



# Nursing

AML National Paediatric Sickle-Cell Blood Platelets Myeloma Metropolitan Lymphoma Myelosuppression South-Australia Thrombophytic Thalassaemia MDS CLL Regional Queensland Neutrophil Research Western-Australia Haemoglobinopathies Leukaemia Packed-Cells Haematology

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

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## HSANZ MELBOURNE UPDATE

**Sam Soggee**  
Vice President HSANZ NG

**With just 3 months until HAA 2016 kicks off – the nurses program is now complete!**

As mentioned in the last edition, we have secured a fantastic international speaker in Sandra Kurtin. Sandy is a Nurse Practitioner, Clinical Assistant Professor of Medicine and Adjunct Clinical Assistant Professor of Nursing at The University of Arizona Cancer Centre in Tucson, AZ. She has 30 years of oncology nursing experience, 25 of those in advanced practice, 20 as a Nurse Practitioner in oncology. She maintains a busy clinical practice in an NCI-designated Comprehensive Cancer Center with expertise in haematological malignancies, GI malignancies, clinical trials, symptom management, and caregiver support. She is currently enrolled in the PhD program at the University of Arizona. Her research will focus on caregivers of cancer survivors evaluating the impact of a multimedia eHealth intervention in reducing caregiver and cancer survivor symptom burden (in particular fatigue), improving patient and caregiver self-efficacy and quality of life.

In addition to Sandy's expertise there is a plethora of topics that will be covered this year. The Victorian group have been hard at work developing a program which includes, but is not limited to, Symptom Management, Survivorship, 'Bugs and Drugs', the caregivers perspective, an AYA and an apheresis focused session as well as an interesting case study discussion of a Jehovah witness patient having an allograft for MDS.



There will also be a myeloma masterclass hosted by Sandy Kurtin and the Myeloma SPN. This year the concurrent 'How to Sessions' will cover understanding cytogenetics, understanding myeloproliferative neoplasms and nursing research 101.

Abstract submissions are now in and the successful grants will be announced in due course. For the successful abstract applicants - don't forget about the available grants in your state to assist you in getting to HAA.

Lastly, remember the Gala Dinner is an event not to miss so remember to purchase your tickets. It is a great way to enjoy an evening with colleagues, meet new people and network".

I hope you will be as thrilled as we are with the diversity and broad scope of interesting presenters and topics that will be covered at this years meeting!

## COLLABORATION WITH EBMT NURSES GROUP

David Collins

President HSANZ NG

Last year HSANZ NG entered a memorandum of understanding with the EBMT Nurses Group. The memorandum is there to foster growth between the two groups and allow the exchange of ideas, and where possible become involved in each other's research projects. The memorandum is a great opportunity for us to become involved with our colleagues across the world, sharing information. I was invited as a guest of EBMT to attend their annual meeting to cement our collaboration further.

This year the conference was in the beautiful town of Valencia, Spain. I had two presentations to make, one was on the HSANZ NG and how we developed and operate, the other was on telehealth in Australia. The second presentation was a bit of a challenge for me, however, with the magic of being an HSANZ member I was able to tap into colleagues and find out what was going on throughout Australia. I must mention the haematology team at Townsville who supplied me with a lot of information about the model of care they use and the benefits to patients. As well as some of the hurdles that have to be jumped over.

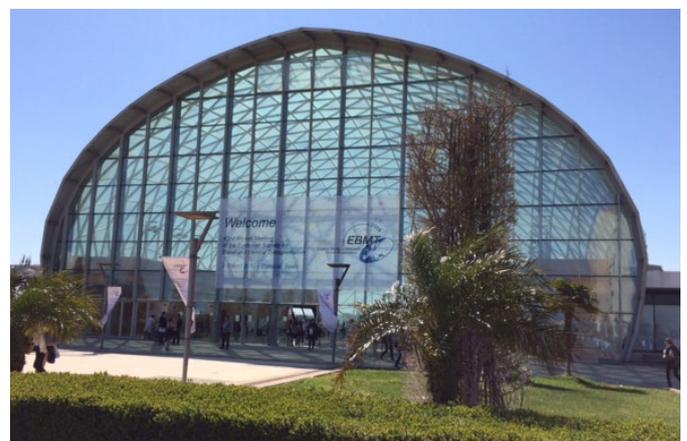
The EBMT Nurses Group is spread across the whole of Europe. However, the land mass fits nicely into Australia, and travelling across Australia can take longer than travelling across Europe, and for some of our European colleagues, this is a hard concept to understand.

It was also good to see a number of Australians at the conference. Not only medical staff but nurses as well. As you will be aware we did offer a grant this year to members, and I hope that we will be able to award a

grant again next year. Three of our nurse members who attended also presented, posters and oral presentations, so well done to Elise Button, Katrina Wycek, and Gemma Dyer.

Of course, EBMT is very much focused on BMT, so it was interesting to see how our practices stand up against those of our European colleagues, and for me especially in the area of stem cell collection, in particular the area of Plerixafor use was especially interesting. There were a number of studies presented that looked at using Plerixafor upfront as opposed to the way we use it as a rescue in stem cell harvest. Unfortunately, I think that currently, the cost would be the barrier for us here.

If you have a project that you think may benefit by being involved with the EBMT Nurses Group, please contact me on [nurses@hsanz.org.au](mailto:nurses@hsanz.org.au) and I will send you the appropriate contact.





## A WORD FROM THE PRESIDENT



As I sit and write this note to you HSANZ membership fees are due. Paying my fees caused me to reflect upon my history with HSANZ. I attended HAA for the first time back in 2003 in Melbourne. Back then we did not have a formal nurses group; we had one day of the conference for nurses, and very few nurse members. I have been lucky to attend many HAA conferences over the years and believe I have only missed four. So what has HSANZ given me over the years? Number one on the list has to be haematology friends. There are a large number of people that I have met over the years at the conference or through local group meetings, and with that comes contacts. When you make these contacts, you will always find someone who can answer any questions you have.

Over the years the knowledge I have gained is immense. This has been done by attendance at HAA, local meetings, reading the newsletter, and just by talking to HSANZ friends. I would like to recommend to you the Special Practice Networks. The Myeloma SPN is now well established and doing some great work. The MDS/MPD SPN is working to establish itself, and I am sure will develop as the year goes on. There are also two other groups looking at developing into SPN's, these are Apheresis and Long Term Follow up. All of these groups will be holding meetings at HAA and calling for HSANZ NG members to become involved. So if you have an interest in any of these areas please think about joining a group. If you are not going to HAA but would still like to be involved, please email me and I will pass your details onto the SPN chair.

If you are reading this and you are not a member, then think about joining us. If you are a member, then consider becoming involved with your local committee. This way you will have a say in what your group does and how it does it.

As we come closer to HAA in November within the lively city of Melbourne, I look forward to seeing you there. From what I have seen and heard of the preparations it is going to be a great conference. We will be holding the Nurses Annual General Meeting at HAA, and if you cannot attend this year, then please take the time to read the minutes of last years AGM when they are sent to you. If there are points you would like to raise or questions you have please send them to me at [nurses@hsanz.org.au](mailto:nurses@hsanz.org.au), and I will endeavour to answer them for you. There will be one or two items that will require your vote; proxy forms will be sent out with the minutes so that you can vote in absence.

I hope you enjoy this edition of the newsletter; Please feel free to send any contributions to us. Remember it's your newsletter and it would be good for us to hear from you.

**David Collins**

President HSANZ NG

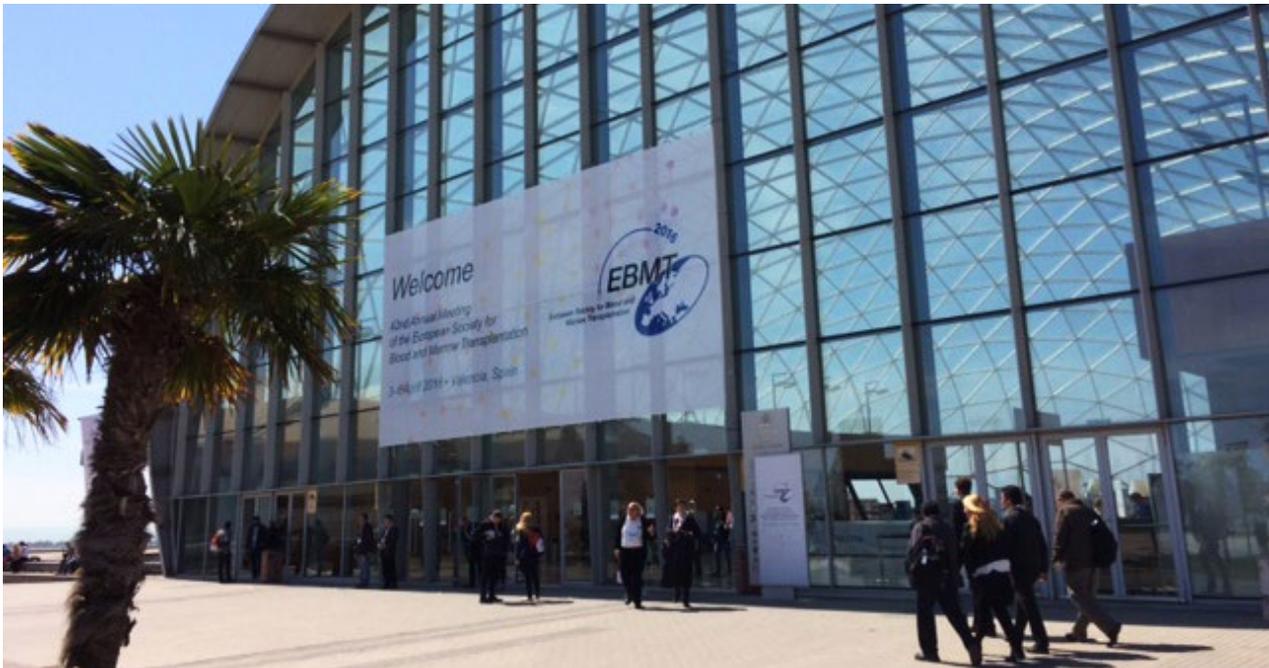
[david.collins@health.nsw.gov.au](mailto:david.collins@health.nsw.gov.au)



## HSANZ NURSES GROUP EBMT TRAVEL GRANT REPORT

Elise Button

Royal Brisbane & Women's Hospital



I was the recipient of the 2016 EBMT / HSANZ Nurses Group Travel Grant. With this funding I attended the European Society for Blood and Marrow Transplantation Annual Scientific Meeting in Valencia, Spain from the 3rd – 6th April 2016.

### Location

Valencia is a beautiful city on the shores of the Mediterranean Sea and is the second largest city in Spain. The city is unique in its mix of modern yet historic sites and activities. The city centre is fun and vibrant with many places to eat, drink and relax. The conference centre, in which EBMT 2016 was held is called Feria Valencia, and approximately 15 minutes from the city centre by car. The train ride and short walk to the conference centre that I took, allowed me the opportunity to see beautiful traditional Spanish houses in the surrounding neighborhood. The conference centre itself is sleek, modern and sophisticated. The outer roof is made of glass and the rest of the facility is underground.

