wednesday 23rd September.

### CALL FOR ABSTRACTS

We warmly welcome abstracts for oral and poster presentations from nurses working the field of myeloma who have undertaken myeloma related research and/or initiatives which develop myeloma nursing care. Abstracts can be submitted only through the meeting website (www.imw2015.it) choosing topic 7 related to "Nurse Session" **until May 31, 2015**. Guidelines are available on the "Call for abstract" section.

### PROGRAM HIGHLIGHTS

| | |
|---|---|
| Keeping patients on Treatment: Management of Toxicities Related to New Therapies and Challenges of Symptom Management Research | **Beth Faiman** NP<br>Multiple Myeloma Program ,<br>Cleveland Clinic, Ohio |
| Toxicities Associated with SQ Bortezomib: An Update of the Italian Experience | **Alessandra Malfitano** Research Nurse<br>Citta della Salute e della Scienza di Torino |
| The Devils in the Dex: the Experience of High Dose Dexamethasone and Implications for PRO Tool Development | **Tracy King** Myeloma Nurse Consultant,<br>Royal Prince Alfred Hospital, Sydney |
| "We are the Nurses all the Time": the Experience and Supportive Care Needs of the Family in the Era of Novel Myeloma Therapies | **Monica Morris** Myeloma Clinical Nurse Specialist,<br>St George's Hospital, London |
| Integrating Myeloma Genomics into Nursing Practice: Patient Education and Shared Decision Making | **Joseph Tariman** A/Prof,<br>School of Nursing, De Paul University, Chicago |
| Submitted Papers – 4 best abstracts submitted under 'Nursing' to IMW | |

## CORE ORGANIZING COMMITTEE

**Host Italy: Elena Ponticelli,** Manager Nursing Oncology Department **,** City of Health and Science, Turin

**Chair Australia**: **Tracy King** RN MSc, Myeloma Nurse Consultant RPAH Sydney, Clinical Research Fellow Sydney University, Sydney

**UK**: **Monica Morris** RN MSc, Clinical Nurse Specialist , Myeloma, St George's Hospital, London

**USA**: **Beth Faiman** PhD, MSN, APRN-BC, AOCN, Nurse Practitioner Multiple Myeloma Program , Cleveland Clinic Ohio

**Tiffany Richards** MS, ANP-BC, Nurse Practitioner Multiple Myeloma, MD Anderson, Houston

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## National Lymphoma Nurse

*Are you looking for a career change?* Lymphoma Australia is currently seeking an experienced haematology nurse to work with our organisation. Lymphoma Australia is a national charity dedicated solely to the lymphoma cause. With more than 5000 Australians diagnosed with this cancer each year we want to ensure patients and their families are supported with information about lymphoma, treatments that are available including clinical trials and life after a diagnosis.

The initial focus of this role will be to develop relationships and strategies for ongoing communications with lymphoma nurses and trial sites across Australia. This position can be located anywhere in Australia and the remuneration will be negotiated with the successful applicant.

**The key areas for this role include the following:**

- The development of strategies and materials to engage with haematology nurses to further support and deliver the Lymphoma Australia brand
- Assist with patient education days
- Assist with advocacy and promotion of clinical trials

**Aim**

- To increase the profile of LA with nurses and doctors
- Support patients and carers
- Develop the LA community to further support LA

**Requirements**

- Nurse with experience in haematology (Lymphoma)
- Above average networking skills
- Good computer skills
- Able to travel and has own vehicle
- Initially a part time role

**For further information please contact Sharon Millman CEO Lymphoma Australia**

Mobile – 0431483204

Email – sharon.m@lymphoma.org.au

**Website Lymphoma Australia www.lymphoma.org.au**

Cancer Nurses Society of Australia

**18th WINTER CONGRESS**

# CANCER NURSING: EXPANDING THE POSSIBILITIES

**REGISTER NOW!**

Early Bird Deadline for Registration: **30 April 2015**

**For the first time combining the National Breast Care Nurse Conference**

## Sun 14 June – Tues 16 June 2015 | Perth Convention and Exhibition Centre

## Invitation to Attend

The Local Organising Committee for the 18th CNSA Annual Winter Congress would like to welcome you to Perth, a city of great beauty and prosperity. Our theme "Cancer Nursing: Expanding the Possibilities" will focus on exploring the opportunities that exist in cancer nursing in 2015 and beyond and now incorporating the National Breast Care Nurse Conference into it's new home within CNSA Winter Congress.

The program will incorporate a blend of invited plenary speakers, abstract presentations and integrated workshops both within the Congress format and prior to the commencement of Congress. For 2015, delegates can expect to be offered greater insights from radiation oncology, research, advanced practice, breast cancer care, education and evolving clinical care.

We look forward to you joining us for a scientifically robust meeting in a city that is second to none.

