Nursing
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Newsletter
Haematology
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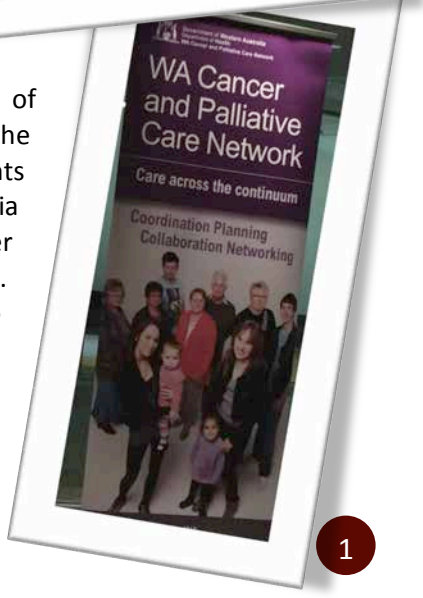
HSANZ
Haematology Society of Australia and New Zealand

Inside:

Plus much more…!

Newsletter design and publishing:
Natalie D'Abrew

Highlights from HAA 2014 Perth



HAA 2014 Perth from 19th-22nd October provided a jam-packed program for the nurses' stream. Our international guest speaker, Dr Kathryn Tierney, travelled from California to share her experiences and knowledge with us through her participation at conference. Her Masterclass and presentations in the symposiums featured talks in the area of bone marrow transplant, GVHD, sexual health, quality of life issues and care considerations of the older haematology patient. We were grateful of Kathryn's passion and expertise for the altered pathophysiology of GVHD, we certainly all went away reminded of the ravishing effects this condition can have on our patients and their families. Kathryn's visit was her first to Australia and luckily she had some time to visit Australia with her husband for a few weeks holiday after conference. Through her active participation at HAA in Perth we hope to build a lasting relationship with Kathryn and haematology nurses in the United States and look forward to welcoming her, and her colleagues back at a time point in the future.

We were fortunate to have some amazing local and

national speakers participate within the nurses program. On behalf of the local organising team and nurses council, I thank them all for their contributions, time and effort. The panel discussions, workshops, free communication sessions and nurses symposiums were very well attended and the feedback, so far, has been overwhelmingly positive. Our sessions were frequently attended by members from the other 'streams' and the combined sessions with HSANZ discussed the important issues of 'Fertility & Malignancies' and 'Late Transplant Side Effects'.

The Social Program kicked off with the Welcome Reception and Dr Robin Warren the Nobel Prize in Medicine winner was the guest speaker. The Gala Dinner, 'Bling it on!' was a time to enjoy the amazing food, wine and entertainment. It was a fabulous evening with many photos taken!

(If you can name the people in the picture – I'll send you a prize! Email tracy.king@sswahs.nsw.gov.au – excludes those who appear in the picture!)

I would like to thank our committee; Kerin Young, Barb O'Callaghan, Sue Darby and Meg Plaster. Without your ideas, exhaustive emailing & continual support the nurses' stream would not have been so well attended and cohesive. Thank you to Julija Sipavicius who organised the 'Tale of 2 marrows' panel discussion. The extended panel delivered a complex and thought provoking case study with expertise and compassion for all the dimensions presented.

I'd also like to acknowledge the tireless work of our HSANZ national nurses committee. You all helped to make this an amazing conference. Tracy King, the president of the HSANZ nurses group, guided and supported me through the past 12 months. Thank you, I appreciate all your efforts.

I look forward to Adelaide 2015!!

Back2Basics pre-conference haematology study day

The HSANZ nursing group hosted a Back2Basics study day for nursing and allied health as a pre event to HAA 2014. The day was held at St John of God Hospital in Subiaco and was supported by the WA Cancer and Palliative Care Network and WA Clinical Oncology Group. Biljana Vojnovic, the Oncology Clinical Educator at Fiona Stanley Hospital, facilitated the smooth running of the day which included a number of both local and national speakers. The aim of the study day was to provide a broad introduction to the specialty of haematology, including an overview of malignant haematology, bleeding disorders and patient management issues including treatment side effects and bone marrow transplant. The program included sessions on

- Haemopoeisis
- Safe administration of blood products
- Cancer Institute NSW eviQ – navigating the online resource
- Treatment side effects – the possible treatment related side effects and the management of these effects
- MDS – disease complexity and challenges in managing MDS
- Haematological malignancies – an overview of what is haematological malignancy
- Bleeding disorders – some of the common bleeding disorders and their management.
- Bone marrow transplant – an overview of the process of bone marrow transplant, its indications and management.

A number of not for profit organisations also held information stalls on the day and provided a presentation on what

resources they provide for patients and their families and included Canteen, Leukaemia Foundation and Cancer Council. The state wide Adolescent and Young Adult cancer service also presented on the impact of cancer diagnosis to the AYA population and the role they have in supporting young people. The day was attended by over 30 nursing and allied health from a variety of public and private institutions and the day was well evaluated with the majority of the attendees reflecting that the day substantially enhanced their professional knowledge.

Many thanks need to go out to the presenters for giving up part of their Saturday to present:

Thanks to:

Sue Darby (Transfusion Services Clinical Nurse Consultant, Sir Charles Gairdner Hospital); Ailsing Kelly (Senior Pharmacist eviq); Annita House (Haematology Clinical Educator, Fiona Stanley Hospital); Matthew Vodanovich (Transfusion Medicine Clinical Nurse Consultant. Fremantle Hospital); Claire Bell (Clinical Nurse Consultant Royal Perth Hospital); Julija Sipavicius (Bone Marrow Transplant Nurse Practitioner, The Royal Melbourne Hospital).

A special mention and thanks to Biljana Vojnovic, the Oncology Clinical Educator at Fiona Stanley Hospital, for the smooth running of the study day and her presentation on haemopoeisis.

Happy Christmas to all from Haematology at RPA Sydney – Ward 7W1

A word or two from the President…

OK, so it wasn't quite my last word, sorry about that!

To bring you up to speed with changes to your council this year…Jenelle Peppin was unable to continue with her commitments to HSANZ NG and with regret chose to resign. An interim measure has been for an existing council member to take up the President's position for the next year whilst the leadership is determined. In the absence of others choosing to take up the Presidency, I have agreed to remain on for 1 more year, so you'll hear a few more 'words' from me.

Meanwhile regular nominations were sort for council positions of vice President and Treasurer. We had 1 nomination for each position; both met the criteria and were approved by council without ballot to members. Council congratulates David Collins (Sydney) as the new vice president and Gillian Sheldon-Collins (Tasmania) as the new Treasurer. I thank David and Gillian for committing to support HSANZ NG by choosing to join council and contribute to the work of the nurses group for the next few years. We look forward to working with them in the years ahead on Council. I also thank, on a personal level and on behalf of the whole Council, Allan Heyward for his many years of commitment and work on Council as Treasurer. Allan remains involved representing SA and NT.

This edition of the newsletter is full of highlights from the recent HAA 2014 conference. Foremost, a report from Cassi Lawrence the chair of the nurse's local organising committee who reflects on a busy few months and successfully delivered nurses program in Perth. On behalf of council and the nursing membership I thank Cassi and her team for their efforts, mostly carried out in their own time after hours, which we thank you and your patient families for!

Our wonderful overseas speaker Kate Tierney contributed in several sessions showcasing her extensive experience and knowledge in the field of BMT nursing. She generously gave of her time and shared stories and experiences from her research work and clinical role. We hope to work again with Kate and welcome her and her colleagues to come visit us here in Australia any time.

Congratulations to the 3 top scoring abstracts submitted for oral in the nursing stream. Sally Taylor, Kristen Houdyk and Trish Joyce share their winning abstracts in this edition. Congratulations are also given to Eleanor Williams, for winning best poster. We also hear from several members and junior nurses who attended HAA 2014 c/o travel sponsorship. Of note, our Bayer Travel Sponsorship awardees – the next generation of Haematology nurses! Alyce Francis (TAS), Loren Beaber (VIC) and Claire Phillips (SA).

A new initiative we are pleased to bring to your attention is the ability of members to establish Special Practice Networks (SPN) within the HSANZ nurses group. Utilising the CNSA model of establishing groups, we have adapted the CNSA Guidelines for the establishment of SPNs – available on our webpage for review. A Myeloma SPN is likely 1st cab off the rank with an MDS / MPN group keen to hear from interested members.

So – you have me for 12 more months. May I take this opportunity to thank you all for your hard work during the past year and hope you have a peaceful and healthy holiday with your friends and families. I particularly send my best to those of you working over the Christmas holidays in the clinical areas and hope you get some time in your busy days, to give and receive some festive spirit!