### Attendees

EBMT 2016 was the 32nd meeting of the EBMT Nurses Group and was truly an international event, with delegates and presentations from Europe, America, Asia, Australia and the Middle East. The bulk of nursing delegates came from European countries and included researchers and clinicians. The main conference is

attended by approximately 5,000 delegates however, the nursing stream was somewhat smaller.

### The conference program

The conference program was interesting and varied and covered the following topics (to name a few):

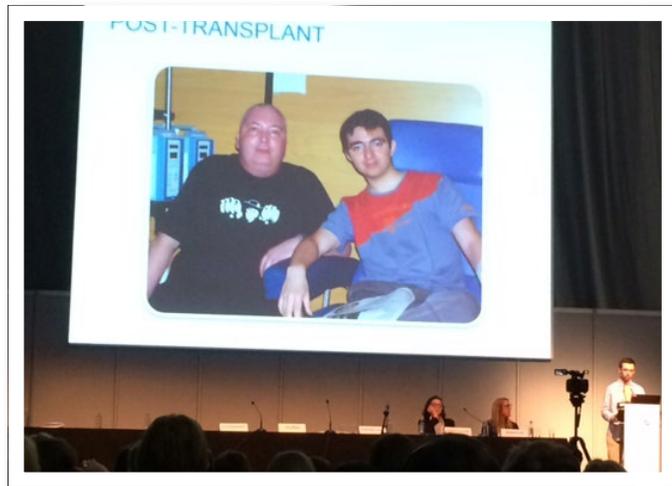
- 1.) Survivorship care;
- 2.) Fertility preservation;
- 3.) Palliative care;
- 4.) Mucositis management; and
- 5.) Advance Practice Nurses.

The presentation on fertility preservation was quite thought-provoking. There is fantastic work happening in the UK that enables young patients to parent children post-transplant. It has motivated me to look into this issue more at my hospital as it is often overlooked. The presentations on mucositis management were of a high quality and included clinically relevant information for all transplant centres. I have made contact with one of presenters who has recently visited Australia on a lecture tour and participated in the mucositis workshop at the MASCC Annual Meeting in Supportive Care from the 23-25th June in Adelaide. This expert is kindly sharing his knowledge on how to improve mucositis management at my hospital which is much appreciated.



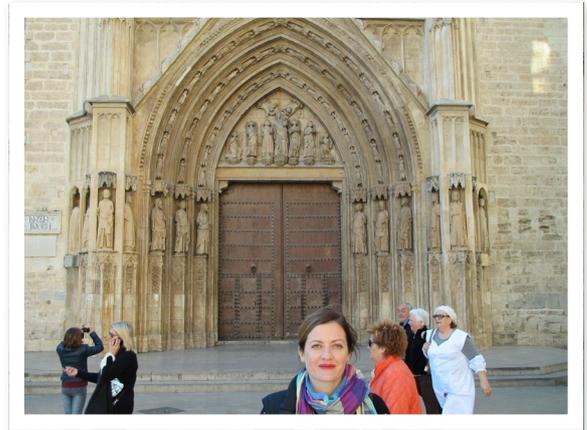
Another highlight of the conference was a joint presentation by a medical specialist and an Advance Practice Nurse from the UK talking about the evolution of palliative care. They explained the important role of palliative care teams in supporting haematology patients throughout the illness trajectory, particularly in regards to symptom management. The speakers re-iterated that palliative care teams are experts at treating symptoms throughout the transplant journey and don't just help people when they are nearing the end of life anymore. For this reason, many palliative care teams in the UK and USA are changing their name to the 'Supportive Care Team', as they help support the patient throughout their entire treatment journey and want to be called on earlier to help people with difficult symptoms. This concept is slowly taking off in Australia but we have a long way to go.

One of the most inspiring presentations was delivered by a nurse-scientist-researcher from the Netherlands who spoke on the evolving role of the transplant nurse. He reminded us that as nurses we often find inadequacies in the health care system and we have a responsibility to our patients to generate evidence to address these issues.

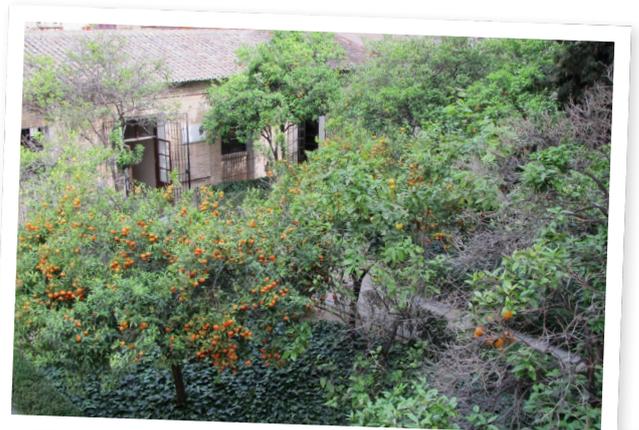


I very much enjoyed listening to excellent speakers talk on such important topics. It was a great opportunity for me to increase my awareness of current work in other countries and health care systems. By being exposed to internationally leading research in the field, I now know that these issues are hot topics. I can now make sure that I incorporate these ideas into my own research to make it more internationally relevant. I took many notes through the different talks and have been referring to them since I came back, to remind myself of what others are doing and how I can learn from them.

### My participation



I gave an oral presentation at the conference titled: Hope for the best, yet prepare for the worst: A systematic review of Advance Care Planning Prior to stem cell transplantation. After my presentation, several members of the audience asked questions regarding the review and the topic in general. I found this interaction incredibly useful and it has given me some ideas of new directions I can take my work in the future. I was really pleased with the encouraging and helpful feedback that I received after the presentation from fellow PhD students or recently graduated researchers. It was rewarding to be able to contribute to the meeting and I felt a real sense of achievement at being able to present at an international conference.





### Connecting with EBMT Nurses

The delegates and speakers at EBMT 2016 were all very approachable and friendly. The conference provided a wonderful opportunity to network with nursing clinicians and researchers. Everyone was very friendly and willing to establish future links and contacts and share any advice they could offer. I truly admire the presenters who speak in a second language to their own, which must be such a daunting task. Their participation in the congress truly demonstrates their dedication to sharing knowledge and improving care for people with a haematological cancer.



I would sincerely like to thank the HSANZ Nurses Group for supporting me to attend this conference. I would also like to acknowledge the support provided by the Adem Crosby / Leukaemia Foundation of Queensland Nursing Award, to attend this conference. Attending an international conference is an expensive venture, one which I value greatly for my professional development. Without generous financial support it would not have been possible for me to attend.

## PRESENTING YOUR ABSTRACT AT HAA

**Rosemary Hoyt**

Dunedin Hospital, New Zealand



So your abstract has been accepted for an oral presentation at HAA 2016. How exciting to have the opportunity to share your research, practice innovation or experiences with a wide audience of haematology health professionals.

If you are seasoned conference goer and have presented many times before then you will have your own process for developing a presentation and preparing for your moment on the podium. For those of you new to this activity some advice is included in this article.

It is your moment to shine and share new knowledge with the audience. Most people use PowerPoint slides to convey their research and to accompany their oral

narrative. These first two points might assist with helping you start this process.

### 1. Prepare a logical series for your presentation

- Introduction/Background
- Objective
- Methods
- Intervention/Activity
- Results
- Conclusion.



Remember people mainly want to hear about your activity and the results. This is why we usually go to conferences to learn about what others are doing, what is new/ interesting and what we might be able to do to improve patient care. You do not have time to include a

‘Cochrane like’ review of the literature before explaining why you started your research. Save this for your thesis.

If you want to say more you can always submit a report to the HSANZ nurses newsletter.

## 2. If you are using PowerPoint please be kind to your audience

- Consider visibility- can people actually read your slides- check your font sizing
- Consider bullet-points- then talk around these
- Try and not read verbatim what is on your slides. This is hard especially if you are nervous but practising on your own or in front of friends/colleagues will help you to perfect this style
- Consider using multi-media to ‘spice’ up your slides. Photos, You-Tube clips, cartoons, music may all be appropriate media to employ depending upon your topic. It should complement your message not overtake it.
- Try and avoid ‘the busy slide’, too much information packed into one slide that no one can read
- Label graphs, illustrations and data tables clearly so people can understand what you are showing them
- Most of the time people can read faster than you can talk so if you wish to quote patient accounts or others reflections and have these on your slides you do not always need to read it out as well.

## 3. Keep to time

DO NOT go over your allotted time, as this is extremely frustrating to your audience and for those chairing your session. Plan according to how long you have been told you are to talk for and stick to this time.

## 4. Time for questions

Sometimes a discussion following a presentation is the best part as people can complement you on your research, offer advice, ask questions (which show they have listened to what you have said!) and it can be very stimulating, creating new knowledge. Try and leave time for questions, do not be afraid of them, again practising in front of colleagues may help you gain confidence before hand.

## 5. Presentation styles

- Dress the part- tidy, suit/dress, hair brushed
- Work out where you are going to be, what notes if any you will take with you and if time, stand behind the podium for a quick practice
- If you tend to fidget, shake or stammer when nervous, consider ways to keep this under control- no not drugs! Hold a pen, have a glass of water near-by.
- Look up and out at your audience- remember you are NOT reading verbatim from your slides so you do need to look at the audience
- Try and not become distracted if you see an audience member nodding off, playing on their computer or a phone goes off.
- Breathe and remember this is your hard work that you are sharing with people so be proud of it.

*Good luck*



“You’re not allowed to use the sprinkler system to keep your audience awake”



## CORRESPONDENTS REPORT FROM WOCOVA 2016

Peter Haywood

The Royal Melbourne Hospital

I recently attended the World Congress of Vascular Access (WoCoVA) in Lisbon, Portugal. Made up of a mixture of medical and nursing attendees - it was basically 3 days of central line nerds talking to each other. About half of the conference seemed to be dedicated to 'inserters', though there were plenty of presentations relevant to haematology nurses. Indeed, haematology nurses have a lot to offer other specialities when it comes to managing lines over a long period of time.

Three presentations were particularly relevant. Firstly, one addressed the minefield of which needleless connector to use to minimise infections (Poster 12). There is a real lack of evidence driving the decisions and we are often left weighing up the claims of the manufacturers. A haem/onc ward in Birmingham, UK, conducted a RCT comparing two popular brands (one 'positive pressure' and one 'neutral pressure') on their haematology/BMT unit. 'Positive pressure' style needleless connectors have been given a bad name over the last 10 years or so, but interestingly they found the neutral connector had statistically significantly more internal contamination when they took used connectors to the lab and looked inside. Although, there was no difference in line infection rates.

Some Belgian haematology nurses have developed a simple standardised system of measuring line occlusion (Presentation I-39). Occlusions are an incredibly frustrating complication, particularly



for nurses, but rarely studied as they are often considered less important than infection or thrombosis. The studies that do exist all tend to use different definitions of occlusions, making consensus conclusions difficult to make. In short, a lumen of a central line can be flushed 'easily' or 'not at all' - these are uncontroversial and can consistently be applied. Anything line that can be flushed, but not 'easily' is the intermediate category. Then, the same 3-option scoring system is used for yielding a lumen.