**Dr Ruth McConigley**
***Local Organising Committee Chair***

## The Congress at a glance ...

- Sat 13th: **Delegates arrive** > Small Bar Tour
- Sun 14th: Pre-Congress Workshops > Welcome Reception > BMS Educational Dinner
- Mon 15th: Breakfast Sessions > **Opening Ceremony** > Congress Sessions > Gala Dinner
- Tue 16th: Breakfast Sessions > Congress Sessions > **Closing Session** > Small Bar Tour
- Wed 17th: Post Congress Tours Available

**With thanks to our Major Supporters:**

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The Flinders Centre for Innovation in Cancer held the 2015 Survivorship Conference in February. Overall, I had great experience. What I found interesting and thought was quite valuable was the active consumer engagement throughout the conference. They not only presented their own experiences as well as their visions, but also actively participated in discussions to advocate the views of consumers.

What I particularly enjoyed was listening to the story of Mr Matthew Zachary, the founder of Stupid Cancer. **Stupid Cancer** is an online non-profit youth cancer advocacy group based in the US. He told us how excited he was to find other young adults in a similar situation, and to know that he wasn't alone. He created an online community where these young adults belonged, felt supported, and eventually gained empowerment to actively navigate their lives. This is a short version of his story. https://www.youtube.com/watch?v=sLus6ftO0YA

Canteen Australia also does a similar work. It seems like there is something magical about meeting other people going through similar experiences and sharing them. Andrew Solomon, an author of the book 'Far from the tree' said the following in one of his interviews. Although he said this in the context of marginalised minority groups, to some extent, there is still something here that resonates with the cancer community;

> *We live the age of internet, and all kinds of people once been quite isolated, now can find one another. So online has been a place where their identity have hatched out of nothingness. Suddenly people with any given quality in common can all find another. They can all talk about it, they can all formulate it as an identity. That has been an incredible and radical transformation and it couldn't happen until now because we didn't have the internet. When it happens, it's generally very empowering. People find other people who are like them, they don't feel so alone, they feel as though they have connected with other human being, and they reinforce to one another as sort of validation of experience and I think that's the essence of identity...*

I also met Pamela, another inspiring (and witty) spirit, who presented a poster at the conference to resolve the problem she encountered during her treatment. She founded **Ur the Cure** to improve ethnic diversity on the Australian and worldwide stem cell registries. I won't go too much in detail as Pam has written a lovely piece that is on the following pages.

In my opinion, these active consumer engagements and collaborations reflected the nature of survivorship well. Moving from the acute treatment phase, which can often be intervention driven, to a space where people start to reflect on what they have gone through, and realign their values and priorities, allows the focus to move from combating cancer to building a more meaningful life. Many projects presented at the conference focused on building personal capacities (e.g. resilience, healthy life habits).

Several questions were on the table; How can we support a rapidly growing survivorship population in a sustainable and economic way?, How can we collaborate effectively to provide holistic care when people often have other comorbidities, thus requiring various specialty care?; How should 'survivorship' be defined and what should be the goal? Is the term 'survivorship' appropriate? Overall, it was such an inspiring and thought provoking conference with a warm and welcoming spirit. I look forward to the next survivorship conference.

**Bora Kim,** RN

*Royal North Shore Hospital Sydney*

# ur the cure

## Improving ethnic diversity on the Australian and worldwide stem cell registries

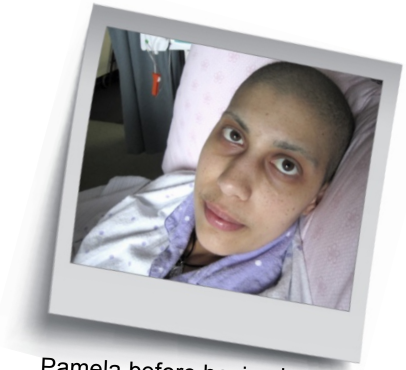
*Pamela Bousejean, cancer survivor and founder of Ur the Cure*

## Background information and my personal story

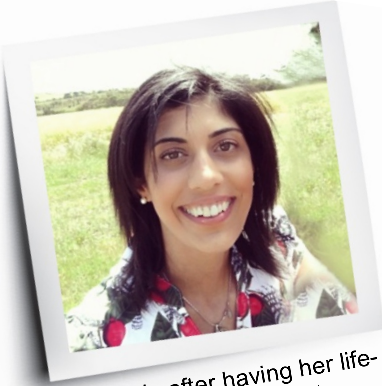
I was 26 years old and already 2 years down the cancer path when **my Lebanese background threatened to discriminate my search to find a stem cell match. I needed a stem cell transplant as my final hope to cure my cancer**. Ethnicity is an important factor when securing a stem cell match and unfortunately there are not many people of ethnic backgrounds on the worldwide stem cell registries for Doctors to search. I felt completely hopeless and in despair. The wait for my match was agonising.

In a desperate attempt to find a match, my brother created a Facebook page for people to share amongst the Middle Eastern community, pleading for them to join the bone marrow registry. This caught media attention and the story was spread through national and international media. I even met the President of Lebanon in Melbourne and travelled to the country to discuss the issue of the non-existent bone marrow registry in Lebanon; a team has since been set up to establish one! It was an overwhelming time and it highlights the extreme measures my family and I took to find a match.

Finally in the end I was lucky enough to be eligible and have a double cord blood transplant at the Royal Melbourne Hospital. I have been in remission since December 2012!