Tracy King

President HSANZ NG

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Best Abstract Award Winners: HSANZ Nurses Group HAA 2014 Perth WA

BEST Abstracts submitted for ORAL

Extended Nurse Practice Roles in Haematology: Groundwork for changing practice

Sally Taylor, Nurse Educator, Haematology / BMT Unit, Institute of Haematology, Royal Prince Alfred Hospital, Sydney, Australia

Advanced practice or extended scope of practice for nurses is now widely adopted in healthcare where there is clear evidence of benefit to patient care. The Haematology Department identified the benefits of nurse performed bone marrow aspirate and trephine (BMAT). The development of evidence based and clearly articulated procedural, educational and clinical assessment guidelines, would be critical prior to implementing a change in scope of practice. Throughout the literature, audits and literature reviews have highlighted that it is evident that there is a high patient satisfaction from nurses performing the bone marrow biopsies. There has been other institutes such as the Royal Marsden in the United Kingdom that have developed a course specifically for nurses to be able to receive the best possible training in becoming competent in BMAT. There is a necessity for training and resources for nurse-led services at RPAH because of the large volumes of patients and the efficiency of the nurse-led models of care. This paper will describe the preparation phase for implementing extended scope of practice for Clinical Nurse Specialists (CNS) in BMAT.

AIMs:

1. To implement nurse performed BMAT.
2. To develop an evidence-based education training program to guide the implementation of nurse performed BMAT. (Focus of paper)
3. To evaluate the acceptance of, and patient outcomes relating to, nurse performed BMAT.

Method: A systematic approach was taken including engagement with key clinical and managerial stakeholders providing expert guidance on content and processes to support practice change. In line with the Cochrane Collaboration Standards, a systematic search strategy was developed and completed using electronic databases (PubMed, Cinahl, Medline). In addition, key grey literature related to BMAT procedures, risk factors and adverse events were examined. Key authors identified in the review were contacted for additional expert input into the findings. Evaluation of clinical indicators such as infection rates, performance measures, quality of slides, patient experience and competency measures were assessed.

Sally Taylor and Dr Blake Hsu, Medical Mentor

Key findings from the review: Nurse delivered BMAT can improve pain management, patient experience, quality of care and decreased waiting times. A lack of educational training programs exists leading to the development of a local BMAT program.

Implications for practice: With the rising number of advanced practice nurses and therefore the desire to expand the scope of practice, there is a requirement for educational programs to be able to support this expanded practice in order to be able to meet evidence-based practice. It is hoped upon implementation and ongoing evaluation; we will be able to demonstrate the benefit of implementing a robust program supporting expanded practice.

HSANZ

Results of an Exploratory Study of the Care Experiences of Patients Diagnosed with Myeloma

Kristen Houdyk[1], Miles Prince[2,] Mei Krishnasamy [2,3]
1. Myeloma Foundation of Australia Inc. Richmond, Australia, 2. Peter MacCallum Cancer Centre, East Melbourne, Australia, 3. University of Melbourne, Australia

Background
Myeloma is an incurable blood cancer that predominately affects the elderly. Developments in the treatment of myeloma have resulted in better disease outcomes for some groups but survival has not improved for older patients.

Aim
To explore the unmet physical and supportive care needs of non-transplant eligible patients diagnosed with myeloma. Primary objectives are:

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

Method
20- 30 newly diagnosed or relapsed myeloma patients to be recruited. Patients completed a series of validated measures at T1 (3- 6 weeks post commencement of treatment) and T2 (8-12 weeks post T1). Measures report on QOL, emotional wellbeing, medication adherence and supportive care needs. At six months patients participated in an audio tapped interview to explore their experience of living with myeloma. Patients' treating specialist and GPs participated in a taped telephone interview to explore their perceptions of care provision for patients with myeloma.

Results
Of the 20 patients referred 10 completed the study. 4 declined to participate, 4 passed away and 2 withdrew. Key findings include:

- Patients Global Health Status improved over time (T1 m=56.5, T2 m=62.1). Symptomology scores varied between patients. All patients reported high levels of fatigue and insomnia.
- Anxiety scores drop over time (T1 m=5.2, T2 m=3.9).
- High levels of medication adherence reported.
- Need for more information on disease and treatment is greatest at T1. There was limited engagement with support care services.

Key findings of audio taped interviews include:

- Patient interview themes include living with uncertainty, loss, relationship with specialist, role adjustment and resourcefulness to self-manage symptoms and disease
- Challenges perceived by specialist to treating older myeloma patients include: social supports, complexities of treatments, toxicities of treatments, medication adherence & existing co morbidities
- GPs report poor disease knowledge.

Conclusion
Findings suggest the symptomology experienced by the older myeloma patient is varied for each individual. Patients and specialist appear to have a dynamic relationship with limited involvement from other health care providers.

There's No Place Like Home! A Nurse-Led Ambulatory Program to Manage Neutropenic Fever

Trish Joyce[1], Ben Teh[1], Chris Brown[1,3] Karin Thursky [1,2]

1. Peter MacCallum Cancer Centre, Melbourne, Victoria. 2. Royal Melbourne Hospital, Parkville, Victoria. 3. Western & Central Melbourne Integrated Cancer Services, East Melbourne, Victoria

Neutropenic fever (NF) is a significant complication associated with cancer chemotherapy. The incidence of NF is 50% in solid tumours and as high as 80% in haematological malignancies (Freifeld et al. 2011). The course of bacterial infection can be fulminant in patients with NF which cemented the treatment paradigm of prompt admission for intravenous empiric antibiotics until fever and neutropenia resolved (Klastersky, 1983). However, recent evidence suggests that using a validated risk assessment tool when the patient presents with a NF will identify if the patient is 'low-risk' of medical complications and thus making them suitable for a less intensive approach to management (Talcott et al. 2011).

The Multinational Association for Supportive Care in Cancer (MASCC) is a well validated risk assessment tool to evaluate risk of medical complications in patients presenting with NF (Klastersky et al. 2000). The MASCC tool accrues points for good outcome predictors in seven criteria such as outpatient status, age less than 60 years old, no hypotension or dehydration, no chronic obstructive airways disease, mild to moderate symptom burden of disease and no history of fungal infection. It is presented in greater detail in Table 1 (Klastersky et al. 2006).

Table 1

Characteristic	Point score
Burden of illness	
No or mild symptoms	5
Moderate symptoms	3
No hypotension	5
No chronic obstructive pulmonary disease	4
Solid tumour or no previous fungal infection‡	4
Outpatient status§	3
No dehydration	3
Aged < 60 years	2

†The maximum value in this system is 26. A score of ≥21 predicts a ≤6% risk for severe complications and a very low mortality (<1%) in neutropenic febrile patients. ‡Previous fungal infection: means demonstrated fungal infection or empirically treated suspected fungal infection. §Outpatient status: means onset of fever as an outpatient. MASCC, Multinational Association for Supportive Care in Cancer.

Not all patients risk assessed with the MASCC tool and identified as 'low-risk' will be suitable for oral antibiotics and home based management. Kern et al. (2013) pointed out that approximately 30% of patients suitable identified as 'low-risk' will not be suitable for home based management because of non-clinical criteria such as lack of a primary carer, distance form the hospital and emergency department facility or because of another medical problem not captured by the MASCC tool.

In March of this year, the Peter Mac Callum Cancer Centre in Melbourne introduced a low-risk NF ambulatory program. An educational blitz over a period of several months was undertaken to increase the knowledge and awareness around MASCC risk assessment, patient eligibility criteria regarding de-escalation to oral antibiotic and discharge to ambulatory care setting. This is a nurse-led program. Potential patients suitable for outpatient management for their NF episode are referred to the nurse consultant. The nurse consultant assesses the patient's eligibility for the program and discusses with the treating medical team. Patients entered into the program have their care delivered by the Peter Mac @Home Nursing service. The nurses visit on Day 1 (Day 0=day of discharge) and Day 2 to assess the patient and take bloods. Future visits occur if ongoing neutropenia. Pathology results are reviewed by the nurse consultant and the treating team are kept updated on the patient's progress. All patients discharged to the ambulatory program have a face-to-face clinical review with the nurse consultant 5 to 7 days following their episode of NF.

To date we have had 17 patients admitted to the program. Three patients required readmission, two with recurrent fevers and one with a tachycardia unrelated to episode of infection. The feedback from patients is very positive with the majority of patients admitted to the program feeling very comfortable with home-based management. The median inpatient stay is

1 day (range 1:3). The median duration of intravenous antibiotics is 1 day.

The program has significant benefits through reduced health care costs as a result of reduction in inpatient days. In addition ambulatory management improves the patient experience. Moreover reduced time in hospital reduces the risk of hospital acquired infections.

The program is still in its infancy and we envisage as time goes on our referrals will increase. This is a good example of an evidence-based patient-centred model of care, which is nurse-led.

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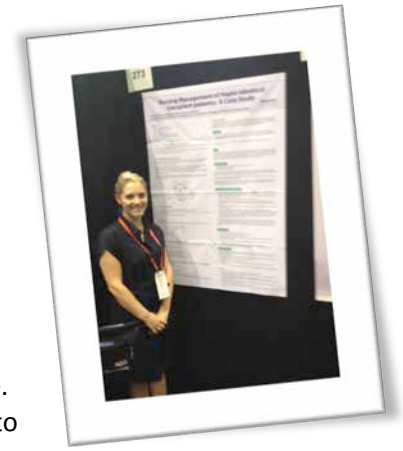
BEST POSTER

Case Study – Nursing management of Haplo-Identical transplant patients

Sarah O'Brien, Eleanor Williams and Elizabeth Collin – South Island Bone Marrow Transplant Unit, Christchurch, New Zealand



Haploidentical transplants offer an important alternative for patients requiring transplant who do not have a sibling match or matched unrelated donor. A Haploidentical transplant uses a donor who is a partial HLA match. This type of donor is often more accessible as they can be a parent, sibling or child. 90% of patients have a haploidenical family member. The disadvantages associated with haploidentical transplant are: increased risk of graft verses host disease, graft rejection and delayed recovery of the immune system making the patient more susceptible to infectious complications.