Thirdly, several speakers talked of the necessity of removing cuffed, tunneled catheters (what I would call a Hickman) in a controlled surgical environment using local anaesthetic and a cut-down technique. In the institution I work in, Hickman catheters are removed at the bedside by nurses with no anaesthetic. There's a real lack of data, even observational data, of which method should be preferred and it has us thinking of collecting some data. I am interested in what other institutions do, and how they justify their practice.

All abstracts are published in the Journal of Vascular Access (available free <http://www.vascular-access.info/pub/wocova>). There is an Australian Vascular Access Society that holds an annual scientific meeting. Next year it is in Perth (<http://avas.org.au/>) I'd encourage any nurses interested in the management of central lines to attend, or even put together an abstract! The next WoCoVA is in Copenhagen in 2018.



## AN ALLOGRAFT IS 4 LIFE ....

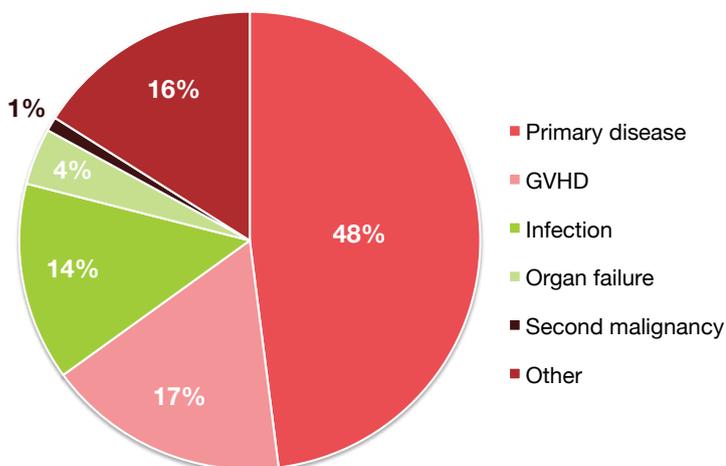
Yvonne Panek-Hudson RN MN

Nurse Practitioner

Allograft and long term follow up service, Peter MacCallum Cancer Centre & Royal Melbourne Hospital, Victorian Comprehensive Cancer Centre.

With a decrease in early and late transplant related morbidity and mortality and consequent increase in survival, it is not surprising that dedicated multi-disciplinary follow up is a routine part of post-allogeneic transplant care. Despite this allogeneic transplantation is complex and poses many clinical dilemmas for health care providers. For patients and carers the process of treatment and recovery can take years, beginning with a lengthy inpatient hospital admission and frequent outpatient follow up in the period from discharge to day 100. This period is widely acknowledged as having the greatest risk post transplant. Primary causes of early post-transplant morbidity and mortality include relapse of primary disease, graft versus host disease, infection and organ failure.

### CAUSES OF DEATH AFTER HLA MATCH SIBLING TRANSPLANTS DONE IN 2012-2013



PASQUINI MC, ZHU X. CURRENT USES AND OUTCOMES OF HEMATOPOIETIC STEM CELL TRANSPLANTATION

Early post-transplant management and monitoring is dynamic and focused on preventing these potential issues however also includes monitoring and management of psycho-social and sexual health issues as well as coaching around nutrition, physical activity and return to work and study.

Although this paper will not cover late effects monitoring of allogeneic stem cell transplants, we are gratefully obliged to provide this service to all allograft patients who are two or more years post transplant. This is essential given risk of premature health issues, and in order to optimise physical and emotional functionality,

employment and study opportunities and meaningful contribution to relationships, vocation and community.

The early post transplant setting provides an ideal environment for haematology nurses to be actively involved in advanced clinical assessment, symptom management and high quality education. There are numerous opportunities for development of advanced practice roles and nurse-led care for appropriate patients in the post transplant setting. Allograft patients are well-served with a collaborative, multi-disciplinary approach with strong nursing involvement throughout all stages.

Allograft patients attending for outpatient review require thorough assessment of fluid intake and nutritional status, as well as respiratory, cardiac and abdominal assessment; looking for positive signs of infection, organ dysfunction and enlargement, disease relapse, medication toxicity and GvHD. Vital signs including oxygen saturation and respiratory rate are essential as well as direct questions to identify respiratory issues, appetite, nausea, bowel activity and urinary symptoms. Pain may be associated with healing oral mucosa, abdominal cramping related to GvHD and primary disease eg: multiple myeloma related bone pain; so assessment should form part of every outpatient review.

Having outlined all these rudimentary assessments, I always begin my consultation when greeting the patient in the waiting room. You can learn a great deal about a patient's respiratory, cardiac, general physical and emotional wellbeing during the 10-20 metre walk into the consultation room.

Begin your consultation with a series of open ended questions that address general feeling of wellbeing; measurement of energy levels; assessment of physical activity; assessment of sleep; identification of stressors and causes; relationship concerns and identification of depression and anxiety that may require further specialist referral. Invite your patient to discuss their sexual health queries, and provide advice related to sexual activity if appropriate. This may include conversations around vaginal dryness and discomfort due to hormone deficiency or GvHD, erectile dysfunction due to androgen deficiency, decreased libido and arousability, and the effect of emotional distress on sexual health.

Although patient's have received substantial amounts of education by this stage it's imperative to provide ongoing information relevant to point in time post transplant and



specific issues they are experiencing. Take a thorough medication history and be prudent about identifying potential drug – drug and drug - food interactions which are of high relevance to immunosuppressants and anti-infective drug absorption and efficacy, as well as potential toxicities. Assess for medication side effects such as headache, tremor, neuropathy, renal impairment and hypertension with cyclosporine; and insomnia, mood affect, glucose intolerance, proximal weakness and cushingoid symptoms with cortico steroids.

**Acute graft vs host disease (aGvHD)** is a reaction of donor t-cells against host and can affect organs either in isolation or multiply including the skin, gastro intestinal tract and liver. Risk is related to degree of HLA parity, donor source, cell source and donor sex. Severity depends on amount of damage to affected organs and is related to inflammatory cytokines and direct t-cell toxicity (Ferraro et.al 2009). Diagnosis is made based on clinical symptoms eg: maculo papular rash, raised liver function tests, acute abdominal pain and voluminous diarrhoea +/-nausea and vomiting. Tissue sampling via skin biopsy and colonoscopic biopsy can be helpful for diagnostic confirmation and exclusion of other contributing factors such as infection.

Assessment should include examination of skin for isolated or florid signs of maculo papular rash, erythema, excoriation and ulceration. This should include the oral mucosa and in women question the presence of genital tract symptoms and in men presence of cutaneous penile symptoms.

Examine current and recent blood results looking for patterns of elevated liver function tests, renal impairment, as well as reductions in full blood count and hypoalbuminaemia. A thorough abdominal examination should be completed looking for positive signs including hepato/splenomegaly, abdominal pain, distension and ileus. Presence and location of pain is important as well as bowel activity including volume and description of faeces. Upper gastro intestinal GvHD can manifest as nausea, vomiting, gastro-oesophageal pain and dyspepsia although these symptoms can sometimes be hard to differentiate from healing digestive mucosa, medication toxicity and pre existing gastro oesophageal reflux disease.

Treatment for acute GvHD includes systemic immunosuppression such as cyclosporin, tacrolimus and mycophenolate mofetil (just to name a few); moderate to high dose cortico steroids and topical therapy as adjuvant treatment and for symptom management. Steroid refractory acute GvHD may require treatment with anti thymocyte globulin or a TNF inhibitor.

**Common infections** in the first 3 months are usually of a bacterial, viral and fungal nature. Thorough examination looking for signs of infection is imperative and most patients present with a febrile illness and associated

symptomology. Ensuring patients are taking their anti infective therapy appropriately and providing detailed education about indication, dosage and frequency as well as assessment for toxicity will contribute to efficacy. Viral reactivation involving the herpes group of viruses; CMV, HSV and HZV is a risk in the allograft patient and managed with a combination of prophylaxis and viral monitoring using PCR, as well as treatment dose anti viral therapy if indicated.

**Monitoring of disease response and engraftment** is a focus for patients and health providers particularly in the first 100 days after transplant. Monitoring is specific to disease but always includes thorough physical examination looking for lymphadenopathy, bruising/ petechiae, organomegaly and monitoring of blood counts to establish a pattern of improvement and presence of aberrancies. Bone marrow biopsy is important for monitoring of bone marrow disorders such as acute leukaemia and multiple myeloma, but is also useful in other diseases to measure engraftment, chimerism and marrow cellularity. Imaging and nuclear medicine investigations are usually completed in this time frame for patients with lymphoma. This can be a considerable period of anxiety for patients and family waiting for investigations and results. Haematology nurses are well placed to provide thorough education about utilisation of diagnostic and monitoring investigation and interpretation of results alongside medical colleagues.

**Preparing for transplant recovery** and long term health begins from admission. A multi disciplinary approach to nutrition and exercise education and coaching is important in assisting to implement long term health behaviours to aid recovery and contribute to reducing known long term premature health burdens associated with high dose chemo and radiotherapy and transplantation.

Access to outpatient physiotherapy and exercise physiology is variable between hospitals but there are many community based services available and referral is best facilitated by patient primary care providers (PCP) who can coordinate a chronic disease management plan.

Regular communication with patients PCPs and a detailed discharge letter with transplant centre staff contact details is a priority to foster a collaborative care arrangement for allograft patients, and to support primary care and community health providers in caring for this complex population of patients.

Finally although most centres encourage patients to take a reasonable period away from paid employment and study, being in paid or unpaid work is a common goal for patients and for many a symbol of recovery (Winterling et.al. 2014). Regular goal setting regarding gradual return



to work and study plans are an important part of post transplant assessment and management. Ensuring employers are informed and supportive in return to work plans should be considered.

This is frequently a time of redefinition and reflection for allograft patients and their families and support and resources should be provided for patients wanting to change direction in order to optimise physical and emotional quality of life.

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## EXPRESSIONS OF INTEREST

### Special Practice Network (SPN) in Long Term Follow Up (LTFU) & Survivorship Post Blood & Marrow Transplant (BMT)

Megan Hogg

Westmead Hospital, Sydney

The first meeting for this new LTFU & survivorship SPN will be held during HAA on Monday 14th of November from 12–1pm in room (to be advised). If you have an interest in this specialty and commitment to a national approach to LTFU & survivorship care, education and guidelines please come along.

Steering committee members include:

#### 1. Yvonne Panek-Hudson

([yvonne.panek-hudson@petermac.org](mailto:yvonne.panek-hudson@petermac.org)):

Nurse Practitioner in the Haematology Service, Peter MacCallum Cancer Centre, Melbourne.

Yvonne specialises in the long term follow up of patients post-allogeneic bone marrow transplant. She has a particular interest in late effects surveillance and management, chronic graft versus host disease and sexual health.

#### 2. Priscilla Gates ([Priscilla.Gates@austin.org.au](mailto:Priscilla.Gates@austin.org.au)):

Advanced Practice Nurse and Blood & Marrow Transplant Nurse Consultant at the Olivia Newton-John Cancer Wellness Centre at Austin Health, Victoria.