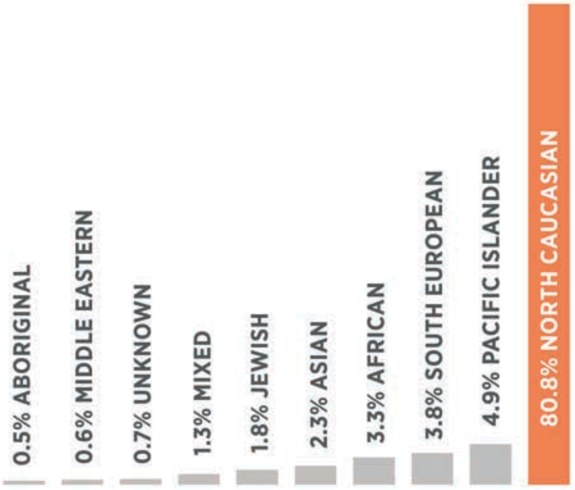
Pamela before having her life-saving transplant



Pamela after having her life-
transplant

## Establishing Ur the Cure

I continued hearing stories of many others struggling to find a match because of their ethnic background and realised that no one was actively promoting the cause in Australia. So I established “Ur the Cure” – because the cure for many blood cancers is in your body, the “ur” in the “cure”! **81% of donors on the Australian Bone Marrow Donor Registry are of North Caucasian background and the remainder are split across tiny percentages** of various ethnic backgrounds. Sadly many groups have less than 1% representation (1). **The aim of Ur the Cure is to improve HLA (Human Leukocyte Antigen) and ethnic diversity on the stem cell registries through education and awareness; in the hope that everyone, no matter what their ethnic background has the same chance for a cure**. I have applied my marketing skills and personal experience to educate people about joining the bone marrow registry in a simple and easy to understand manner; all information has been sourced and verified by a health professional.



PERCENTAGE OF ETHNIC BACKGROUNDS REPRESENTED ON THE AUSTRALIAN BONE MARROW DONOR REGISTRY

Through much research and many observations, I have developed the work to target the information to young people and make it relevant (you need to be aged 18-45 to join the registry). There are also many misconceptions on the topic, for example many people think they will need to donate their stem cells on a regular basis, so in communications I include the fact that only 1 in 1500 Australians are a match in any given year. Many also don't realise how easy it is to join (a blood sample taken at the Red Cross) and also don't know that technology exists which can extract their stem cells via the bloodstream.

## Social Media: Like – Share - Join

Social media is a powerful tool and I plan to replicate what happened with my experience on a larger scale. Gathering "likers" for the Facebook page from a variety of ethnic backgrounds is the social media aim. Many people have friends of the same ethnicity and as posts of patient stories searching for their match and other information spreads, the targeted groups will be accessed.

## Action I need from you

1. **If you have access to transplant patients of an ethnic background** who are searching for a match, please direct them to the website/Facebook page and contact Pamela. Patients, their stories and extended network are strong drivers of the message.
2. **If you work or live within an ethnically diverse population** and would like to spread this message, please contact Pamela.
3. **If you have connections to the New Zealand Bone Marrow Donor Registry,** please contact Pamela. The New Zealand registry demonstrates a great commitment in promoting ethnic diversity, visit www.bonemarrow.org.nz
4. Of course Like the Facebook page and follow Ur the Cure on social media to show your support! **Search "Ur the Cure"**

Currently all activities relating to Ur the Cure are independently managed and to progress our aim, collaborations with health organisations will be needed. The Ur the Cure action plan details workable strategies, please contact Pamela (details below) if you would like to help.

## Request a brochure and more

Send an email to info@urthecure.com.au to receive an e-copy of the brochure

**Reference list:** 1. GN Samuel, IH Kerridge, M Vowels, A Trickett, J Chapman, T Dobbins 2007, "Ethnicity, equity and public benefit: a critical evaluation of public umbilical cord blood banking in Australia", Bone Marrow Transplantation, 40, pp. 732-733.

# Spotlight on a Trial

**Hayley King**
*Myeloma CNC – Royal Melbourne Hospital*
*Support Nurse Manager – Myeloma Australia.*

Brentuximab vedontin (Adcetris) is a CD30-directed antibody that gained PBS approval in March 2014 for the treatment of relapsed or refractory systemic anaplastic large cell lymphoma in patients who are suitable for further systemic curative intent salvage therapy. In clinical trials evaluating the efficacy of brentuximab vedotin in relapsed or refractory Hodgkin lymphoma (HL) patients, the overall response rate (ORR) was 75%. This included 33% of patients who achieved a complete remission and 41% who received a partial remission. 94% of patients at least experienced a reduction in tumour size. Now the time has come to evaluate the efficacy of brentuximab vedotin in the frontline setting. In Australia many sites are currently recruiting to:

## A Randomized, Open-label, Phase 3 Trial of A+AVD Versus ABVD as Frontline Therapy in Patients With Advanced Classical Hodgkin Lymphoma

**Study Aim**

The aim of this study is to compare the modified progression-free survival and overall survival obtained with brentuximab vedotin plus AVD (doxorubicin, vinblastine, and dacarbazine; abbreviated A+AVD) versus that obtained with ABVD (doxorubicin, bleomycin, vinblastine, and dacarbazine) for the frontline treatment of advanced classical Hodgkin lymphoma (HL), ie. Ann Arbor stage III or IV.