We present the case of Mr Smith, a 49 year old male, diagnosed with CML in acute phase. Following high dose chemotherapy of CHOEP, Hyper CVAD and radiotherapy the plan was to proceed with a sibling allogeneic stem cell transplant. Unfortunately no full sibling match or matched unrelated donor was found and he proceeded with haploidentical stem cell transplant with his brother.

Post transplant, Mr Smith's major complications were muscositis, neutropenic sepsis, diarrhoea and severe hiccups. Two months post transplant Mr Smith unfortunately developed transverse myelitis causing a complete paraplegia from T9.
This case study will discuss nursing management of these complications. Mr Smith is the second patient in the South Island to have a haploidentical transplant. Although the principals of nursing care are similar to that of allogeneic transplant, the identification of risk factors and early effects is important to ensure best interventions are carried out.

Eleanor Williams RN
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Kathryn Tierney Keynote Speaker: Nurses Stream HAA 2015 enjoys her 1st trip to Australia

I would like to offer my congratulations to the organizing committee for putting together an outstanding nursing stream for the HAA 2014 Annual Scientific Meeting. The speakers and topics selected were terrific. I particularly liked the Free Communication sessions. What fantastic work you are all doing in caring for your patients. Your programs are innovative and well executed. The Free Communication sessions are a wonderful forum for sharing ideas. Your abundance of energy and enthusiasm is inspiring. The Master's Class is not a format we have here in the United States, but the opportunity for a didactic session is a great way to learn from each other. I really enjoyed our discussion of the unique considerations in caring for "older" transplant recipients.

Each of the orations honoring leaders in the field was a wonderful reminder of how far we have come and sometimes how difficult it is to challenge the status quo. These orations remind me that progress in medicine and nursing is built one tiny step at a time. It is often hard to see where a discover will lead. I confess to a love of nursing history. If you haven't spent time at the Florence Nightingale museum in London, it is worth a visit. She was a remarkable woman for her time, but if she were alive today she would be equally remarkable. Our current practices in nursing are not so very far from the principles she articulated many years ago. Forgive me, but one more plug for history. A great look at the historical developments in cancer therapies is the book; "The Emperor of All Maladies" by Siddhartha Mukherjee.

It is also noteworthy that after a hard day of learning, you enjoy a bit of fun. For those who attended the "Bling It On" dinner and dance, it was clear you know how to let your hair down. After the conference, I spent a little over two weeks touring Australia with my husband. We enjoyed Sydney, Lady Elliot Island and some wonderful hiking in Carnarvon Gorge. We will have to come back as there is so much more to see.

I am honored to have been invited as a speaker and enjoyed not only the conference, but also meeting so many of you. Many thanks for your warm welcome.

D. Kathryn Tierney, RN, PhD
Oncology Clinical Nurse Specialist
Blood and Marrow Transplantation
Stanford Health Care

HSANZ

The Bayer Award - Junior Haematology Nurse HAA 2014 and Grant winners feedback from their attendance at HAA 2014.

Alyce Francis, *RN, Royal Hobart Hospital, Tasmania*

With thanks to the Bayer Australia Ltd who kindly supported the sponsorship provided by the HSANZ nurses group, I was one of three fortunate junior haematology nurses from across Australia, who was generously supported to attend the 2014 HAA conference in Perth, WA. The scholarship included registration to the conference, return flights, and accommodation.

The day chemotherapy unit, RHH,

On a regular workday you will find me in my hometown of Hobart, where I work amongst a dynamic team of nurses in the day chemotherapy unit at the Royal Hobart Hospital (RHH). We are responsible in providing care to patients undergoing treatment for a wide variety of both malignant and non-malignant haematological conditions across the full range of the treatment spectrum from acute to palliative care.

Attending the HAA conference 2014 was an extremely positive experience for me. To be amongst such an abundance of health care professionals with such passion about their profession, was inspirational to say the least. It was a privilege to gain insight in to the workings of other units similar to ours in Hobart and see the positive results gained from research by individuals who are specialists in their fields. On a number of occasions I found myself with a sense of pride when hearing of research findings that were congruent with projects that my colleagues are currently undertaking, such as the setting up of a subcutaneous immunoglobulin program which was presented by the Sunshine Coast Hospital and Health Service, QLD. At other times I was in awe of just what can be achieved in haematology nursing. An example of which was Trish Joyce from the Peter MacCallum Cancer Centre, VIC, who presented her extensive achievements in nurse-led clinics.

Overall, it is safe to say that each talented presentation that I was fortunate enough to attend heightened my ambition to continue my professional development at every opportunity that presents itself to me in this fascinating field in which we work.

I highly recommend that all of those working in this dynamic specialty to take the opportunity to attend the HAA conference.

Loren Beaber, *RN, Haem/Onc/BMT, The Alfred Hospital, Melbourne*

The recent HSANZ Conference in Perth provided professional development opportunities for both junior and senior clinicians. As the recipient of a generous sponsorship from Bayer through HSANZ I was able to experience it firsthand. The highlight from the first day was the introduction of Kathryn Tierney, the nursing group's international speaker. Kathryn provided amazing insight on GVHD, 'older' patients and sexuality throughout the conference.

The remainder was more of the same, great presenters from across the allied health spectrum covering a variety of topics. Transplantation, medication and therapy, GVHD, sexuality and reproduction, myeloma, blood transfusions, nurse led programs and apheresis were all covered. The topics provided knowledge and ideas that I will be sharing

with my colleagues and patients. Knowledge wasn't the only thing I gained at the conference.

The presenters were inspirational not just in their topics. I found that they all possessed a passion for haematology nursing with patient centric focus. They were also approachable and answered my many questions. The tea breaks also allowed me to meet other nurses not presenting. Nurses were from all over Australia, urban and rural and from both inpatient and outpatient settings. Tea breaks also allowed me to visit the expo and meet the exhibitors. I spoke with some exhibitors who offered to provide in services and will discuss those with my CS&D. Socialising also extended to the Gala Dinner with some great and less great dancing as well as an amazing gold jacket that had to be seen to believe.

I had an amazing experience that I hope to continue in 2015 when the conference travels to Adelaide. I would like to thank Bayer for the sponsorship and HSANZ for facilitating it, particularly Tracy King.

Claire Phillips, *RN, Oncology / Haematology, St Andrews Hospital, Adelaide*

Earlier this year I was fortunate enough to be selected as one of the three scholarship recipients to attend the HAA Conference supported by Bayer in Perth of October this year. The opportunity to attend this conference was invaluable in allowing me, a junior oncology nurse, to expand my professional knowledge and develop my scope of practice. Currently I work in a small privately owned and run hospital in Adelaide within an oncology and haematology ward setting and also within a chemotherapy suite.

The HAA conference scholarship allowed me to me to meet other like-minded health professionals from around the world and to discuss current practice and protocols and also what is potentially the future of haematology nursing. The networking that attending this conference allowed is significant with both national and international relationships being formed and maintained.

International speakers from countries including Singapore, Canada, France, Denmark, United States of America, Germany and United Kingdom spoke about a broad range of relevant topics including Graft versus Host Disease, Childhood Acute Lymphoblastic Leukaemia and 'A Cytogenetist's Tale'.

Each of the speakers shared knowledge that I have not only applied to my own practice but I also shared with my own haematology/oncology team within my hospital. Since my return from the HAA conference I have shared much of the knowledge, skills and my experience learned through presentations and the development of a learning package.

The opportunity to attend the HAA conference in Perth would not have been possible without the support provided by Bayer to attend an interstate experience. Thank you to Bayer for providing me with such an amazing 'once in a lifetime' opportunity.

Rachel Carter, *RN, Haematology, Auckland City Hospital*

As a member of the HSANZ nurses group I was very lucky to receive a grant to attend 'The World Federation of Haemophilia Congress' held in Melbourne in May 2014, thanks to Bayer. I am an 'acute' haematology nurse, currently working on ward 62, Auckland City Hospital. I do not see many patients on the ward with Haemophilia so I was feeling very excited but anxious at the prospect of attending the conference, worried I would be completely out of my depth.

As I expected the learning curve for me was steep, however it was a fabulous opportunity for me to be immersed within the conference attendees that consisted of health professionals, Haemophilia patients and their families. I particularly enjoyed meeting the patients and their families as they were very frank in explaining the complexities of living with Haemophilia and the impact it has on their lives. Two of the mothers and sons I met explained their experiences of 'healthcare' from

diagnosis to now. Diagnosis for their sons and then learning to live with Haemophilia was for both of them frustrating and scary and meant lots of interactions with various members of healthcare. Both of the Mums said that the key thing I should take from them was to 'listen' as they said that they often felt hurried or not listened too and this made them feel much more anxious than they already were in acute scenarios. Interestingly for me, the sons who are in their teens were less anxious at the prospect of healthcare interactions as they felt secure in their knowledge of their bodies and how to deal with it.