Priscilla has many years' experience in haematology nursing and survivorship care and currently leads a survivorship clinic for patients post BMT'

#### 3. Louisa Brown ([Louisa.brown@calvarymater.org.au](mailto:Louisa.brown@calvarymater.org.au)):

Clinical Nurse Consultant for Allogeneic Blood & Marrow transplant at the Calvary Mater, Newcastle.

Louisa has 23 years' experience in the care of oncology and haematology outpatients. Her role focuses on the care of patients in preparation and follow-up after allogeneic bone marrow transplant. Louisa's interests are in the area of Late Effects and she is currently in the process of establishing nurse-led late effects follow up model of care.

#### 4. Megan Hogg ([megan.hogg@health.nsw.gov.au](mailto:megan.hogg@health.nsw.gov.au)):

Clinical Nurse Specialist for Long Term Follow Up of Blood & Marrow Transplant at Westmead Hospital, Sydney.

Megan has facilitated the development of a formalised multi-disciplinary team approach to Long Term Follow Up (LTFU), including the opening of NSW's first Late Effects Clinic catering for survivors two or more years post BMT. Her aim together with the transplant team is to prevent, manage & treat long term health issues that can affect the overall quality of life of patients post-transplant.





## HIGH DOSE VITAMIN C INFUSIONS FOR CANCER – ARE THEY SAFE?

Jocelyn Livesey

Medicines Information Pharmacist

Dunedin Hospital

Many patients with cancer wish to use complementary medicines during or after chemotherapy. In a response to a recent request by a patient wishing to combine high dose vitamin C infusions together with chemotherapy an exploration of the literature was conducted. Before any such treatment can be included several questions need to be considered:

- Are there any adverse effects of the treatment including additive effects with chemotherapy? e.g. effects on blood cells (especially platelets, neutrophils), GI effects, hormonal effects.
- Could the mechanism of action of the complementary medicine counteract the mechanism of action of the chemotherapy? e.g.
  - Antioxidants may counteract the effect of chemotherapy that relies on reactive oxidative species for its action.<sup>1</sup>
  - Immunomodulating agents could theoretically decrease the immunosuppressant effect of chemotherapy.
- Have any clinical trials shown a benefit for the complementary medicine?

In most cases, few controlled studies have been carried out to demonstrate the efficacy and safety of the medicine. In the case of vitamin C there are a growing number of in vitro, animal and human studies but many are small and without controls. The US National Cancer Institute have published a very comprehensive review of the evidence for the efficacy and safety of high dose vitamin C as well as a simpler version for patients. (2) They have similar information on their website for a variety of other complementary treatments.

Following is a very brief summary of the findings reported in this review, for a full understanding it is recommended that you read the full review:

### Adverse effects

Few adverse effects have been reported in healthy patients or those with cancer who have received high dose vitamin C infusion.

### Mechanism

As there may be several mechanisms for the effect of high dose vitamin C on cancers it is difficult to predict if it might counteract the effects of standard chemotherapy.

### Studies

The majority of studies done have been laboratory studies carried out on cancer cell lines or in animals with cancers. A number of these have shown that vitamin C can slow the growth of a range of different cancer cells under these conditions and when used in conjunction with chemotherapy, may improve the efficacy of the chemotherapy. However, this has not been demonstrated in all cancers or with all chemotherapy and a few studies have shown a worse outcome.

Some small human studies have been carried out with high dose vitamin C that have shown benefit in improving quality of life and decreasing the side effects of chemotherapy. A few small studies have used high dose vitamin C with chemotherapy in patients with pancreatic cancer. Their disease remained stable after treatment but there were no control groups in these studies. However, there are reports of deterioration in some other patients with AML, metastatic colorectal cancer and metastatic melanoma when treated with high dose vitamin C.

### Conclusion

If faced with a patient wishing to receive high dose vitamin C infusions, it would be beneficial to read the review, provide the patient with the appropriate information and discuss this with them, including such factors such as:

- The very limited evidence of significant benefit in humans (no controlled trials)
- Benefits reported with a few cancer types and chemotherapy regimens cannot necessarily be assumed to occur with all cancer types and treatments
- There have been studies with some cancers and chemotherapy that have shown worse outcomes when high dose vitamin C was used.

### References

1. Heaney M et al. Vitamin C antagonizes the cytotoxic effects of antineoplastic drugs *Cancer Res.* 2008 October 1; 68(19). Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3695824/pdf/nihms64385.pdf> (Accessed 26/5/16)
2. PDQ® Integrative, Alternative, and Complementary Therapies Editorial Board. PDQ High-Dose Vitamin C. Bethesda, MD: National Cancer Institute. Updated 11/4/16 Available at: <http://www.cancer.gov/about-cancer/treatment/cam/hp/vitamin-c-pdq>. (Accessed 26/5/16)



## THE APHERESIS PAGE

David Collins

President HSANZ NG

### *Is it me or is there an increase in the number of TTP cases around?*

Talking to colleagues in Sydney there appears to be a number of them, and it seems that this batch seems to be severe. Some the patients have progressed to twice daily plasma exchanges to give the patient the best chance of survival and control the disease.

### *So this has me thinking, is TTP a seasonal illness?*

Proceed to Dr Google, I am not the first person to be thinking about this, and there have been a number of studies to look at a seasonal effect. However, they tend to suggest that TTP is more likely to occur in the warmer months. But the studies that I looked at did suggest that this could only relate to the USA where the studies were done and that there may be a different disease trigger in other areas of the world.

### *So is there an increase or have we just had some sicker patients around?*

For further reading check out:  
Blombery P, Kivivali L, Pepperell D,  
et al. Diagnosis and management of  
thrombotic thrombocytopenic purpura  
(TTP) in Australia: findings from the  
first 5 years of the Australian TTP/  
thrombotic microangiopathy registry.  
Intern Med J. 2016, 46(1):71-9.

### *A question to you all, did anyone go to ASFA this year?*

If so we would love to hear a report from you. The American Society for Apheresis holds an annual conference, usually at the beginning of May each year. This conference is attended by nurses, doctors, scientists and technicians, all involved in different types of apheresis and is a good chance to get up close and personal with some of the well-known apheresis specialists.



Some you have indicated that you would be interested in forming a Special Practice Network (SPN Apheresis), therefore, we shall be holding a meeting at HAA this year to get the group off the ground. If you are interested and are going to HAA, come to our lunchtime meeting. If you are not coming but are still interested, please make sure we have your details so we can keep you up to date on the group.

Once again if you have a question you would like to pose on the apheresis page or something you would like to share, then please contact us on [nurses@hsanz.org](mailto:nurses@hsanz.org) or send them to the editor.





## HSANZ WESTERN AUSTRALIA APHERESIS FOCUS GROUP

**Andrew Steele**

CNS Haematology, Sir Charles Gairdner Hospital

On June 29th the WA branch of HSANZ held its inaugural Apheresis Focus group for 2016. The meeting was sponsored by Sanofi and was held at Acqua Viva in Perth.

The aim of the group is to align practices and share knowledge within the field of apheresis and stem cell collection.

Twenty apheresis nurses from the 3 major hospitals in WA met to discuss various issues encompassing the field and enjoyed presentations from each unit on specific areas of interest. The presentations encouraged lively discussions



and debates around our current practices and highlighted areas that can be developed to improve practice. The nurses were also joined by medical staff and scientists to facilitate a multi-disciplinary discussion and this was a great success.

The group's aim is to meet bi-annually thereby continuing the collaborative approach that was initiated at the meeting. It will examine variations in practice and aims to standardise best treatment options.

Email: [Andrew.Steele@health.wa.gov.au](mailto:Andrew.Steele@health.wa.gov.au).



## SPECIAL PRACTICE NETWORKS

### MDS/MPN

**Sam Soggee**

Myelodysplastic Syndrome (MDS) and Myeloproliferative Neoplasms (MPN) are groups of rare chronic blood cancers. There are around 1400 people newly diagnosed with MDS and 950 people newly diagnosed with an MPN in Australia each year. MPN is an overarching term for seven different disease subtypes – the most commonly known are chronic myeloid leukaemia (CML) and myelofibrosis (MF).

The interest in this group continues to grow with a meeting planned during HAA 2016. If you wish to be involved or have questions about the network please contact: [sam.soggee@austin.org.au](mailto:sam.soggee@austin.org.au).

### Lymphoma

**Karen Matoga**

Expressions of Interest are being sought from nurse members who are interested in forming a steering group to establish a Lymphoma SPN.

Potential areas for development could include:

- Establishing educational guidelines and resources for nurses providing education and support to new diagnosed Lymphoma patients
- Collaboration opportunities for research activities
- Formulating a discussion forum on clinical practice updates

If you are interested in being part of a steering group to develop the aims and activities of such a group please contact Karen Matoga at: [karen.matoga@mh.org.au](mailto:karen.matoga@mh.org.au) or [Rosemary.Hoyt@southernhb.govt.nz](mailto:Rosemary.Hoyt@southernhb.govt.nz)



Government of Western Australia  
Department of Health  
WA Cancer and Palliative Care Network

REGISTER NOW  
**CHRONIC MALIGNANT HAEMATOLOGY  
STUDY DAY**

**Saturday 3rd September 2016**

**Venue:** University Club of Western Australia  
2 Hackett Drive, Crawley  
(Hackett Entrance #1, Hackett Drive)

**Time:** 8.15am: Registration  
8.30am–14.00pm: Presentations

**Cost:** FREE

**Parking:** Car parking is provided free of charge  
across all university car parks on  
weekends.

**Catering:** Morning tea and lunch provided.  
(Please include special dietary  
requirements with your RSVP)

**Topics Covered:** Current management of myeloma,  
lymphoma, MDS and chronic leukaemia

**Guest speakers include:**



**Tracy King**  
Myeloma CNC  
Royal Prince Alfred Hospital,  
Sydney



**Dr Chan Cheah**  
Haematologist  
Sir Charles Gairdner Hospital



**Dr Matthew Wright**  
Haematologist  
Fiona Stanley Hospital



**Claire Munsie**  
Exercise Physiologist  
WA Youth Cancer Service



**Dr Melita Cirillo**  
Haematology Registrar  
Fiona Stanley Hospital

**RSVP by Friday 26 August 2016**

Register your free attendance by emailing:  
[Kerin.Young@health.wa.gov.au](mailto:Kerin.Young@health.wa.gov.au).

Please include your full name, organisation details and  
any **dietary requirements**.

For any queries contact:

Kerin Young, Haematology Cancer Nurse Coordinator  
Tel: 0400 023 562





## THE HSANZ NG MYELOMA SPECIAL PRACTICE NETWORK 'M-SPN'

Tracey King

Chair HSANZ NG MM-Special Practice Network

[Tracy.king@sswahs.nsw.gov.au](mailto:Tracy.king@sswahs.nsw.gov.au)

It's been a busy few months for the M-SPN as we launch our groups communication App 'myeNURSE'; host our 1st annual nurses myeloma educational seminar and submit an abstract for HAA!