**Study Design**

Patients are randomised 1:1 to either ABVD or A+AVD and receive treatment on days 1 and 15 of a 28 day cycle. Disease is assessed after 2 cycles with PET and CT scans. If the Deauville score returns at 1 – 4 the patient continues on current treatment. If the Deauville score returns at 5 the physician has the choice to switch to another therapy regime of their choice. Patients that continue on study treatment complete 6 cycles of therapy. Disease assessments are then performed again 1 month post completion of treatment and follow up CT scans are performed every 3 months for 36 months then every 6 months until study completion.

Radiotherapy can be considered for those patients who have residual disease at the completion of treatment.

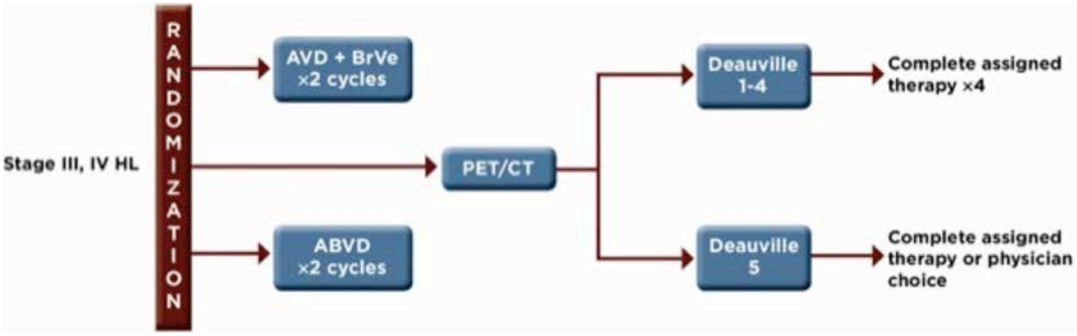
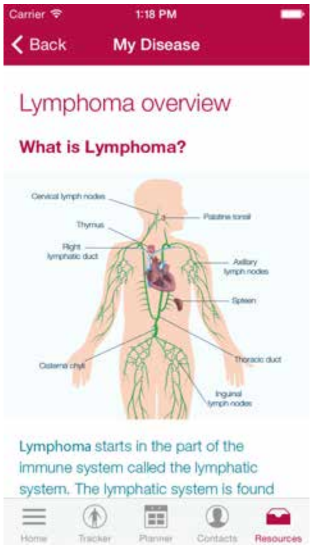


Image 1: Tolerability of Brentuximab Vedotin

Brentuximab vedotin is a 30 minute intravenous infusion. Anaphylaxis and tumour lysis have both been noted in some cases and precautions should be adhered to. In those with HL who have had brentuximab vedotin in the relapsed/refractory setting the most common side effects were:

- Peripheral neuropathy
- Fatigue
- Nausea
- Upper respiratory tract infection
- Diarrhoea
- Pyrexia
- Neutropenia
- Vomiting

Cough



Lymphoma overview

What is Lymphoma?

Lymphoma starts in the part of the immune system called the lymphatic system. The lymphatic system is found

If you have a patient on brentuximab vedotin there is now a patient resource app. Search for MyAdectris in the app store.

## New Apheresis Nurses Focus Group in NSW

Apheresis units are an integral part of the Blood and Marrow Transplant process, performing collection of stem cells from healthy donors and those patients donating for their own autologous transplants, however, there are also a number of other procedures that these units carry out on patients. These can be patients with haematological, neurological, renal diseases, and even post cardiac transplant. In fact the number of indications for the different apheresis procedures has increased. Because many of these patients are managed by haematology nurses, and with assistance from a couple of pharmaceutical companies, on March 20 under the HSANZNG NSW banner we held an Apheresis Nurses Focus group. This was a chance for those nurses working in the area to get together to network. There was a presentation by Dr Danny Hsu from Liverpool Hospital who updated the group on the use of plasma exchange in Thrombotic Microangiopathies (TMAs), and a nursing presentation, which gave the group a chance to exchange ideas.

The plan is to meet again later in the year, If you are interested in apheresis and didn't get a chance to attend please contact David Collins David.collins@health.nsw.gov.au to get your name on the list.

# HOLD THE DATE: HAA 2015 Adelaide 18th – 21st October

In preparation for HAA 2015 and to offer some helpful advice to those of you thinking about submitting an abstract, we are re printing the short article below. Don't forget, there are prizes!

HAA 2015

HSANZ ANZSBT ASTH

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PLATINUM SPONSORS

WELCOME TO HAA 2015

The Organising Committee takes great pleasure in inviting you to attend the Annual Scientific Meetings of the HAA (Haematology Society of Australia and New Zealand, the Australian & New Zealand Society of Blood Transfusion and the Australasian Society of Thrombosis and Haemostasis) to be held at the Adelaide Convention Centre on 18th – 21st October 2015.