I am so thankful for the opportunity to attend this congress and feel it has deepened my understanding of the impact of bleeding disorders. Thank you once again Bayer and HSANZ Nurses group.

Ally Marven, *ANUM (Associate Nurse Unit Manager)***,** *Victoria*

I wanted to attend this congress because I hoped it would enable me to be a more effective advocate for people with inherited bleeding disorders, such as haemophilia, whilst they are in hospital. The congress is unique in that patients attend. It enables a wonderful networking experience, and patients contribute with presentations and experiences. Some of the myths people believe about haemophilia is that a person bleeds a lot (and faster than anyone else) because their blood does not clot. Well, I knew this is not the case. In fact, I thought I knew a fair bit about haemophilia as I have worked in the Haematology ward at The Alfred for 7 years. The Ronald Sawers Haemophilia Centre is at The Alfred, and it is the state referral service for adults in Victoria. Patients with a bleed requiring 'factor' are admitted to my ward.

Some background: A person with haemophilia lacks the protein that controls bleeding or is unable to produce sufficient protein to form a stable clot. Haemophilia A is the most common type, and a person lacks Factor VIII, with Haemophilia B it is Factor IX. The aim of giving 'factor' is to stop the bleed as quickly as possible and allow the blood to clot. In Australia, most people with severe haemophilia have treatment with prophylactic Factor replacement to prevent bleeding. Bleeding may be cause by trauma, injury, or it may be spontaneous. With haemophilia, the bleeding is usually *internal* so the symptoms are pain and swelling. Bleeding tend to be into joints or muscle. Joints are small spaces with not much room for an influx of fluid – hence the severe pain.

In Victoria, people with haemophilia are often well managed at home from the Ronald Sawers Centre and never come near a hospital ward. Needless to say, I was overwhelmed the variety of topics addressed, and I realised nothing about haemophilia can be viewed in isolation. Haemophilia effects the whole family, from parents trying to keep their child bleed free, children prevented from participating in an activity because it is deemed 'high risk' and their sibling might have a bleed, to going on holiday. Imagine having to carry Factor overseas, the customs forms, locating haemophilia centres in other countries in case of an accident – imagine getting travel insurance! There was a large psychosocial component to this congress. There were presentations from countries who have done lots of work with peer and youth councillors (often from countries with little treatment to offer their patients). How is it best to help young people who don't want to have this disorder, who are fatigued by the inconvenience of daily factor infusions? How do you help a parent address sexuality with their teen? – And I don't just mean reproduction, it seems a person can bleed from any place blood goes!

What about the future? In the developed world, people with haemophilia are reaching life expectancy similar to those without haemophilia, and a new set of problems is emerging. A person may self inject today, but what happens when their veins get tired, when their eyesight is not as good as it was and they are not as dextrous mixing up the factor, or getting the needle in? What happens when they are ill, or their partner can no longer help them, they are the carer for their partner, or they develop dementia? How do we support aged care facilities care for people with haemophilia?

There remains a disparity across the world with treatment availability. Only 30% of the world population has access to adequate treatment. In India, for example, factor is only available for bleeds and it is often expensive for the patient. Imagine the nursing challenge in providing care when if you use the available factor for one patient and you will not be able to treat the next patient who may have a more serious bleed! In Serbia, there is on person on-call for every 3000 patients.

There is SO much more I could tell you, the topic is HUGE. Every person at the Congress had a story to tell. I have learned more than ever from the congress that the best way to advocate for your patient is to let them speak. Their experience is so much greater than yours; they live with their disorder, they manage it, they know what they need from you!

Nita Lee O'Halloran, *Haematology Nurse VIC*

The HAA 2014 conference in Perth was truly a thought provoking and inspiring experience for a haematology nurse like myself. Being the recipient of the HSANZ Junior Grant, I was very excited to attend this conference and be part of a world of haematology professionals who are so committed to advancing haematology care and medicine. One of the first lectures of the first day was by Dr. Kathryn Tierney an Oncology Clinical Nurse Specialist for the Blood and Marrow Transplant Program at the Stanford University Medical Centre USA. Her wealth of experience as a haematology nurse was incredible. She spoke about the effects and severity of graft-versus host disease as well as stem cell transplantation in the older patient and the specialty nursing care they required. Working in a busy haematology ward at Peter Mac, this was invaluable knowledge. As medicine is advancing and people are living longer, we do see patients of more advanced ages becoming eligible for autologous stem cell transplants. This population of patients have very unique nursing care needs that include psychosocial, emotional and physical aspects. Other topics of interest included whether to transfuse one or two units of packed red blood cells in anaemic patients. Excessive transfusion does not come without risks. This was an interesting topic as one could argue if a patient is anaemic but not symptomatic, do they require 2 units of blood? One of the presentations noted that over transfusing can in fact suppress the drive of erythropoeisis and further exacerbate the lack of red blood cell production in the bone marrow. I found this topic to be of high relevance to my practice as it is often standard practice for medical staff to prescribe 2 units of red blood cells for transfusion in patients who are deemed anaemic. This could definitely be an area of clinical interest on our Ward heading into the future. The last topic that really resonated with me was palliative care in haematology, or rather the lack off. Too often are patients treated so aggressively with the aim of cure that their quality of life is impacted. How can we as nurses advocate for the early introduction of palliative care? As one of the presenters noted, palliative care is not about dying but living life as best one can under the circumstances. Overall, I came away from the HAA 2014 conference feeling motivated to make a difference in haematology nursing. I am excited by all the opportunities and ongoing projects in this field of medicine and hope to have a bigger role in being a part of this in the future. I would highly encourage other junior haematology nurses alike to attend the conference as the knowledge and experience gained will be of great benefit to future practice in haematology nursing. Thank you to HSANZ for your support in enabling me to attend this conference!

Lindley Randle RN, *Chris O'Brien Lifehouse, Sydney*

Amgen Sponsorship HAA 2014 Nurse Member NSW

Being able to attend a conference such as the HAA was a great opportunity to broaden my understanding and meet other members of the haematology community. When attending a large conference it's important to take some time and plan your sessions to gain as much as possible with relation to your interests and work. I also think Nurses shouldn't just stick to the nurses sessions as there is much to be gained from multi disciplinary team talks including research, treatment changes and introductions to novel therapies. However I did learn a lesson early on when attending a lecture on haemostasis, run by pathologists. It's fair to say I understood 10% of what was said, and that's being 100% generous. Of particular interest to me was a session by Georgina Whelen about her experience of opening a brand new chemotherapy day centre on the Sunshine Coast. Having spent the last year as a senior registered nurse at the brand new Chris O'Brien Lifehouse I could relate to their issues, trials and success. One particularly interesting insight Georgina shared with us was how they used staff satisfaction as a way of measuring success. Another highly informative session was a workshop run by Trish Joyce and Jacquie Jagger titled "Nurse led clinics: the what, why and how". Topics of discussion included both face to face and telephone clinics. Their inspiring presentation included information from previous studies on the benefits to both patients and the clinic outcomes as a whole by improving symptom control through structured follow up practices. By engaging with patients more, symptoms can be better managed, therefore treatment side effects and disease symptoms better supervised and acted upon. So having attended the HAA, my thoughts turn to how I can apply what I learnt in my current role. With The Chris O'Brien Lifehouse just reaching its 1st year of service, there are many exciting opportunities for nurses to take a more proactive role in the creation of nurse led clinics. The 'how' is what I find challenging! Specific insights I gained from the talks included understanding how to develop such an environment. By collaborating with stakeholders, defining concise and achievable aims and objectives, being evidenced based and collecting baseline data, a clear vision can be developed for a service and success measured once up and running. Alongside such specifics, the HAA conference certainly provided me with a solid appreciation on how our role as nurses can contribute to improving patient experience and help drive outcomes that can elevate our hospital towards a centre of excellence. I'd like to take this opportunity to thank Amgen and the HSANZ nursing group of NSW for the grant they awarded me, enabling me to attend the HAA. I am extremely grateful. My trip was well organised, stress free and accommodation that surpassed my expectations. Thank you!

HSANZ

Myeloma & related diseases registry

Real world management of multiple myeloma: An initial snapshot from the Australia and New Zealand Myeloma and Related Diseases Registry (MRDR)

Zoe McQuilten[1,7], Gabrielle Abelskamp[1], Nick Andrianopoulos[1], Bradley Augustson[2], Hilary Blacklock[3], P. Joy Ho[4], Noemi Horvath[5], Peter Mollee[6], John McNeil[1], Hang Quach[7], Erica Wood[1] and Andrew Spencer[1,8]

[1]Monash University, Melbourne, VIC, [2]Sir Charles Gairdner Hospital, Perth, WA, [3]Middlemore Hospital, Auckland, NZ [4]Royal Prince Alfred Hospital, Sydney, NSW, [5]Royal Adelaide Hospital, Adelaide, SA, [6]Princess Alexandra Hospital, Brisbane, QLD, [7]St Vincent's Hospital, Melbourne, VIC, [8]Alfred Hospital, Melbourne, VIC

Aim/Background

Myeloma accounts for a high burden of disease in the community, with evidence of variation in care and disparity in patient outcomes not explained by disease characteristics alone.