MEMBERS APP: MYENURSE

As a group of nurses with an interest in myeloma, we know there is a wide range of very useful MM specific resources available to us from local and international MM groups. We wanted to bring those all together in an easily accessible platform. We undertook a scoping exercise to establish what the most useful MM resources were, and then worked with **myINTERACT** technology to bring that all together in an APP – **myeNURSE**.

### What is myeNURSE?

myeNURSE is the M-SPN secure information and communication App, available to access on smartphone, ipad or desktop PC. It contains a comprehensive range of MM specific information resources, guidelines and 3rd party resources that may be of use to a nurse working with those affected by MM. Members are able to share resources with others, including passing on patient information resources utilising QR code technology. We are also able to use myeNURSE to manage our meetings, store documents and slide kits and engage members with surveys and interactive sessions within meetings!

### Who can access myeNURSE?

Our new **myeNURSE** App is available free to all M-SPN members.

### How do I join the M-SPN?

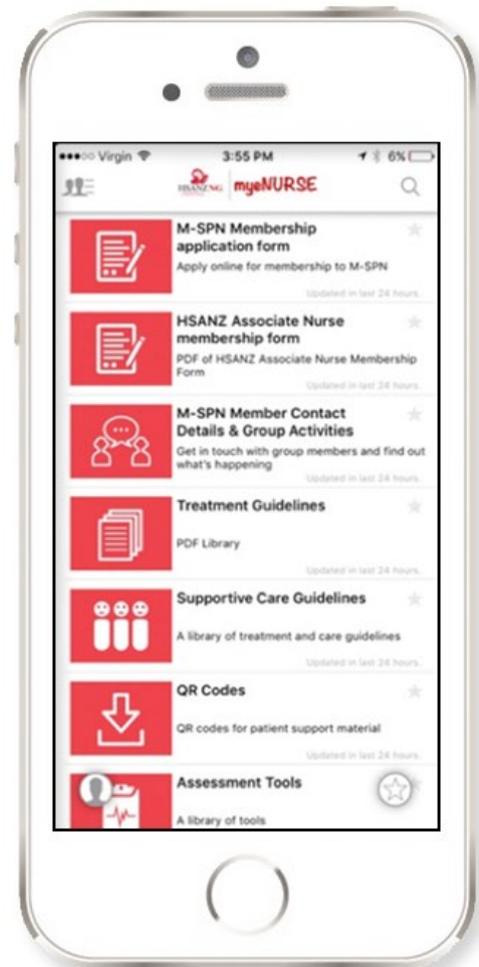
HSANZ Nurses Group members with an interest in myeloma can apply to join the M-SPN.

Email the chair ([tracy.king@sswahs.nsw.gov.au](mailto:tracy.king@sswahs.nsw.gov.au)) to receive an application form or obtain form the HSANZ NG webs page.

New members will be sent an e-invitation to join myeNURSE and once you have set up your login and password, you can freely access myeNURSE content on any device. We had a chance to use myeNURSE to deliver content for our recent MM seminar at the Alfred, many of you may already be benefiting from its use.

### How do I find out more about the M-SPN or myeNURSE?

Why not come along to our M-SPN meeting being held during HAA this year in Melbourne. Details to follow, or look for us on the HAA program.



We would particularly like to thank Sally McLeland and Mike Thompson from INTERACT Technology for their support of our M-SPN with the myeNURSE App. Their generosity of time and effort, and endless patience with our lack of IT know-how has been exceptional.



SALLY PATIENTLY TRAINING TRACY KING (AND JULIJA SIPAVICIUS TAKING PHOTO) TO THE MYENURSE SYSTEM AND CONTENT MANAGEMENT.



## THE INAUGURAL M-SPN NURSES ANNUAL EDUCATIONAL SEMINAR 2016 THE ALFRED HOSPITAL, MELBOURNE

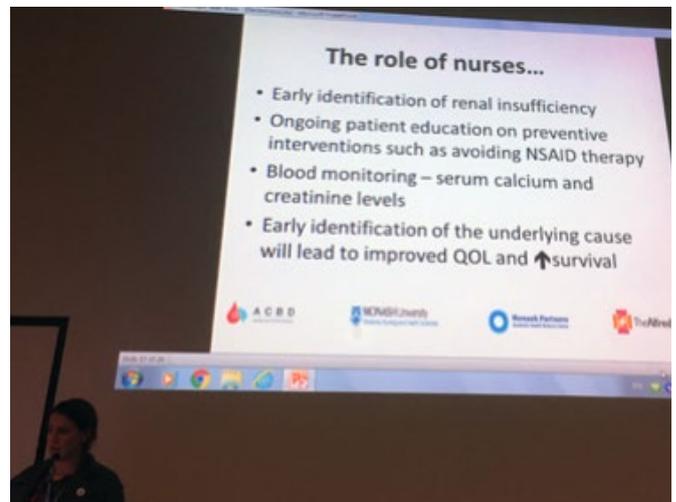
### Making sense of a complex cancer: clinical updates and treatment approaches

The M-SPN held its first annual educational seminar at The Alfred Hospital in Melbourne on 6th August. Our focus was on clinical updates and new treatments with a star cast of speakers from The Alfred, VCC, Box Hill and Monash University presenting on a range of subjects aligned to best practice in the treatment of myeloma and amyloidosis. We also had an update from the Myeloma and Related Disease Registry (MRDR), and had the opportunity to update those 110 nurses in attendance, to the work of our M-SPN.

It is clear from listening to the speakers deliver their presentations that MM remains a complex blood cancer with new understanding of tumour biology and the bone marrow microenvironment, providing new targets for treatment. Prof Spencer outlined some of the newer targeted therapies we are able to access in Australia through compassionate access programs or clinical trials. The HDAC inhibitor (panobinostat); proteasome inhibitors (carfilzomib, ixazomib) and monoclonal antibodies (elotuzumab and daratumumab). Whilst access to new more targeted therapies is essential in improving outcomes for our patients, it provides the health system with some real challenges, not least how to fund combinations that often include more than one novel agent. Dr Gibbs, Director of the VIC/TAS amyloidosis service presented an overview of amyloidosis, with a focus on systemic AL amyloidosis (monoclonal Ig light chain).

A key message from his talk was that AL amyloidosis is a treatable condition with early diagnosis and use of new targeted therapies (as per MM), improving outcomes for patients. The afternoon session focused more on supportive care in myeloma with Daniela Klarica presenting an overview of disease and treatment related effects in MM with a focus on bone and renal issues. She reinforced the nurses role in managing common morbidities and early identification and of side effects to improve outcomes overall. Trish Joyce completed the formal program with an excellent overview of the challenges of identifying and managing infections in this very vulnerable patient group. Infections remain the most significant contributor of morbidity and mortality in MM and the nurses role in education, assessment and management was again highlighted.

The patient organisations (Leukaemia Foundation; Myeloma Foundation) were also present and had the opportunity to engage with nurses during breaks and present a range of their programs and services.



DANIELA KLARICA NPC MM ALFRED

**myeNURSE** had a test run with program, speaker bio's and evaluation delivered via the App. Speaker slides as available, will be made available to delegates after the event and accessible to all M-SPN members.

A good time was had by all with plenty of lucky door prizes to please everyone – some educational and some not so!!

We would like to take this opportunity to thank all the speakers who gave up their personal time to come and take part so enthusiastically on a Saturday. We thank: Daniela Klarica (our host); Dr Krystal Burgin; Dr Anna Kalf; Prof Andrew Spencer; Dr Trish Walker; Dr Simon Gibbs; Elizabeth Moore; Trish Joyce; Jenny Hempton & Julija Sipavicius.

We would also like to thank the following companies who supported catering for the day. Amgen; Celgene; Janssen & Takeda, without their help we would not have been able to host our seminar.

### M-SPN National Group Activities

Alongside developing the new **myeNURSE** resource, our group continues to work to produce a) generic business case for a MM APN to assist local submissions for a MM nurse b) best practice with bortezomib consensus. The group continues to work on these projects and have submitted an abstract to HAA reporting on our work. We will also present an update during our M-SPN meeting at HAA this year.



## M-SPN Local Group Activities

### Western Australia

Kerin Young and her colleagues are hosting a Chronic Malignant Haematology Study Day on 3rd September in Perth. Open to nurses and those working in allied health. To find out more see flyer (*page 15*) or email [Kerin.Young@health.wa.gov.au](mailto:Kerin.Young@health.wa.gov.au)

### New Zealand

Amanda Foster reports from NZ with a successful MM study having been recently hosted on 1st Aug by Celgene for local nurses. The meeting was held in Auckland with nurses from around New Zealand attending. Dr David Simpson was the guest speaker who spoke extensively on Myeloma covering topics from the background of myeloma through to pathophysiology, genetic mutations

as well as treatment algorithms in New Zealand and upcoming treatment availabilities overseas. Kelly Harrison Myeloma nurse specialist at Wellington hospital gave us an overview on her role.

Other MM news of interest from our region includes:

- A Myeloma nurse specialist role has been created at Auckland Hospital. We look forward to hearing more from the incumbent once on board!
- Waikato hospital is having great success with their bortezomib home administration programme.
- A Myeloma summit to be held in Queenstown towards the end of August. Key note international speakers are Dr Paul Richardson and Dr Ola Landgren.

**Do you want to share experiences, find a myeloma mentor and share resources with like-minded nurses? Then the M-SPN is for you.**

We welcome associate nurse members of HSANZ NG who have an interest in myeloma and would like to contribute to improving nursing care of those with myeloma. Application forms can be found at the [hsanz.org.au](http://hsanz.org.au) website or by

emailing us at [nurses@hsanz.org.au](mailto:nurses@hsanz.org.au) or email me directly – [tracy.king@sswahs.nsw.gov.au](mailto:tracy.king@sswahs.nsw.gov.au) to find out more about our group.

## Enhance your knowledge of Cancer Nursing to build your skills and advance in your career. Study with ACN.



If you would like to gain in-depth knowledge about specialty areas of cancer nursing, ACN offers a range of online subjects that can be studied individually or as part of a Graduate certificate. Single units of study include: Haematology; Blood and marrow transplant; Chemotherapy; Symptom management in advanced disease states; and many more.

Studying a single unit is a great way to fit studying into your lifestyle and articulate into a Graduate Certificate in Cancer Nursing. Both these courses include professional practice subjects to develop your communication and leadership skills.

**Enrolments are now open for Graduate Certificate courses commencing January 2017.**

ACN also offer a number of CPD short courses throughout the year, these include: Assessing and managing vascular access devices, Organ and tissue donation awareness, Wound Management, Infection prevention and control.

A full lists of courses, dates and locations can be found on our website

[www.acn.edu.au/cpd-short-courses](http://www.acn.edu.au/cpd-short-courses)



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For more information  
[www.acn.edu.au](http://www.acn.edu.au)



Australian College of Nursing



## WE ARE LYMPHOMA AUSTRALIA

[www.lymphoma.org.au](http://www.lymphoma.org.au)

Sharon Millamin

CEO Lymphoma Australia

In 2003, Lymphoma Australia was founded by a volunteer group based on the Gold Coast, Queensland and became incorporated in 2004 as a registered charity.