We look forward to welcoming you to Adelaide in 2015.

## HOW DO I WRITE AN ABSTRACT?

An abstract serves two purposes. Firstly, it allows conference organisers to select papers for various sessions at their meeting. The abstract will help the programme committee decide which presentations should be given orally and those that should be presented as posters, and in which sessions they should appear. Secondly, at the meeting itself, it allows delegates to decide which presentations interest them.

An abstract is a concise summary of your work. Mostly, abstracts are limited to 250-300 words in length so the author has to achieve as much impact as possible in a short space. As a general rule, abstracts should convey findings in ordered, brief and uncomplicated sentences. Although abstracts may very subtly, most consist of the following standard layout and design.

**Title, Introductory sentence, Method, Results and Conclusion.**

- **The title** should be short and give an accurate indication of what you will talk about. The reader should be able to read the title and decide if the abstract is of interest to them.
- **The introduction** provides a brief background and explains what you looked at and why you did it. In essence, use the introduction to detail why you did the work.
- **Method**: What did you do? Use one or two sentences to explain what you did or how you tested your question.
- **Results**: What did you find? The key part of the abstract. This section provides any data obtained in its analysed form. As a rule of thumb, the layout of the results section parallels that of the methods section.
- **Conclusions**: What does it mean? The hard bit! The abstract should end with a concluding sentence / paragraph pointing out any potential significance of the findings to clinical practice or more specifically, the field of interest.

## SOME FURTHER TIPS

- Make sure your abstract is clear.
- *Always read and follow* the conference abstract submission guidelines – this is what your abstract is marked against.
- Ask someone with experience to help you write your first one. Any of the committee members would be happy to.
- Ensure appropriate research and ethics committee (HREC) approval is obtained

**Abstracts are scored by a committee of nurses using a scoring system with set criteria. Don't forget 'best abstract grants' are available to the highest scoring abstracts submitted based in set criteria. Four criteria to think about when preparing your abstracts are:**

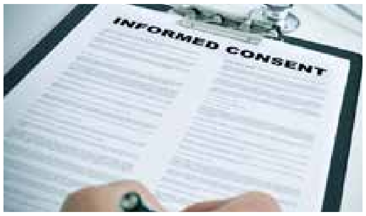
1. **Originality:** abstracts containing significant new findings or that present innovative practice will be given higher scores than those that describe updates or modifications to older findings
2. **Quality:** abstracts that contribute to the knowledge of haematology nursing practice and /or /patient care and demonstrate the use of sound scientific (qualitative or quantitative) methodology or evaluation will be given higher scores.
3. **Importance:** abstracts that present new information about practice or care, or that add relevance to the broader context framed by the subject heading, will receive higher scores.
4. **Presentation:** higher scores will be awarded to abstracts that clearly state the specific objectives to be attained, the methods used, the main results, and provide a concise interpretation of the findings or discussion.

**Written by Editor.** *Re-printed from 2013.*

Medicine, Nursing and Health Sciences

## News from the Myeloma and Related Diseases Registry

# The Myeloma 1000 Project: a biobank of the Myeloma and Related Diseases Registry



The Myeloma and Related Diseases Registry (MRDR) is a bi-national project that aims to monitor, explore and improve practice and outcomes in patients with MRD.

The Myeloma 1000 Project (M1000) is a biobank sub-project of the MRDR. The aim of M1000 is to establish a repository of blood samples for future assessment of biomarkers that better predict treatment response and patients at risk of developing myeloma and accelerated disease progression.

A one-off blood specimen (80-100 mL) will be taken from 1000 patients with myeloma and 1000 patients with MGUS who are newly diagnosed and have not received any treatment.

MRDR sites participating in M1000, will invite eligible patients who have not elected to ‘opt off’ the registry to participate in the Myeloma 1000 Project through a formal consent process. Consent to participate in the MRDR and M1000 can be obtained simultaneously.

Once blood is taken from participants, specimens will be sent to laboratories on the Alfred Hospital campus where they are processed. Duplicate samples will be fractioned and freeze-stored in 2 separate facilities for greater safety and security.

Blood is taken at sites, sent to the Alfred Hospital campus, processed then freeze-stored

The Alfred and St Vincent’s Hospital, Melbourne are the only sites currently participating in M1000, and the project will soon be rolled out to other sites. A separate ethics submission is required for participating sites.

The M1000 biobank will support research to improve the prevention, diagnosis and treatment of people with myeloma and related diseases. It is supported by Amgen Australia, Bristol Myers-Squibb & Janssen-Cilag. We thank all the HSANZ NG readership that contribute in any way to the MRDR and M1000.

Novartis and Celgene continue to support the MRDR, and Takeda Corp has recently provided funding. We appreciate their support which enables this important research to continue.