Methods

The Myeloma and Related Diseases Registry (MRDR) aims to improve quality of care through systematic data collection on myeloma management and outcomes. Data on all incident cases at participating sites (Fig 1) are collected via a secure web database.

Results

521 patients from 9 hospitals have been registered between Jan 2013-Oct 2014 (Fig 1). Data have so far been analysed on 283 patients. Diagnosis was symptomatic myeloma in 206 (72%) and MGUS or asymptomatic myeloma in 77 (28%).

Patient characteristics are shown in Table 1. Therapy data were available for 150 patients. Indication for first-line therapy was CRAB in 72%, plasma cell burden or rising paraprotein in 13%, other in 6% and not specified in 9%. Induction regimens by age and risk are shown in Figure 2.

Responses were recorded in 72 patients, of whom 14% had a CR, 24% VGPR, 41% PR, 10% minimal response and 11% stable disease. Nine patients went on to second line therapy, 3 for relapse and 6 for sub-optimal response.

Information on ASCT was available for 76 patients (Table 2).

Conclusion

Early results from the MRDR describe current management of myeloma in Australia. The MRDR will be a valuable research and clinical quality improvement tool, will enable analysis of patient outcomes and costs and effectiveness of 'real world' myeloma therapy.

Further information is available at www.mrdr.org.au

The Myeloma 1000 Project biobank linked to the MRDR commenced during 2014.

Table 1: Patient characteristics

Patient Characteristic (all patients)		Symptomatic myeloma (n=206)	
Age (median) years (IQR)	66 (58-75)	Age (median) years (IQR)	65 (58-75)
Male	163 (57%)	No cytogenetics/FISH available	72 (35%)
Co-morbid disease/s	121 (42%)	High risk*	73 (35%)
Prior malignancy	18 (6%)	Prior history of MGUS/asymptomatic myeloma	29 (14%)
Diagnosis		Symptoms at presentation:	
Asymptomatic myeloma/MGUS	80 (27%)	Renal	21 (10%)
Symptomatic myeloma	206 (73%)	Bone lesion/s	100 (49%)
		(>3 lytic lesions)	48 (17%)
		Anaemia	55 (27%)
		Hypercalcaemia	17 (8%)

*based on diagnosis, ISS, LDH, cytogenetics and FISH

Figure 2: Initial therapy by risk and age groups

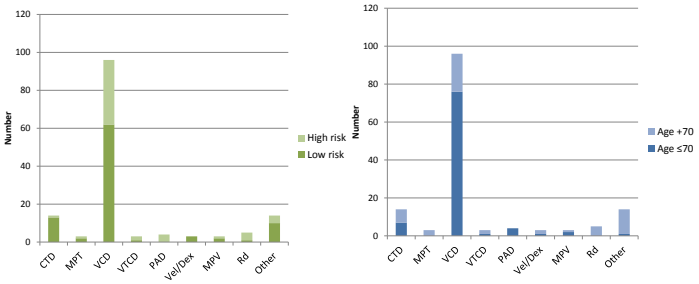
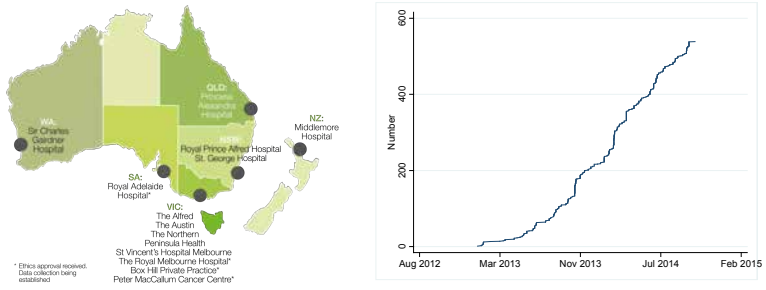


Table 2: Patient characteristics according to planned ASCT

Characteristic	ASCT *	No ASCT*	P
Number (%)	48 (63%)	28 (37%)	
Median age year (IQR)	59 (53-65)	77 (69-81)	<0.001
Male	28 (58%)	16 (57%)	0.919
High risk	15 (31%)	8 (28%)	0.806
Comorbid disease (≥ 1)	19 (40%)	22 (79%)	<0.001

*Performed or planned

Figure 1: Participating sites and case accrual to October 2014



Conflict of interest

This research is supported by The Myeloma Foundation of Australia, Amgen, Bristol-Myers Squibb, Celgene, Novartis and Takeda. These organisations had no role in analysing the data or preparing the poster.

AlfredHealth

MONASH University Medicine, Nursing and Health Sciences

A Clinical Update: Causes of Thrombocytopenia

Dr Clare Weatherburn. *Haematology Fellow Institute of Haematology RPA, Sydney University Medical School*

Thrombocytopenia is defined as a platelet count of less than 150 x 10^9/L and is commonly detected incidentally on blood tests. If not an incidental finding it can present clinically with petechiae, bruises in non-contact areas (inner thighs and inner biceps), bleeding gums or new menorrhagia but not usually before the platelet count is less than 10-20 x 10^9 /L and is usually preceded by trauma.

Platelets are produced in the bone marrow by megakaryocytes "shedding" their cytoplasm and once released into the circulation have an average survival of 8-10 days. One third of the platelets can be found in the spleen at any one time. When they are needed they move into the blood to circulate to the bleeding site.

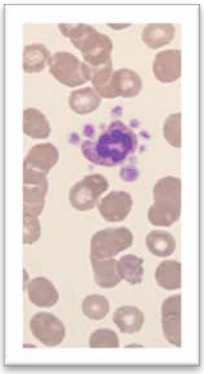


Figure 1: Platelet Satellitism around a neutrophil

Mechanisms of thrombocytopenia:

Pseudo-thrombocytopenia

Pseudo-thrombocytopenia- is a falsely low platelet count often as a consequence of difficult blood collection or prolonged tourniquet use. The platelets become activated or "sticky" in the tube resulting in a clot. The clots are accidentally counted as white cells by the automated cell counters rather than platelets and can be seen on blood film (see Fig 1).

Platelet satellitism is when platelets create a ring around white cells and therefore cannot be counted correctly and the platelet count will seem lower than it actually is. This is due to antibodies to the EDTA gel lining the collection tube (see Fig 2).

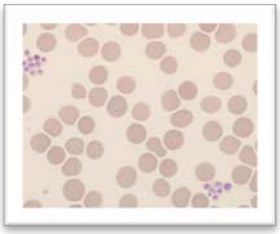


Figure 2: Platelet clumping

Dilutional thrombocytopenia

Dilutional thrombocytopenia is commonly seen in pregnancy due to the increase in blood volume without the increase in platelet production leading to an apparent reduction in platelet count. This is similarly seen during traumas when massive transfusion of red cells occurs, diluting the platelets.

Distributional thrombocytopenia

The platelets are distributed in the enlarged organs seen in conditions with splenomegaly, such as with portal hypertension in liver disease or myeloproliferative disorders.

Decreased platelet production in the bone marrow

There are 2 groups - i) Primary bone marrow failure syndromes such as aplastic anaemia and Fanconi's anaemia are very rare and won't be discussed here; and ii) external factors directly affecting marrow function such as viral infections (for example hepatitis C and HIV), infectious agents (antibiotics and antifungals) and other drugs (methotrexate, hydrea, alcohol). The mechanisms of thrombocytopenia are varied including direct infection or suppression of the bone marrow or indirectly via decreased production of thrombopoietin by the liver, leading to decreased stimulation of megakaryocytes to produce platelets.

Increased destruction of platelets

The mechanisms are broadly classified into i) immune (antibody involvement) or ii) non-immune mediated. Immune mediated destruction can be further classified into autoimmune, alloimmune and drug related mechanisms.

Immune mediated:

Idiopathic/Immune Thrombocytopenic Purpura (ITP) is the commonest cause of thrombocytopenia due to increased platelet destruction. Often there is no obvious precipitating trigger and is a diagnosis of exclusion. Sometimes the body just sees the platelets as 'foreign' and develops autoantibodies which coat the platelets labeling them for early destruction leading to thrombocytopenia.

Alloantibodies develop when the trigger is foreign such as in Neonatal alloimmune thrombocytopenia (NAIT) and Post transfusion purpura (PTP). NAIT is a rare disorder resulting from maternal platelets being exposed to the father's platelet proteins which are on the foetus's platelets as the foetus inherits half from mum and half from dad. The mother recognizes them as foreign and develops an alloantibody to destroy them and therefore destroys the unborn foetus's platelets.

PTP is a rare complication of red cell, platelet and granulocyte transfusion with formation of alloantibodies to foreign antigens thought to be in the transfused products. The platelets become coated with the alloantibody and are destroyed.

Most cases of drug induced thrombocytopenia (DITP) are thought to occur via immune mediated mechanisms although rarely they can also suppress the bone marrow, directly decreasing production of platelets. The thrombocytopenia only occurs in the presence of the drug and begins to improve within several days of cessation.

Common drugs that cause thrombocytopenia:

- Quinine and quinine derived medication and drinks (tonic water)
- Bactrim
- Rifampicin
- Danazol
- Vancomycin.