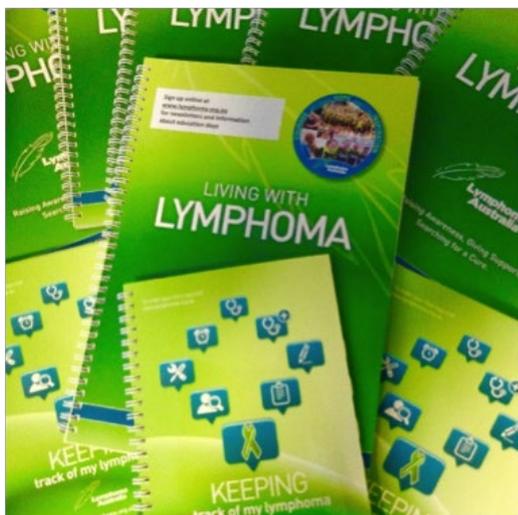
The feather signifies that everyone has a guardian angel in their lymphoma journey to look after and care for them. No one will ever be alone. As the only organisation in Australia that works solely with lymphoma we provide a national network of support services and information resources for patients and their families. Our mission is to:

Support Australians touched by lymphoma,  
raise awareness of this cancer, and  
support research for a cure.

### Our free Lymphoma resources

Lymphoma Australia has developed a wide range of useful patient information, covering all aspects of lymphoma. Our resources are designed to give patients and their families an understanding of lymphoma and to support them through the various phases of their lymphoma journey.

These resources can be ordered online or we can send them to hospitals and cancer clinics to be given to patients when they need them. Please use this link to order your copies <http://www.lymphoma.org.au/page/39/patient-support> or email us at [enquiries@lymphoma.org.au](mailto:enquiries@lymphoma.org.au).



### Lymphoma Australia Education Days

One of the biggest challenges for Lymphoma Australia has been ensuring that all lymphoma patients and their families have access to up to date information about lymphoma regardless of location. With advanced technology we have been overcoming this issue with the rollout of some education days that allow for live audiences at different locations but with the ability for others to also join us online.



Over the last 12-18 months it has been a privilege to host the following international speakers at our patient & carer education days.

**Professor Gilles Salles**, Chair of the world leading clinical research organisation Lymphoma Study Association.

**Professor Mathias Rummel**, from the Department for Haematology at the Justus-Liebig University-Hospital, Gießen and lead for the German lymphoma organisation STIL.

**Professor Andreas Engert**, major clinical focus of his work is the German Hodgkin Study Group.

**Professor Tim Illidge** from the United Kingdom. An international expert in antibodies and radio immunotherapy.

**Professor Massimo Federico** is the Director of the Modena Cancer Registry and President of the Angela Serra Association for Cancer Research.

**Dr. Bill Wierda** from MD Anderson Cancer Centre, Houston, Texas.

**Dr. Adrian Wiestner** NHLBI, NIH, Bethesda, MD, USA

**Dr Brian Koffman** Medical Director CLL Society Inc. Claremont, CA, USA.

**Professor Martin Dreyling** Head of the Lymphoma Programme in the Department of Medicine III, University Hospital Großhadern, Ludwig Maximilians-University in Munich.



## World Lymphoma Awareness Day

Along with our global colleagues from the **Lymphoma Coalition** we aim to increase awareness for both Lymphoma and chronic lymphocytic lymphoma (CLL) on September 15, World Lymphoma Awareness Day and throughout the month of September.

Please order your September Awareness kit by emailing us at [enquiries@lymphoma.org.au](mailto:enquiries@lymphoma.org.au)

This includes posters, ribbons etc.

## Legs out for Lymphoma – Save the Date

Legs Out for Lymphoma is happening again across the country!

We are walking for awareness and walking for change.

- Perth
- Brisbane
- Melbourne

To find out more visit: <http://www.lymphoma.org.au/page/1092/legs-out-for-lymphoma-landing>



## Australian Red Cross BLOOD SERVICE

### KEEP YOUR TRANSFUSION KNOWLEDGE UP TO DATE

The Australian Red Cross Blood Service offers a range of learning experiences to help you keep up-to-date about blood and transfusion.

Listen to the following webinar recordings to enhance your knowledge and gain CPD points.

#### Administering iron products

In this 30-minute presentation, our speaker discusses how managing iron deficiency anaemia is a patient blood management strategy that can reduce the need for a transfusion.

The session explores a range of iron preparations and how managing iron deficiency anaemia can be embedded into clinical practice.

[VIEW THE RECORDING](#)

#### IVIg practicalities and take-home messages

In this presentation, our speaker discusses the practicalities of IVIg, what can be done in a clinical setting to reduce adverse events, take-home messages, and not just criteria for issue.

[VIEW THE RECORDING](#)

#### Find out about future transfusion education events

[SUBSCRIBE TO OUR MONTHLY NEWSLETTER](#)

to receive information about education opportunities and resources to help you in your practice.



## SEX, DRUGS AND... WAIT, DID YOU JUST SAY CANCER?

FOR NURSES/ALLIED HEALTH  
AND OTHER INTERESTED HEALTH PROFESSIONALS

### Topics include:

HEEADSSS Assessment & AYA Development  
AYA & Oncology; AYA & Haematology  
Sexuality & Sexual Health; Fertility Preservation  
AYA & Palliative Care; Blood product considerations  
AYA perspective; AYA friendly environments

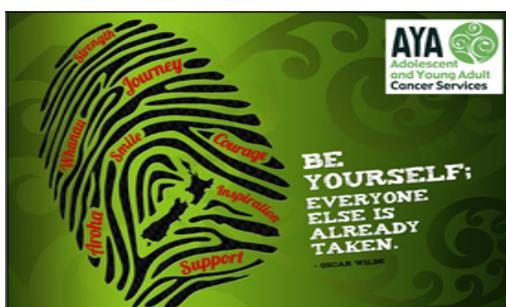
**Saturday 26<sup>th</sup> November 2016**

8.30am to 4.00pm – times & location to be confirmed  
(Registrations from 8am)

Come to presentations in Christchurch or Dunedin or attend via  
videoconference in your Region

**Cost - Free!!**

Registrations close Friday 11<sup>th</sup> November 2016



Registrations and queries from Waitaki River south:  
Val Waugh - [Val.Waugh@southerndhb.govt.nz](mailto:Val.Waugh@southerndhb.govt.nz)  
Southern DHB

Registrations & queries from Waitaki River north:  
Louise Sue – [Louise.sue@cdhb.health.nz](mailto:Louise.sue@cdhb.health.nz)  
Christchurch DHB



## LEUKAEMIA & BLOOD CANCER NEW ZEALAND

Matthew Eby

Support Services Coordinator, LBC-NZ

Leukaemia & Blood Cancer New Zealand is a national organisation dedicated to supporting patients and whanau living with blood cancers and related conditions. We are so pleased to be included in the newsletter and highlight some of the work that our national Support Services team is engaging in. We are building our capacity through the dedicated efforts of 6.0 FTE Support Services Coordinators (SSCs).

As for meeting the educational needs of the clients we support, we manage this by building 'educational' components into our support groups. In the first 6 months of this year our SSCs have sourced a variety of presenters covering topics such as: sleep hygiene, coping with uncertainty/Fear of relapse, understanding how PHARMAC appraises new drug therapies, awareness of Pinc & Steel cancer rehabilitation programme, diet and nutrition, clinical trials, advance directive care plans, awareness of health consumer services, yoga therapy, disease-specific talks (e.g. CLL), mindfulness, and so much more!

As of late July 2016, we 'went live' with a closed Facebook carer's group. This group will be moderated by one of our SSCs and provide yet another tool and 'touchpoint' for those living with a blood condition diagnosis and/or their support persons. We are planning to role out more online groups over time so watch this space!

We also recently rolled out a 'live' referral form as part of the new Leukaemia & Blood Cancer New Zealand website. In other words, if you are considering referring

a patient to our services, this hopefully should make your life easier! You can check out the form here URL:

<https://www.leukaemia.org.nz/information/resources-for-health-professionals/support-services-referral-form/>

If you are not familiar with some of our other programmes, we are proud to offer other psycho-social programmes such as Kids Club, which is a space for offspring and siblings of someone living with a blood cancer. This programme is designed for children ages 5-12 and facilitated by a trained play therapist. At present this occurs monthly from our Auckland head office but we are considering its expansion to other regions of the country. In addition, we also support this age-demographic through our Monkey in My Chair programme. These monkeys take the place of a child in the classroom when they are receiving treatment and provide an opportunity to explain the child's condition to their classmate.

Finally, over the month of August, we are hosting 'Winter Workshops' around the country starting in Christchurch, Wellington, Auckland and finishing in Hamilton. These provide an opportunity for haematology health professionals to plug into an educational up-skill event amid a wonderful collegial atmosphere complete with yummy food and drink, of course. This year's speaker is Professor Martin Connolly who serves as Professor of Geriatric Medicine, University of Auckland with a talk entitled 'The Older Haematology Patient: Defusing the Demographic Time Bomb.'





## UNSCHEDULED EMERGENCY DEPARTMENT PRESENTATIONS BY CANCER PATIENTS

P. Dufton<sup>1,2</sup>, M. Krishnasamy<sup>1</sup> & M. Gerdtz<sup>1</sup>

1. Department of Nursing, The University of Melbourne, Australia

2. The Olivia Newton John Cancer, Research and Wellness Centre, Austin Health, Heidelberg, Australia

Corresponding author contact details: [polly.dufton@unimelb.edu.au](mailto:polly.dufton@unimelb.edu.au)

### Introduction

Emergency presentation is a common consequence of cancer and of cancer treatment complications (Young et al., 2016) and is associated with worse clinical outcomes (van der Meer et al., 2016). Up to 40% of patients who receive anti-cancer drug treatment (traditional chemotherapy, immunotherapy, targeted therapy and hormone therapy) in the outpatient setting make an unscheduled emergency department (ED) presentation during their treatment time (Livingston, Craike, & Considine, 2011), with some countries reporting as many as a quarter of new cancer diagnoses being made following a presentation to a hospital ED (Young et al., 2016). Patients diagnosed with haematological malignancies experience considerable disease-related symptoms and treatment side effects that require a high level of self-management outside of the hospital setting.

This PhD study sets out to identify the number of patients who present to an ED after receiving anti-cancer drug treatment in a Chemotherapy Day Unit (CDU) setting. It will describe the patient population who present and explore potentially modifiable risk factors for ED presentation.

### Results

Seventy-seven (20%) of 379 patients who presented to the ED during the study period had a haematological malignancy diagnosis (Table 1).