For more information, please contact the research team:

**Phone:** 1800 811 326

**Email:** *torc.sphpm@monash.edu* or visit the

**Website:** http://mrdr.net.au

MONASH University

Myeloma & related diseases registry

ACBD Australian Centre for Blood Diseases

AlfredHealth

# Tandem BMT Meeting, San Diego, February 2015

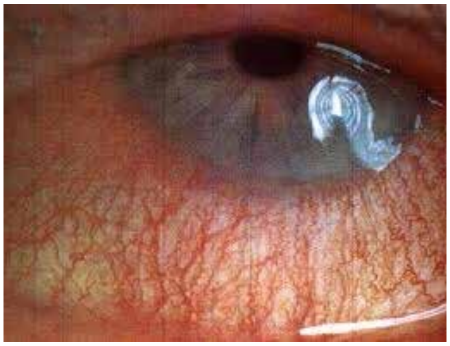
I was very fortunate to attend the Tandem Bone Marrow Transplant (BMT) meetings in San Diego – a far better venue than Texas last year! The Tandem meetings are a number of combined BMT meetings that run concurrently. As a registrant for the conference, the attendee is able to dip in and out of any of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

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

It was an excellent meeting to attend with a number of excellent presentations giving an overview and update of many areas of stem cell transplant.

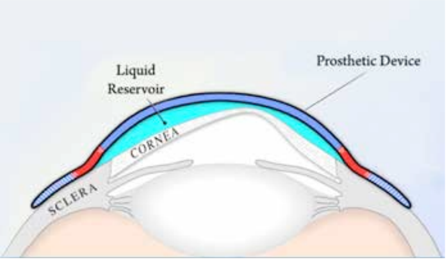
## Ocular Graft Versus Host Disease

One topic that was of particular interest to me was ocular graft versus host disease (GVHD). There were two presentations by Tueng T. Shen, Professor of Ophthalmology from the University of Washington. She talked about the use of bandage contact lenses in the treatment of this very distressing post-transplant complication.



Ocular GVHD occurs in approximately 60% of patients who have chronic GVHD. It significantly compromises quality of life due to eye pain, dry eye syndrome and photophobia. It causes a decrease in visual acuity and may lead to permanent eye damage. Treatment for ocular GVHD includes the use of lubricating eye drops, topical immunosuppression (steroid or cyclosporin eye drops) or surgery to plug the tear ducts to decrease tear loss and increase lubrication of the eye. Many of these treatments are ineffective.

One treatment that has shown some promise over the past few years is the Boston Sight® Prose Treatment. This is an individually made special contact lens made out of a gas-permeable hard plastic that allows oxygen to reach the cornea. It is designed to create a space between the prosthetic device and the eye. This is filled with sterile saline, providing constant lubrication by bathing the eye in a pool of artificial tears. This is however very expensive therapy at a cost of $US3,000.00 and is only available at limited locations throughout the USA.



Professor Shen has found that bandage contact lenses are a much cheaper option for the treatment of ocular GVHD. Bandage contact lenses are disposable soft contact lenses used for a diseased or injured cornea to protect or treat it. Patients wear these 24 hours a day with each set of lenses lasting approximately one month.

A phase II clinical trial was undertaken with the primary endpoint being an improvement in eye symptoms over three months. Approximately 53% patients had a substantial improvement in eye symptoms and a decrease in corneal ulceration. This is exciting news for patients especially as bandage contact lenses are readily available. Our transplant team will be discussing this with our ophthalmology colleagues and we hope that this will be a treatment that we can offer patients in the near future.

## Medical Marijuana

The BMT nurses conference had a controversial session about the use of medical marijuana for stem cell transplant patients. In some states in the USA, it is legal to use medical marijuana. There was a debate about the pros and cons of medical marijuana and what might be some of the risks and benefits if it was used in the transplant population. I have to admit to being completely naïve about medical marijuana – I always thought that it would be sold as a tablet. It can be, but often users go along and buy the leaves from a legal dispensary for either smoking or eating. Patients are not prescribed marijuana as such but doctors write a letter of authorisation that allows the patient to buy marijuana.

Medical Marijuana may be beneficial in controlling pain, nausea, anorexia, depression, sleep disturbance and may have a disease modifying role. Using inhaled marijuana may be associated with a higher rate of invasive aspergillis infection. It may also be associated with xerostomia (dry mouth syndrome) – something that many patients with GVHD already experience.

There were no firm conclusions drawn about the use of medical marijuana in stem cell transplant patients. There is increasing legalisation of the use of marijuana and it maybe sooner rather than later before one of our patients asks us if it can be used during transplant. For further information see the following link on Medscape http://www.medscape.com/viewarticle/839155

There were many other excellent presentations. The Clinical Education Conference in particular had some very practical sessions. Highlights include:

- Preserving fertility.
- Bone health post-transplant.
- Hormonal side effects for both males and females.
- Cardiovascular health after transplant.
- Survivorship and late effects.