Heparin Induced Thrombocytopenia (HIT) is a rare disorder that follows administration of unfractionated heparin. It classically occurs 7-10 days after commencing heparin for the first time and leads to an immune complex's destroying platelets.

Non –Immune Mediated:

Disseminated intravascular coagulopathy (DIC), Thrombotic Thrombocytopenic Purpura (TTP) and the HELLP syndrome (Hemolysis, Elevated Liver enzymes, Low Platelets in pregnancy) are conditions associated with non-immune increased platelet destruction. They share a number of common features including a microangiopathic haemolytic anaemia, elevated liver enzymes, and thrombocytopenia. The thrombocytopenia is due to platelet consumption in micro-emboli through out small vessels.[9] If suspected, urgent referral to a tertiary hospital is indicated.

Can Mindfulness help haematology nurses improve self and patient care?

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

Mindfulness is an awareness of what we are experiencing in every moment, both the physical experience and our emotional response. It is a technique, which has gained increasing popularity in many settings, including social media, the police force, schools, prisons and healthcare. Practicing mindfulness enables us to tune into how we react, both physically and emotionally, to stress. It helps us to understand the choices that we have in the way that we respond to certain situations and circumstances. It also allows us to feel a greater acceptance of situations as they arise, and it gives us control over where we rest our attention e.g. on an uncomfortable response, to a stressful situation, or the physical sensation of our breathing. By focusing our attention on our breathing we can disengage with negative thought patterns.

The benefits of mindfulness for people living with and beyond cancer are well established, with reduced anxiety, depression, and stress most commonly reported. An emerging literature suggests that mindfulness may be valuable for healthcare professionals in improving self and patient care. The areas in which it shows promise include reduction of stress, anxiety and burnout, and also the enhancement of compassion, focus, self-awareness and relationships, as well as responses to stressful situations (Cohen-Katz *et al.,* 2005; Mackenzie *et al.,* 2006; Moody *et al.,* 2013; Abeni *et al*., 2014).

There are a few mindfulness practices that are easily incorporated into everyday life:

- Using a routine activity in order to remind yourself to bring your attention to the present moment. For example, instead of washing your hands and thinking about all the tasks that need to be done, be present to the physical sensations of the movement of your hands, and the feel of the soap and the water.
- Taking a mindful minute – count how many breaths you take in a minute (e.g. 12 breaths), and then at any time during the day if you find yourself in a stressful situation take 12 breaths and notice the physical experience of the breath, at the nose, mouth, chest or stomach.
- Use the acronym STOP – during a busy or stressful period, **S**top what you are doing. **T**ake a breath, **O**bserve what is going on around you and how you are responding to the situation, and then **P**roceed, mindfully!
- Use the acronym WAIT – **W**hy **A**m **I** **T**alking? In a heated moment, WAIT! Take a moment to think about what and how you want to say something before saying it.
- Mindful eating – instead of eating lunch whilst on the phone, reading the newspaper or replying to emails, take the time to eat mindfully; by being completely present, tasting and enjoying each mouthful.
- Many hospitals are now offering mindfulness training to staff, but there are also many fantastic resources available online.

The following websites and applications are recommended:

- www.ted.com/speakers/andy_puddicombe
- www.bemindful.co.uk
- www.breathworks.co.uk
- App – 'Smiling Mind' Guided mindfulness meditations, training and tips

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HSANZ

Pre-screening for capacity to consent as a potential family bone marrow donor

Maria Presta, *Social Worker, Allied Health, Bone Marrow Transplant Service, Royal Melbourne Hospital, Victoria*

I provide a social work service to the Bone Marrow & Haematopoietic Stem Cell Transplant Program at The Royal Melbourne Hospital. It was recently my great privilege to attend the HAA Conference in Perth this year, on behalf of our multidisciplinary BMT team, with a poster presentation on the development of best practice processes concerning potential family donors capacity to consent to prior HLA blooding testing.

The Royal Melbourne Hospital (RMH) is one of two Victorian specialised adult haematology facilities that offer allogeneic transplantation. When allogeneic bone marrow transplantation (allo-BMT) is indicated, identifying a suitable donor is often a matter of urgency. Donation by a patient's family member presents substantial psychosocial, ethical, medical and medico-legal challenges different to those presented by volunteer unrelated donors. These issues are more complex when donors have impaired capacity or are <18 years old. The World Marrow Donor Association (WMDA) sets standards for the care of unrelated donors (URD). However, to date there are no guidelines for pre-test counselling and consent for potential related donors.

With increasing numbers of transplants performed each year with our Bone Marrow & Haematopoietic Stem Cell Transplant service, raising the possibility of family donor impaired capacity, this has highlighted the need for our BMT service to explore alternative models and processes which better inform our policies and procedures. As a result, a literature search was conducted using the following databases: Medline (2000-2014), CINAHL (1995-2014), Psych INFO (1995-2014) and The Cochrane Library (1999-2013). A review of Australian national and state government health care publications was also undertaken.

There are limited references acknowledging the issue of donor capacity. Several studies address the vulnerability and perceived obligation felt by family members and highlight the need for evaluation and information about the donation process. These studies are limited and do not address the management of potential donors with impaired capacity.

The aims of our review were to:

1. Evaluate our clinical practice in the identification and screening of potential family donors.
2. Formalise RMH policies and procedures for the pre- screening, education and consent of family members prior to HLA typing.
3. Develop specific procedures for the care of potential donors who have been identified with impaired capacity.

We assessed the incidence of potential related donors under the age of 18 years or where impaired capacity for consent was identified from family searches over an 18-month period (Jan 2013 to end-June 2014) from Victoria and Tasmania for patients referred to the RMH for allo-BMT. A total of 706 family members were HLA tested between Jan 2013-June 2014. From these we identified 15 potential donors with impaired capacity (intellectual impairment (n=2), <18 years old (n=12), and psychiatric illness (n=1). In the cases of intellectual impairment there were significant medico-legal implications that delayed HLA testing and the release of results.

At RMH we have implemented a policy and procedure for the pre-screening, education and consent of all potential family donors prior to HLA tissue typing. This process aims to help address family concerns, enhance administrative processes and mitigate potential delays in the timing of donor identification. Consultation with State legal governing bodies regarding potential related donors who have impaired capacity to decide on HPC donation is essential. In Victoria, only The Victorian Civil & Administrative Tribunal (VCAT) can determine consent to a 'special procedure' in which a donor who has impaired capacity and is being considered as a HPC donor. Special Procedure refers to a potential donor who has impaired capacity and being considered for the removal of tissue for transplantation to another person. VCAT determines if the potential donor who has impaired capacity can or cannot proceed with HLA typing.

We recommend that all potential related donors be pre-screened for capacity to consent prior to HLA typing. All related donors should have access to an independent advocate to provide counselling regarding the implications of HLA matching. Specific consent for the release of results to the patient and /or the treating medical team must be obtained prior to initiating testing. Transplant centres have a legal and ethical responsibility to protect and care for all family HPC donors. Although donors who lack capacity to consent present infrequently, they raise complex ethical and legal concerns that differ from those associated with unrelated donation. Evaluation of related donors who lack capacity presents an opportunity for transplant centres to examine current policies and procedures. We recommend that all centres involved in family typing develop, implement and evaluate policies and procedures for the pre-screening and education of family members *prior* to HLA testing.

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David Collins joins the HSANZ Nurses Group Council

As a long-term member of HSANZ I decided it was time for me to step up to the mark and accept a nomination to join the council for the HSANZ Nurses Group. Having worked in haematology for the past 30 years, and having held a number of different positions within the speciality; I hope to bring some of my experience to the group. My work has included both malignant and non-malignant haematology, so I have a good overall view of the speciality. At present I run the apheresis unit at Royal North Shore Hospital in Sydney, and have a special interest in optimizing the collection of stem cells for transplantation.

I became a member of HSANZ back in 2003, not long after I migrated to Australia, and since then have watched the nurses group grow from strength to strength. From the time when we just had one day at the annual conference to now when we have three days for us to learn, interact, present and socialise with our colleagues. It has also been great to see the growth of the local chapters in each of the States expanding under the guidance of their respective council members. I look forward to working with these colleagues over the coming years as HSANZNG continues to grow.

HSANZ

CHRISTMAS QUIZ... *Win a prize!*

A copy of *Lewis's Medical-surgical Nursing*, Australia and New Zealand Edition, 4th Edition, (see previous page). The winner will be drawn randomly from the 1st ten correctly answered questions *submitted by HSANZ Associate Nurse Members* and received by email to Tracy King **by 19th January 2015**. Tracy.king@sswahs.nsw.gov.au

Quiz Questions

1. In the human body, at approximately what age does fetal haemoglobin normally diminish allowing adult haemoglobin to take over?
2. What does the apheresis acronym ECP stand for and what is it primarily used for?
3. True or false: In general, patients with Sickle Cell Disease are not immunocompromised?
4. What are Reticulocytes?
5. Why are blood products sometimes irradiated?
6. 'Acquired' haemophilia affects males, females or either sex? List 2 groups of individuals or conditions that it most commonly affects?
7. The characteristic cytogenetic abnormality, t(9;22)(q34;q11.2) is more commonly known as what?
8. What are:
    a. Coagulation Factor IX deficiency and
    b. Coagulation Factor XI deficiency more commonly known as?
9. How would a haploidentical stem cell transplant donor be related to the recipient?
10. What is the name of the newly elected HSANZ NG Vice President and what is the name of newly elected HSANZ NG Treasurer?