TABLE 1. PATIENT DEMOGRAPHICS

| Characteristics |                      |              |
|-----------------|----------------------|--------------|
| Age             | Mean (SD)            | 60.2 (18.5%) |
| Sex             | Male                 | 66 (62%)     |
| Diagnoses       | Non-Hodgkin lymphoma | 32 (29%)     |
|                 | Multiple myeloma     | 25 (23%)     |
| Therapy regimen | VCD                  | 26 (24%)     |
|                 | RCHOP/ CHOP          | 20 (18%)     |
| Clinical trial  | Yes                  | 13 (12%)     |

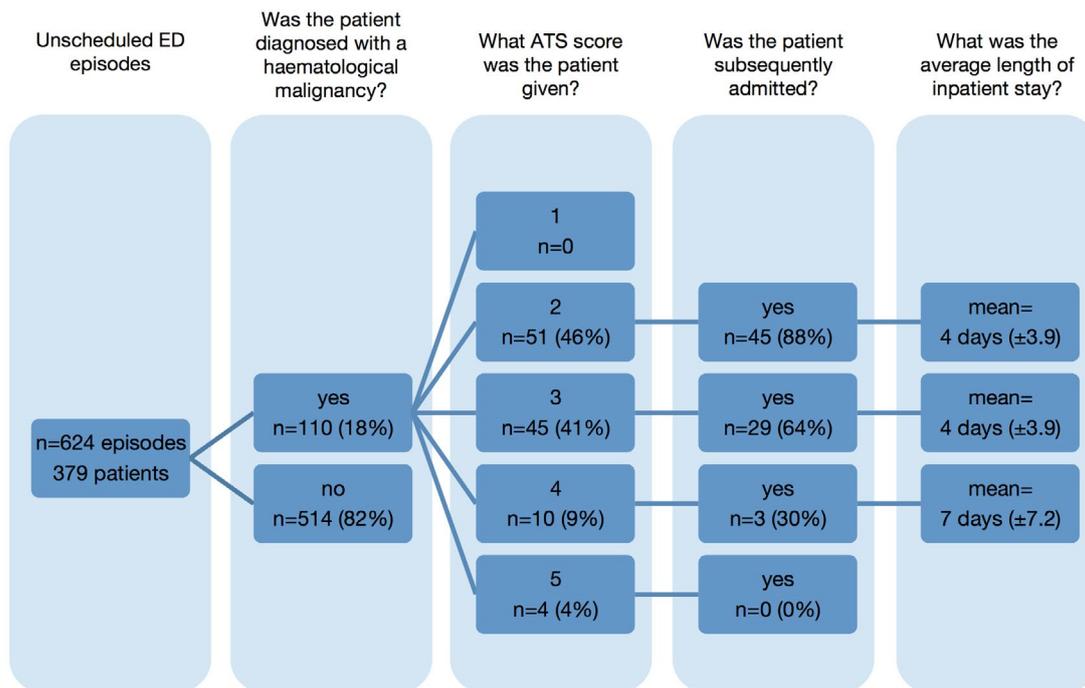
Seventy-seven patients made a total of 110 unscheduled ED presentations during the study period. Fifty (65%) patients had one unscheduled presentation and twenty-seven (35%) made two or more presentations. Ninety (82%) ED presentations were made by patients who presented to the ED independently without a referral from a health professional. The average time from presentation (initial registration) to initiation of treatment in the ED for ED episodes



that subsequently resulted in admission to the inpatient area or the short stay unit for further assessment and care was 12.56 ( $\pm 18.6$ ) minutes, and 17.23 ( $\pm 27.2$ ) minutes for those who were not admitted from the ED. These times are within the recommended timeframe of the operational performance indicators outlined in the Australian Triage Scale (ATS) policy (ACEM, 2013).

For 96 of the 110 unscheduled presentations, an ATS of 2 or 3 was allocated, where 1 is the most severe and 5 the least (Figure 1).

FIGURE 1. PATIENT ADMISSIONS (EPISODES OF CARE)



The most common reasons for ED presentations across all study participants was fever (n=42, 38%), infection (without fever at time of ED presentation) (n=12, 11%), and feeling generally unwell, including fatigue and lethargy (n=11, 10%). For patients presenting with NHL and MM the most common reasons for ED presentation were fever (n=18, 56%) followed by feeling generally unwell, including fatigue and lethargy (n=7, 22%), and pain (n=7, 28%) followed by fever (n=4, 16%), respectively.

**Discussion**

One fifth (20%) of patients in this study who accessed ED services for disease and treatment related symptoms were receiving anti-cancer drug treatment for a haematological malignancy. Further exploration of the data will focus on identifying potential service innovations that may reduce or remove risk factors for an unscheduled ED presentation.

One early insight from the PhD is potential to scope alternative supportive care services for patients receiving ambulatory treatments for haematological malignancies. Telehealth models and implementation of haemato-oncology nurse practitioner services present two service interventions worthy of further consideration.

**References**

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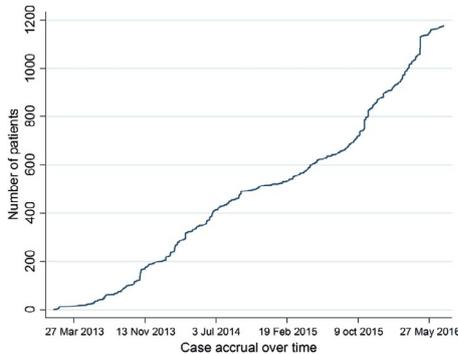


Medicine, Nursing and Health Sciences

# News from the Myeloma and Related Diseases Registry

## Recruitment update

In July we reached over 1180 patients registered on the MRDR. Thanks to all participants and participating hospitals for their ongoing support of the registry. We now have 21 hospitals approved, with Royal Hobart Hospital, Flinders Medical Centre, Latrobe Regional Hospital and Concord Repatriation General Hospital as the most recent additions. We also have 3 more hospitals with approval pending; Liverpool and Epworth Freemasons Hospitals, and Nelson Hospital in New Zealand.



MRDR patient recruitment at the end of July 2016.

Novartis, Celgene and Takeda Corp support the MRDR which enables this important research to continue.

## The Myeloma 1000 project

We now have St George Hospital in NSW participating in this substudy. Welcome aboard St George! This substudy involves collection of one blood sample from newly diagnosed myeloma or MGUS patients before any treatment for their condition has commenced. The Myeloma 1000 project has initially rolled out to Victorian sites to test systems for specimen delivery and receipt. These have proved satisfactory and now with St George Hospital coming on board, we can test the interstate delivery and receipt times with longer distances involved.

The Myeloma 1000 Project is supported by Amgen Australia, Bristol Myers-Squibb & Janssen-Cilag.

## MRDR research output

Our PhD student, Dr Krystal Bergin, submitted a methods paper for publication, titled 'Development of the Australian and New Zealand Myeloma and Related Diseases Registry (MRDR): Implementation and Challenges Faced'. We hope it will be published soon and raise awareness about the registry. It may also be useful to other groups establishing registries.

Two MRDR abstracts were submitted for presentation at HAA, which will be held in Melbourne this year, 13–16 November. The abstracts are:

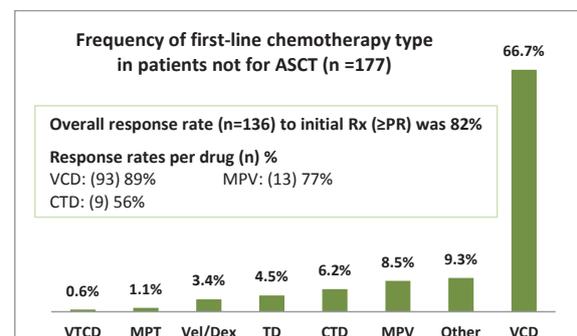
- 'Renal Impairment in Myeloma: A comparison of characteristics and outcomes in patients with and without renal impairment in the Australia and New Zealand Myeloma and Related Diseases Registry', and
- 'Rates of Upfront Autologous Stem Cell Transplantation (ASCT) in Newly Diagnosed Multiple Myeloma (NDMM): A report from the MRDR'.

It is pleasing to see registry data maturing and questions being asked of the registry.

In addition, we are also starting a collaboration with Dr Elizabeth Krakow from the Fred Hutchinson Cancer Research Center in Seattle, USA. Dr Krakow is looking at using statistical/machine learning techniques to personalise myeloma treatment selections. She aims to first look at common data collected in registries / databases in the USA, France, Canada and Australia and arrive at a final dataset composed of core data fields for myeloma registries to collect.

## First-line therapy in patients who are not for autologous stem cell transplants

Recent MRDR data on the variation and frequency of use for first-line chemotherapy combinations is shown below for 177 patients with MM and data available. The overall response rate ( $\geq$ PR) for 136 patients with data available was 82%.



## MRDR: How can your hospital be involved?

Phone: 1800 811 326  
 Email: sphpm-myeloma@monash.edu  
 Website: mrdr.net.au





## The SA/NT HSANZ NURSES GROUP

**INVITE YOU TO ATTEND**  
*an education evening on:*

# Multiple Myeloma

**This evening will focus on:**

- **Multiple Myeloma and the immune system**
- **Immunotherapies used for treatment and mechanism of action**

**Date:** Tuesday 23<sup>rd</sup> August 2016

**Time:** 6pm for 6.30pm

Supper to be provided, *concluding 8.00pm*

**Venue:** Icon Cancer Care Centre,  
520 South Road, Kurralta Park

**This education evening is a cost free event**  
*Certificate of Attendance will be provided*

Register by email to: [SANurseHSANZ@outlook.com](mailto:SANurseHSANZ@outlook.com)  
*Please include your name, workplace and any dietary requirements in email.*

Kindly supported by:





## CNSA UPDATE

Associate Professor Ray Chan

CNSA president

### Key CNSA Appointments

Over the past two months, I had the privilege to announce two key national appointments: Deborah Hoberg (Incoming Annual Congress Committee Chair; taking office in Jan 2017) and Leisa Brown (Education Committee Chair). I believe that both Deborah and Leisa will take the two committees to the next level of success.

### CNSA Annual Congress

CNSA Annual Congress 2016 was a great success on all fronts. I would like to once again congratulate Sam Gibson and the Annual Congress Committee for their tremendous efforts. Without stealing the Annual Congress Committee's thunder, I must highlight that close to 90% of delegates (n= 254) who responded to the evaluation survey, indicated the congress content was pitched at the right level for their professional development needs. Another highlight of Congress was celebrating the success of our Regional Group, Specialist Practice Network and Standing Committees. Over the last 12-month reporting period, in support of the professional development of our members, CNSA offered 26 local education events, 20 travel grants, and 2 special project grants. These amazing outcomes would not be possible without the efforts of the various committees and our staff.

The Annual Congress Committee is already working towards finalising the 2017 CNSA Annual Congress program for which the theme will be "Evolving Cancer Care: Enhancing Quality- Embracing Innovation". We are expecting a great host of international and national speakers including:

- Nicola Roxon (Australia)
- Professor Roma Maguire (UK)
- Associate Professor Alexandre Chan (Singapore)
- Professor Dorothy Keefe (Australia)
- Professor Patsy Yates (Australia)

I believe that many of the clinical and research topics being addressed by these keynote speakers will be highly relevant to the practice of nurses specialised in haematology and bone marrow transplantation.

### Partnership and Representation

In May, I was invited to speak on "Addressing health disparities and the potential role of nurse navigation" from an Australian perspective at the ONS Congress 2016 in Antonio, TX, USA. In the same session, Associate Professor Stella Bialous (ISNCC President of the International Society of Nurses in Cancer Care), Tracy Truant (President of the Canadian Association of Nurses in Oncology) and Associate Professor Winnie So (President of the Asian Oncology Nurses Society) also presented on the same topic from their respective perspectives. It was a great opportunity for us to share our views on the opportunities we have, and how we can continue to focus our efforts to address outcome disparities in different regions of the world. The CNSA continues to enjoy our meaningful partnership with Cancer Australia; as the federal government agency for cancer control.