**Catherine Wood**
Clinical Nurse Specialist BMT,
Wellington NZ

HSANZ NG
Haematology Society of Australia and New Zealand

# NEW: Myeloma Special Practice Network (M-SPN) opens for membership

A new initiative within HSANZNG has been the establishment of Special Practice Networks (SPNs). *'SPNs are communities of members who share ideas, information and experiences with others in the same sub specialist field. Each SPN will comprise associate nurse members who establish networks to address professional and educational issues relating to specific areas of haematology nursing practice'. Visit* our web page for Guidelines and Membership application form. 'Application to join SPN' http://www.hsanz.org.au/news/HSANZ-NG.cfm

I am delighted to inform you that the Myeloma-SPN has now formed. A year in the making, this group welcomes applications from HSANZ nurse members. The M-SPN management committee:

| Name | Role | Position |
|---|---|---|
| **Tracy King** | Myeloma CNC<br>Clinical Research Fellow<br>Royal Prince Alfred Hospital, Sydney University NSW | Chair |
| **Daniela Klarica** | Myeloma / BMT CNC<br>The Alfred Hospital Melbourne VIC | Deputy Chair |
| **Kerin Young** | Haematology Nurse Coordinator WA Cancer & Palliative Care Network | Committee member |
| **Nicole Loft** | Nurse Practitioner Haematology<br>Royal Adelaide Hospital SA | Committee member |
| **Gillian Sheldon-Collins** | Bone Marrow Transplant CNC<br>Royal Hobart Hospital TAS | Committee member |
| **Rosita Van Kuilenburg** | Nurse Practitioner Haematology Stem Cell Transplantation<br>Princes Alexandria Hospital QLD | Committee member |
| **Jacqui Jagger** | Transitional Nurse Practitioner, Haematology<br>Gosford NSW | Committee member |
| **Amanda Foster** | Support Services Coordinator<br>Leukaemia & Blood Cancer NZ | Committee member |
| **Hayley King** | Myeloma CNC Royal Melbourne Hospital<br>Support Services Manager<br>Myeloma Foundation VIC | Committee member |

Aims and objectives of the group include:

- Develop & disseminate resources which support and contribute to advances in MM nursing practice
- Take a leadership role in addressing educational needs within HSANZ NG
- Host and engage in / with educational activities relating to MM
- Facilitate and contribute to MM related nursing research
- Promote MM nurse specialist role
- Provide opportunities for professional networking / development / mentorship

The group will concentrate on attracting memberships; hosting local myeloma related events and establishing a body of shared knowledge around myeloma in Australia and internationally. Several members aim to attend the International Myeloma Workshop (IMW) in Rome Sept 23-26th and are actively involved in hosting of the nursing symposium this year. http://www.imw2015.it/ We look forward to reporting back from that meeting later in the year and bringing you a regular myeloma related report in each edition of the newsletter.

If you are interested in joining the M-SPN please contact us at nurses@hsanz.org.au or complete and submit your application form found at http://www.hsanz.org.au/news/HSANZ-NG.cfm

**A MDS / MPD group is also establishing.**
**If you are interested in being involved, please email nurses@hsanz.org.au**

***Tracy King***
Chair M-SPN
nurses@hsanz.org.au

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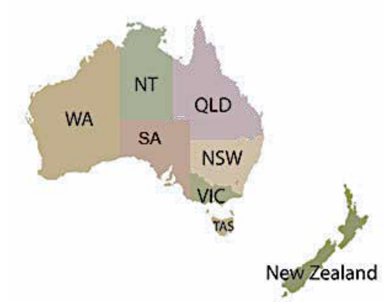
# Regional Round up!



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

## North Island, New Zealand

**Catherine Wood**

The lower North Island is running four education sessions for the 2015 year, with three of these being held in Wellington and one in Palmerston North. Topics selected for each year are based on the evaluations and suggestions received from the previous year. The topics and sponsorship for this year are still to be confirmed but tentative dates for the education sessions in the 2015 year are the 6th May, 1st July, 26th August and the 18th November. I will send out an email to the mailing list once dates, topics and venues have been finalised. There are likely to be some education sessions happening in the upper North Island as well which is great news. Once again, details of these will be sent around once they have been confirmed. If anybody would like further information about any of these meetings or would like to attend then please feel free to get in touch with me. I can be emailed at Catherine.Wood@ccdhb.org.nz

## Victoria

**Hailey King**

It is with great pleasure and anticipation that I take over from Yvonne Panek-Hudson as Victorian rep. Yvonne has gone above and beyond in her reign and I can only hope to be half as motivating and enthusiastic as she is. On behalf of the

Victorian group I would like to sincerely thank Yvonne for all her hard work and dedication during her extended term.
We have had our first education evening of the year, which was jam-packed with 60 members in attendance. Our theme was ASH highlights, which included an introductory speech from Professor Andrew Roberts from the Royal Melbourne Hospital who gave a tribute to the late, great Professor Don Metcalf who lost his battle with pancreatic cancer late last year. Professor Roberts completed his PhD with Professor Metcalf and gave a very entertaining account of their time together as well as highlighting his pioneering discovery of G-CSF. We then heard from Professor Hashal Nandurkar of St Vincents Hospital who gave us a very interesting overview of many MPN and thrombosis related abstracts presented at ASH. The Victorian calendar is taking shape with many metro and regional events being planned. We are looking forward to a great 2015. Hayley King, VIC Chair hayley.king@mh.org.au