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

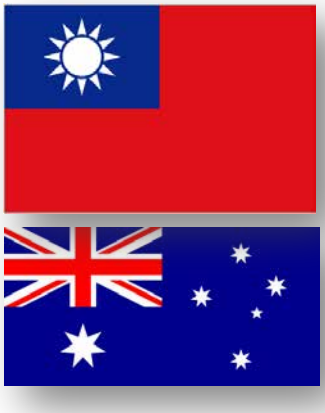
- **Would you like to get more involved with your professional group?**
- **Do you have some time to collect articles and contributions from members with the support of the Council?**
- **Do you have an artistic bone in your body (not mandatory!)? template provided!**
- **Only 3 editions per year. Next edition due April 2015 - so plenty of time to find your feet.**
- **Great for your CV!**

To find out more, please contact Tracy King

Tracy.king@sswahs.nsw.gov.au

HSANZ

Tracy Tears around Taiwan for Myeloma!



Well it wasn't quite as desperate as it sounds – apart from the mad dash for the train station due to Tracy's inability to stop talking about MM had us nearly miss the last train back to Taipei for the night!

I was lucky enough to be invited to Taiwan to speak to nurses about the 'Clinical management of patients with myeloma on targeted therapies'. Hugh Yang from Janssen hosted my visit in conjunction with clinicians from Taipei and Kaohsiung.

In preparation for my talks and visit I took the time to research myeloma in Taiwan.

Taiwan has nearly exactly the same population as Australia (around 23.5 million) but you could fit x 213 Taiwan's into Australia or X 7.5 into NZ! Taiwan is the 16th most populated country on earth. The population to country size ratio has consequences for the delivery of health care in both our countries.

In regards myeloma, Taiwan has one of the world's lowest incidences of myeloma, although this is increasing for reasons not fully understood (Huang et al 2007).

Fact	Taiwan	Australia	New Zealand
Land size	35,980km^2	7,692,024km^2	268,021km^2
Population	23.5 million	23.7 million	4.47 million
Incidence of Myeloma	M:2.5 vs F:1.96	M:7.4 vs F:5	M:5.7 vs F: 3.2
No. of MM diagnosed per year	518	1,467	297
Health System	Public	Public	Public
Quality of dumplings	**********	****	****

AIHW ACIM Books 2014, NZ Cancer Registry 2014

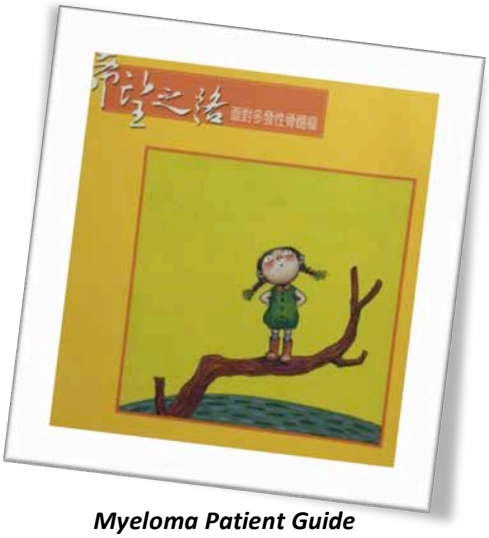
Despite the differences in size and population, our 2 countries do have much in common. The Taiwanese are very friendly people with a great sense of humour, much like the Ausi's! We both have a public health system with reimbursement systems offering our myeloma patient's access to important agents such as bortezomib and lenalidomdie. We both participate actively in clinical trials with Daratumumab and Carfilzomib on study in Taiwan as it is in Australia. Healthcare does happen on a larger scale in Taiwan and for that reason they have larger facilities and efficient systems in place to manage large numbers of patients.

I was lucky enough to visit the Chang Gung Medical Foundation Hospital (CGMH-LK) in Taipei which manages over 8,000 outpatient appointments per day, 450 emergency visits per day and has an incredible 3,715 beds. The 72 bedded haematology department manages BMTs, general haematology and contributes to an outpatient chemotherapy unit that delivers nearly 400 treatments per day! A service like that requires an efficient cytotoxic pharmacy, with Head of Pharmacy Tun Liang Chen and his team open 7.30 – 23.00 Monday to Friday with slightly reduced hours on the weekend, they work every day of the year to help deliver safe ambulatory chemotherapy to their patients.

Patients attend appointments with their doctors in a spotlessly clean and seemingly very efficiently run unit. A row of Drs rooms listed all patients to be seen on the door with patients sitting neatly in rows in front. Electronic numbers appeared above the door letting people know which 'number' patient is next. There is even a hospital 'App' so you can look up how clinics are running and when you will be seen next. A highly efficient nurses 'Observation Station' took each patients 'obs' on presentation at clinic and recorded it ready for the appointment. The payment system for co-contributions is administered via automatic tellers placed around the hospital and the outpatient pharmacy was more like an airport check-in than any pharmacy I had seen. A patient information centre provided access to a range of resources including a very cute looking 'Myeloma Patient Guide'. I was able to leave some of our patient educational resources for the nurses to show what we give our patients.

Tun Liang Chen Head Pharmacy

Nurses Observation Station



Myeloma Patient Guide

Chief nurse Wenhua Chang

On the ward Dr Wang Chief of Haematology and Chief nurse Wenhua Chang (Fanny) welcomed me and described the services and practices of their department. The ward and equipment were technologically advanced. I have to say I was quite envious and nearly stayed on to take up a job there!

I participated in 2 educational seminars whilst in Taiwan, the 1st in Kaohsiung at the southern point of Taiwan. We travelled there on the High Speed Train (HST), an enviously fast trip that puts our train system to shame.

My moderator for the meeting was a Dr Yu Chief of Haematology at Kaohsiung Veterans General Hospital. It turns out Dr Yu and I had worked together previously when he spent 2 years studying at the Hammersmith Hospital in London where I worked as a junior nurse at the same time in the late 90's. Not only did we have that in common but his father lives down the road from me in Sydney – small world.

HSANZ

Dr Yu Chief Haematology Kaohsiung

Dr Hung presented an overview of myeloma and its treatment then I spoke about the clinical care of myeloma concentrating on management of disease and treatment emergent effects. The nurses present had copies of my slides in Cantonese and I spoke slowly in English. For those of you who know me, the required slow speed of my presentation was a personal challenge but I think I managed as there followed some great questions and debate. The difficulties in understanding when best to change goals of care and introduce palliative care services was discussed alongside the psychological distress experienced by the diagnosis of myeloma. My hosts were getting itchy feat as we shared experiences and talked late into the evening….it was then that I noticed the last train left in 20mins and we had a 20 minute taxi ride to the station! Thankfully the taxi drivers share skills with those of Sydney taxi drivers and we 'flew' back to the station just in time for the last train back to Taipei. Hugh Yang my host for the trip is the father of newborn twins – we passed our trip reviewing the latest pictures sent by his wife who passes her time at home dressing the twins up for Dads entertainment! They are very cute babies, and being Taiwanese – they laugh a lot!

The following day I took part in a seminar in Taipei. The program included 2 medical talks and my session focusing on managing disease and treatment related effects. My medical colleagues had slides in English and presented in Cantonese; I had slides translated into Cantonese and presented in English!

Dr Teng gave a wonderful and humorous presentation on the 'Story of Multiple Myeloma' linking Confucius, Sarah Newbury and Dr Henry Bence Jones amongst others, in a way I'll never forget! Dr Ko presented on New Concepts in Treating Myeloma and demonstrated the importance of depth of response; sequential combination treatment strategies and the importance of managing older patients based on level of biological fitness and not just age.

Discussions followed around managing toxicities with similar issues in both our patient groups. We decided that the best question to ask our patients about their neuropathy was not "do you have tingling in your fingers or toes' but 'do you have any difficulties in using your chop sticks'. A great example of how we need to contextualise our management and care to that of the individual patient.

I always take away something from any visit to another centre wherever it is in the world. For me, the Taiwanese reinforced the importance of laughter amongst colleagues; the need to adapt assessment tools to the ethnic group and that technology can improve speed of service and we need to adopt more of it in our departments at home.

Thank you to the Doctors and Nurses I met in Taiwan for your kind hospitality and attention

感謝在台灣遇到的醫師與護士們熱情款待及照料

CNSA News

I am delighted to be invited to update the HSANZ Nursing Group with some of the goings on at CNSA. For many in executive positions the end of the year is one of reflection, looking at past achievements and seeking new opportunities to grow and prosper into the New Year ahead.

In July this year Melbourne hosted a hugely successful 17th CNSA Winter Congress, with more than 500 cancer nurses, including a growing number of delegates from New Zealand in attendance. Our key note speaker Dr Theresa Wiseman presented on patient service co-design, an in-depth engagement with users of services in the UK, to better inform the patient experience and design them to enable positive outcomes and service efficiencies, something that we could all learn from in direct service provision.