I continue to be a representative on the Intercollegiate Advisory Committee, and have recently participated in a Survivorship Care Principles Roundtable meeting.





CNSA 20TH ANNUAL CONGRESS

# EVOLVING CANCER CARE:

ENHANCING QUALITY · EMBRACING INNOVATION

## SAVE THE DATE!

Thursday 15 – Saturday 17 June 2017  
Adelaide Convention Centre  
AUSTRALIA



[www.cnsacongress.com.au](http://www.cnsacongress.com.au)



### Credentialing for Nurses (C4N) Project

Over the last 18 months, CNSA has worked collaboratively with four other speciality nursing organisations in the establishment of the Credentialing for Nurses: a specialist nurse credentialing program (C4N program). The C4N project has been led and managed by the Australian College of Mental Health Nurses (ACMHN) with funding provided by the Department of Health through the Office of the Chief Nursing and Midwifery Officer of Queensland. A Credentialed Nurse is a specialist nurse who has met criteria related to education, practice experience, professional development and professional integrity. Credentialing provides an opportunity to formally recognise

specialist cancer nurses and evaluate their impact on patient outcomes. At the end of the C4N pilot (30 June 2016), we aim to have 25 Credentialed Cancer Nurses in Queensland. After 1 July 2016, C4N credentialing will be available to nurses throughout Australia. This national initiative will potentially facilitate the exploration of alternative models of care to meet the ever increasing demand of cancer care.

I am sure you would agree with me that it has been a very busy year for CNSA. And I look forward to share more news with our HSAZ colleagues as we continue to journey through 2016.

## REGIONAL UPDATES

### New South Wales (NSW)

The NSW group has continued with our regional meetings with our next meeting being held in Wollongong. We hope to be holding other meetings in regional areas soon. Our next meeting in Sydney is in November just after HAA, where we will be lucky to have Sandy Kurtin with us for the evening, so if you can't get to HAA, this will be your chance to hear the nurses international speaker. Details will be sent out nearer the time. Please remember to keep your contact information up to date so we can get information out to you.

*David Collins (Chair NSW)*

### Tasmania (TAS)

Tasmania HSAZ Nursing group continues to quietly grow with membership numbers and enthusiasm. We will be holding an Educational dinner in September, thanks to the sponsorship of Sarah Roscoe at Sanofi, focusing on the Cancer Diagnosis in the Adolescent and Young Adult Setting - the Tasmanian Experience. Tasmania is in the depths of Winter and all the wonderful festivals that happen within it, to entice our community out. We hope that Nursing interest and engagement will also encourage as many as possible to adorn their winter coats and head out to our winter educational evening dinner! It has been difficult for us securing sponsorship this year, and we will need to plan in advance for next year's events to secure sponsorship for the future. I would like to take this opportunity to personally thank Gill Sheldon-Collins for her many many years of commitment, hard work and trail blazing, in developing and strengthening the HSAZ Nursing group in Tasmania. She has been a sentinel member and a fabulous ambassador for Tasmania and HSAZ. Gill continues to offer guidance and support as I learn the ropes as new local chair.

The Winter Solstice has been and gone, and we look forward to the summer of Haematology ahead of us.

*Browne Nealy (Chair Tasmania)*

### Western Australia (WA)

See Andrew Steele's article about the Apheresis Focus Group on *page 14*.

### Victoria (VIC)

See the front page article for the upcoming conference news.

### South Australia/Northern Territory

The SA/NT HSAZ NG held an evening education session on 'Non-Hodgkin Lymphoma' in February. This event was well attended with positive feedback, and we are very grateful to our speakers and supporters for their assistance with this event. The event provided opportunity for networking as well as delivering educational content. The next event is on August 23rd, with a focus on 'Myeloma' presented by guest speaker Dr Noemi Horvath. A follow-up event will be held on September 27th, which is a nurses 'Myeloma Quiz night'. We hope to see you at one, or both, of these events! The committee is exploring initiatives to enable our regional members to also participate in future events.

Members (and non-members) will shortly be invited via email to participate in a survey, and we encourage and would be grateful for your participation to ensure future sessions are meeting the needs of this group.

Please contact the committee at [SANurseHSANZ@outlook.com](mailto:SANurseHSANZ@outlook.com) if you would like to update your email address, suggest potential topics or provide further feedback.

*Nicole Loft (Member SA)*



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## CONFERENCE CALENDAR 2016–2017

Compiled by Peter Haywood

| DATE                  | CONFERENCE   | DETAILS  |
|-----------------------|--|--|
| <b>SEPTEMBER 2016</b> |  |  |
| 4–7 September         | <b>ICCN 2016:</b> International Conference of Cancer Nursing                                       | Hong Kong.<br><a href="http://www.isncc.org">www.isncc.org</a>   |
| 15–17 September       | <b>ASH Meeting on Hematologic Malignancies</b>   | Chicago, USA.<br><a href="http://www.hematology.org/Malignancies/">http://www.hematology.org/Malignancies/</a>   |
| <b>OCTOBER 2016</b>   |  |  |
| 11–14 October         | <b>ALLG Scientific Meeting</b>   | Sydney, Australia. <a href="http://www.allg.org.au/events.html">www.allg.org.au/events.html</a>  |
| 17–18 October         | <b>EONS 10:</b> European Oncology Nursing Society  | Dublin, Ireland. <a href="http://Eonsdublin2016.com">Eonsdublin2016.com</a>  |
| 17–21 October         | <b>18th International Psycho Oncology Society Congress</b>   | Dublin, Ireland. <a href="http://ipos2016.net">ipos2016.net</a>  |
| <b>NOVEMBER 2016</b>  |  |  |
| 13–16 November        | <b>HAA 2016:</b> Haematology Society of Australia and New Zealand annual scientific meeting        | Melbourne, Australia.<br><a href="http://www.haa2016.com">http://www.haa2016.com</a>   |
| 15–17 November        | <b>COSA:</b> Clinical Oncology Society of Australia annual scientific meeting                      | Gold Coast, Australia. <a href="http://www.cosa.org.au/events/annual-scientific-meeting.aspx">www.cosa.org.au/events/annual-scientific-meeting.aspx</a>                        |
| 20–23 November        | <b>ACIPC 2016:</b> Australian College of Infection Prevention and Control                          | Melbourne, Australia.<br><a href="http://www.acipconference.com.au/">http://www.acipconference.com.au/</a>   |
| <b>DECEMBER 2016</b>  |  |  |
| 3–6 December          | <b>ASH:</b> 58th American Society of Hematology annual meeting & exposition                        | San Diego, USA.<br><a href="http://www.hematology.org/Annual-Meeting/">www.hematology.org/Annual-Meeting/</a>  |
| <b>FEBRUARY 2017</b>  |  |  |
| 10–12 February        | <b>ASH Asia-Pacific highlights</b>   | Hong Kong. <a href="http://www.hematology.org/Highlights/Asia.aspx">http://www.hematology.org/Highlights/Asia.aspx</a>   |
| <b>MARCH 2017</b>     |  |  |
| 22–26 March           | <b>BMT:</b> Blood Marrow Transplantation tandem meetings   | Orlando, USA. <a href="http://asbmt.org/meetings-events/bmt-tandem-meetings">http://asbmt.org/meetings-events/bmt-tandem-meetings</a>  |
| 26–29 March           | <b>EBMT 2017:</b> 43rd Annual meeting of the European Society for Blood and Marrow Transplantation | Marseille, France.<br><a href="http://www.ebmt2017.org/">http://www.ebmt2017.org/</a>  |
| <b>MAY 2017</b>       |  |  |
| 3–6 May               | <b>The 14th International symposium on Myelodysplastic Syndromes</b>                               | Valencia, Spain.<br><a href="http://mds2017.kenes.com/">http://mds2017.kenes.com/</a>  |
| 4–7 May               | <b>ONS:</b> Oncology Nursing Society 42nd annual congress  | Denver, USA. <a href="http://congress.ons.org/">http://congress.ons.org/</a>   |
| 6–9 May               | <b>INS 2017:</b> Infusion Nurses Society   | Minneapolis, USA. <a href="https://www.eiseverywhere.com/ehome/ins2017/409727/">https://www.eiseverywhere.com/ehome/ins2017/409727/</a>  |
| 10–12 May             | <b>AVAS:</b> Australian Vascular Access Society annual scientific meeting                          | Perth, Australia. <a href="http://avas.org.au/">http://avas.org.au/</a>  |
| <b>JUNE 2017</b>      |  |  |
| 2–6 June              | <b>ASCO:</b> American Society Of Clinical Oncology annual meeting 2017                             | Chicago, USA.<br><a href="https://am.asco.org/">https://am.asco.org/</a>   |
| 15–17 June            | <b>CNSA:</b> Cancer Nurses Society Australia 20th annual congress                                  | Adelaide, Australia. <a href="https://www.cnsa.org.au/congressevents/cnsa-annual-congress">https://www.cnsa.org.au/congressevents/cnsa-annual-congress</a>                     |
| 22–25 June            | <b>EHA:</b> European Hematology Association 22nd congress  | Madrid, Spain. <a href="http://www.ehaweb.org/congress-and-events/22nd-congress/key-information/">http://www.ehaweb.org/congress-and-events/22nd-congress/key-information/</a> |



## EDITOR'S NOTE

Rosemary Hoyt

Dunedin Hospital, New Zealand

After now coordinating three editions of the HSA NZ nurses group newsletter I am starting to realise that just when I think I will have no content for the newsletter it all suddenly starts rolling in. Thank you to all the contributors for this August edition and special thanks to those future authors who will be contacting me shortly about sharing your activities, knowledge and practice updates with other readers. Please email me ([rosemary.hoyt@southernhb.govt.nz](mailto:rosemary.hoyt@southernhb.govt.nz)).

A few weeks ago one of the haematologists and I meet with the husband of a transplant patient who had died during her allograft. Her husband came in to de-brief with us about the decision to have the transplant, the complications she endured during the transplant and the decision to cease active treatment as her condition deteriorated. As many of you know such meetings can be distressing and so very sad. This was no exception but it did provide the husband an opportunity to account what had happened to his wife, he was able to ask about events he had not quite understood at the time, clarify certain terminology and discuss the decision to withdraw active treatment. This last decision lead to feelings of guilt and a concern that he had taken away her chance of living. We were able to reassure him, answer questions, offer bereavement support and in the end cry a little with him about this devastating loss.

If you ever have the opportunity to meet with a relative after the death of one of your patients I would encourage you to do this. It is a little confronting and in some ways the uncertainty of how they or you are going to react can be unsettling. Anger and regret are common emotions but in discussing what happened some misunderstandings and feelings of guilt might be able to be resolved. It may also provide insight into how care may be improved in the future. After over 25 years of transplant nursing I find I am still learning from patients and families. Lastly, as always, my nursing colleagues inspire me and make me so very proud of their competence and overwhelming acts of kindness when caring for haematology patients and families.