## Tasmania

**Bronwyn Neely**

The 2015 year has started with a hiss and a roar in Tassie. We have had a change of Regional Chairperson, with Bronwen Neely taking over from Gill Sheldon-Collins, who takes up the role of HSANZ NG Treasurer. We have had a steady stream of Stem Cell Collections for our little unit. This is timely as we train up a new group of Apheresis Nurses. Discussions are under way to plan our combined Nursing Education Dinners with CNSA. We continue to actively recruit new members to extend our current small numbers. We look forward to the year ahead.
Bronwen Neely RN, The Royal Hobart Hospital, bronwen.neely@dhhs.tas.gov.au

## WA

**Cassi Lawrence**

The 'Advancing patient care in CML' evening hosted by BMS was a success. It was well attended by nurses, pharmacists and medical staff. The guest speaker Chris Arthur discussed some of his own interesting CML cases and also information that was previously presented at ASH. We are planning an evening education session on myeloma in mid July. We are hoping to have an international speaker come and join us to discuss the latest in myeloma over dinner. The program and speaker are yet to be confirmed so watch this space for the dates of this event.
Email: cassi.lawrence@health.wa.gov.au

## SA/NT

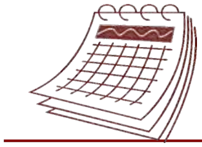
**Allan Hayward/Bev Quested**

The local SA/NT committee is currently seeking interested haematology nurses to become members of the local organising committee. We are seeking to reinvigorate the committee with fresh ideas for professional development opportunities. This year will be a busy time with the HAA conference happening in Adelaide. We are expecting to plan a couple of events in the lead up to HAA to generate local interest in attending the conference and promote networking among haematology nurses. There is also a HAA organising committee who are working on the content of the nursing stream at HAA. If you have an interest in contributing to either of these committees we would love to hear from you. Please contact Allan Hayward at allan.hayward@health.sa.gov.au or Bev Quested at bquested@redcrossblood.org.au for more information.

## New South Wales

**David Collins**

NSW has got the year of to a good start with our first meeting held in Sydney in February. The evening had 35 nurses attending to hear A/Prof Ian Kerridge update the group on autologous transplants and Myeloma. We also had a nursing presentation from Trish Morris the NUM of the Haematology day unit at St George Hospital who presented changes occurring within the unit there. Our next meeting will be on April 16 at Gosford. The next Sydney meeting will be on June 11, venue to be announced.
Please contact David Collins for NSW matters. David.collins@health.nsw.gov.au



# Conference Calendar

| Date | Conference | Details |
|---|---|---|
| **April 2015** | | |
| **23 – 26 April** | **Oncology Nursing Society Annual Conference** | Orlando, Florida. Registration opens 05.12.14<br>http://congress.ons.org/ |
| **May 2015** | | |
| **6 – 9 May** | **ALLG Meeting** | Melbourne, Australia<br>http://www.allg.org.au/events.html |
| **13 – 16 May** | **10th International Society for Apheresis Congress** | Cancun, Mexico, Registration open<br>http://www.isfacongress.com/ |
| **24 – 27 May** | **13th National Rural Heath Conference** | Darwin, Australia<br>Registration open, closes 24.05.15<br>http://www.ruralhealth.org.au/13nrhc/about |
| **29 May – 2 June** | **American Society of Clinical Society** | Chicago, Illinois – USA<br>Registration open<br>http://am.asco.org/ |
| **June 2015** | | |
| **14 – 16 June** | **CNSA 18th Winter Congress** | Perth, Australia<br>Abstract submission: open, closes 06.02.15<br>Registration opens January 2015<br>http://www.cnsawintercongress.com.au/ |
| **18 – 20 June** | **Australia and New Zealand Children's Haematology / Oncology Group** | Fremantle, Western Australia<br>Abstract deadline: 14.04.15<br>Registration open<br>Earlybird deadline: 14.04.15<br>Standard deadline: 18.05.15<br>http://www.anzchogmeeting.org/ |
| **July 2015** | | |
| **8 – 11 July** | **International Society of Nurses Conference** | Vancouver, Canada<br>Abstract submission: closes 26.01.15<br>Registration open<br>www.isncc.org |
| **September 2015** | | |
| **23 – 26 September** | **International Myeloma Workshop** | Rome, Italy<br>Abstract submission open, deadline: 31.05.15<br>Registration open<br>http://www.imw2015.it/ |

| Date | Conference | Details |
|---|---|---|
| October 2015 | | |
| **18 – 21 October** | **HAA** | Adelaide, South Australia<br>Abstract and Registration not open – sign up for email updates via website for abstract and registration opening dates<br>www.haa2015.com |
| **November 2015** | | |
| **5 – 7 November** | 2nd Congress on Controversies in Thrombosis and Hemostasis | Barcelona, Spain<br>Registration available shortly, early bird closes 04.08.15<br>http://www.congressmed.com/cith/ |
| **10 – 13 November** | ALLG Meeting | Melbourne, Australia<br>http://www.allg.org.au/events.html |
| December 2015 | | |
| **5 – 8 December** | American Society of Hematology | Orlando, Florida – USA<br>Abstract submission opens: 04.06.15<br>Advance registration opens: 12.08.15<br>http://www.hematology.org/Annual-Meeting/ |

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