The success of this year's CNSA Winter Congress continues to flow into a range of activities and the development of strong relationships. Under our strategic direction of engaging membership, building and strengthening partnerships, CNSA was strongly represented at this year's International Conference of Cancer Nursing (ICCN), hosted in Panama by the International Society of Nurses in Cancer Care (ISNCC). Close to 30 Australian cancer nurses were in attendance with most presenting oral or poster presentations, many chairing sessions or hosting pre conference workshops, our presence was noted and valued by our international colleagues.

One highlight of the ICCN is always the Robert Tiffany Award. This lectureship was created to keep alive and honour the memory of Robert Tiffany, founding member and President of the ISNCC. Awarded to our Past President Mei Krishnasamy in 2012, CNSA continued our contribution and had the privilege of nominating Professor Julia Downing (UK) and longtime CNSA friend and honorary Aussie for this award and were excited with her success. Professor Downing gave a most inspiring presentation about universal access to Palliative Care and an insight into her work in Uganda and Serbia. Her achievements in cancer and palliative care nursing are numerous and include initiating undergraduate and post graduate Palliative Care training for nurses in Uganda, and for wider health professionals in Serbia, the first EU country to have Palliative care as part of the medical curriculum in all training universities. Professor Downing's lecture can be viewed by members at www.isncc.org.

Sandy McKiernan congratulating Julia Downing, recipient of the Robert Tiffany Award 2014

Looking forward into 2015, some new ventures are on the horizons. CNSA has been reviewing a range of international CVAD Guidelines to bring to our members recommendations on the best available evidence. We will be increasing our member portal resources on our website with more presentations and updates on educational events as well as adding an easy to use CPD record. Of course our 18th CNSA Winter Congress planning is in full swing, with this event coming to Perth for the second time since our inception.

http://www.cnsawintercongress.com.au/

It has been my pleasure to be CNSA President for the last two years and my term will come to an end in a few short weeks. Excitingly Dr. Ray Chan will be taking on the leadership with the above projects and many more to come. I wish him and the National Executive Committee all the best for 2015. For more information visit the CNSA website www.cnsa.org.au

Best wishes for Christmas and 2015,

Sandy McKiernan
CNSA President

HSANZ

‘Monkey in My Chair’ crosses the Tasmin

Dear Editor

Just a quick note to say a big thank you for your time putting together the HSANZ NG newsletter and to let you know that thanks to one of the articles included in the last edition we have been able to bring a resource not previously known about it in New Zealand, Trans-Tasman!

Carolyn Armstrong wrote a great piece about her position as Education Liaison Coordinator at Sydney Children’s Hospital and an initiative called ‘Monkey In My Chair’. We loved the idea at Leukaemia & Blood Cancer New Zealand and made contact with the organisation The Cure Starts Now Australia who distribute the kits in Australia. They were incredibly supportive and we were able to acquire Monkey In My Chair kits from them to start giving out as a resource to school aged children in New Zealand who have been diagnosed with a blood cancer or condition.

Thank you for providing a great place to be able to share and steal ideas!

Rebecca Weeks,
Leukaemia and Blood Cancer NZ

….the evidence that the kids of NZ have got monkeys! Ryu’s mum put this on his facebook page.

Expression of Interest: Formation of Special Practice Network Myelodysplastic Syndrome and Myeloproliferative Neoplasms

Dear HSANZ nurse group members.

Myelodysplastic Syndrome (MDS) and Myeloproliferative Neoplasms (MPN) are groups of rare blood cancers. There are around 1400 people newly diagnosed with MDS and 650 people newly diagnosed with a MPN in Australia each year. The need for continuing education and awareness amongst nurses is pivotal in increasing support for people affected by an MPN or MDS across Australia and New Zealand.

I am keen to hear from other HSANZ nurse members who would be interested in working together to establish a MDS and MPN special practice network (SPN) within HSANZ Nurses Group. At this early stage I am keen to hear from any member who would like to be involved in establishing a group. If there is enough interest from members in Australia and New Zealand, then the goal would be to work towards establishing a representative steering committee to work together to establish our aims, objectives and planned work ahead.

The newly produced ***‘Guidelines on Special Practice Networks’*** are available to review on the nurse’s page of the HSANZ website and provides comprehensive information about establishing a new group. Anyone interested in working together to establish the MDS/MPN SPN, I encourage you to get in touch with me at the email below.

Samantha Soggee

Email: mpn@leukaemia.org.au

The Leukaemia Foundation National Myeloproliferative Neoplasm Survey

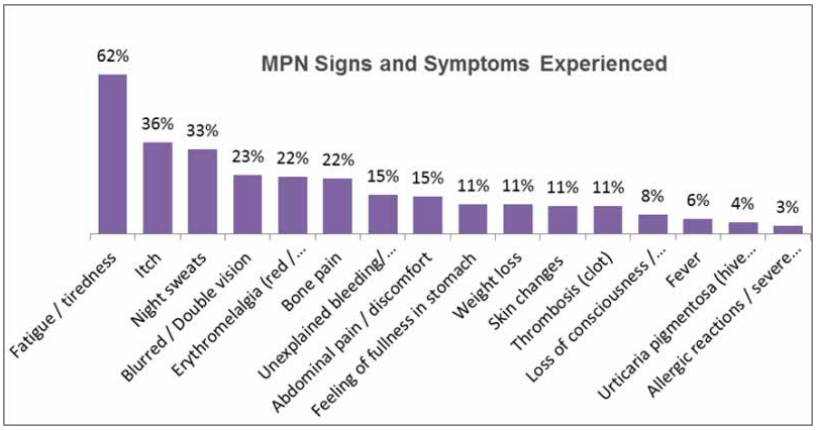
Samantha Soggee, National Myelodysplastic Syndrome (MDS) and Myeloproliferative Neoplasm (MPN) Coordinator at the Leukaemia Foundation.

Sam has a background as an Oncology/Haematology Clinical Nurse Specialist and is currently completing her Masters in Nursing Cancer/Palliative Care by research. The National MPN Survey has been conducted in conjunction with La Trobe University as part of a research thesis.
Email : mpn@leukaemia.org.au

In August this year, the Leukaemia Foundation (LF) conducted a national MPN survey. This survey was developed to help with identifying the needs of this rare and diverse patient population. There previously had been only limited research in this area and this survey helps provide a platform to help identify and meet unmet needs of people living with a MPN in Australia. The Philadelphia chromosome negative (Ph-) myeloproliferative neoplasms are a rare group of six blood cancer subtypes. Only 650 people are newly diagnosed with an MPN in Australia each year. Four of the MPN subtypes were the focus of this research – polycythaemia vera (PV), essential thrombocythaemia (ET), myelofibrosis (MF) and systemic mastocytosis (SM). Only one person with SM completed the survey, therefore, the results were not significant enough to guide future support services for this subtype. The overall aim of the survey was to help the Leukaemia Foundation understand the needs of people affected by a MPN, with the results guiding future actions towards improving services and support.

In total, 158 people completed the 45-60 minute survey. The fieldwork was conducted from 8 August to 12 September 2014. People with a MPN on the Leukaemia Foundation database were invited to participate in the survey. Ethics approval was granted by La Trobe University Faculty Human Ethics Committee on 13 May 2014.

The gender distribution of participants was in favour of females, with 65% of participants being female and 35% being male. There was an equal distribution of respondents from regional (50%) and metropolitan (50%) areas.



The most prevalent symptoms reported by participants prior to being diagnosed with a MPN were fatigue, itch, night sweats, blurred/ double vision, erythromelalgia (red/tingling hands and feet) and bone pain.

Symptoms more commonly reported among females include 29% blurred/double vision (compared to 10% in males). Symptoms more commonly reported among males include 45% itch (compared to 30% in females).

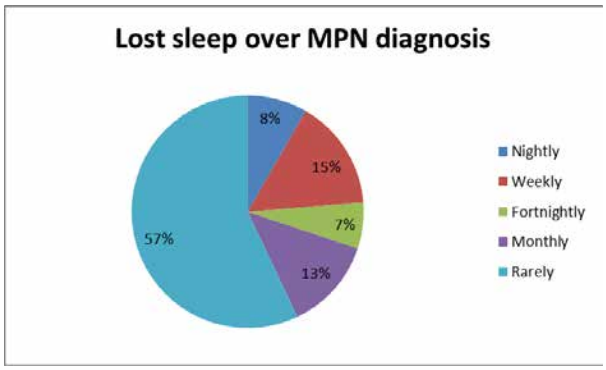
Only 19% of respondents were offered participation in a clinical trial but 74% of them chose to participate in the trial offered to them. Another 64% of people not offered a clinical trial reported they were likely to have participated in a trial had one been offered to them. In comparison to data from previously conducted LF surveys, MPNs were offered more clinical trial participation than lymphoma (15%) and less than myeloma (35%), myelodysplastic syndrome (31%) and chronic myeloid leukaemia (36%).

When asked about treatments, the majority (92%) of participants knew that MPNs were not curable without a bone marrow transplant. However, 7% of participants still thought MPNs were curable without a bone marrow transplant whist

the remaining 1% were unsure.

The majority of participants (60%) stated that their treatment decisions were shared between themselves and their treating doctor.

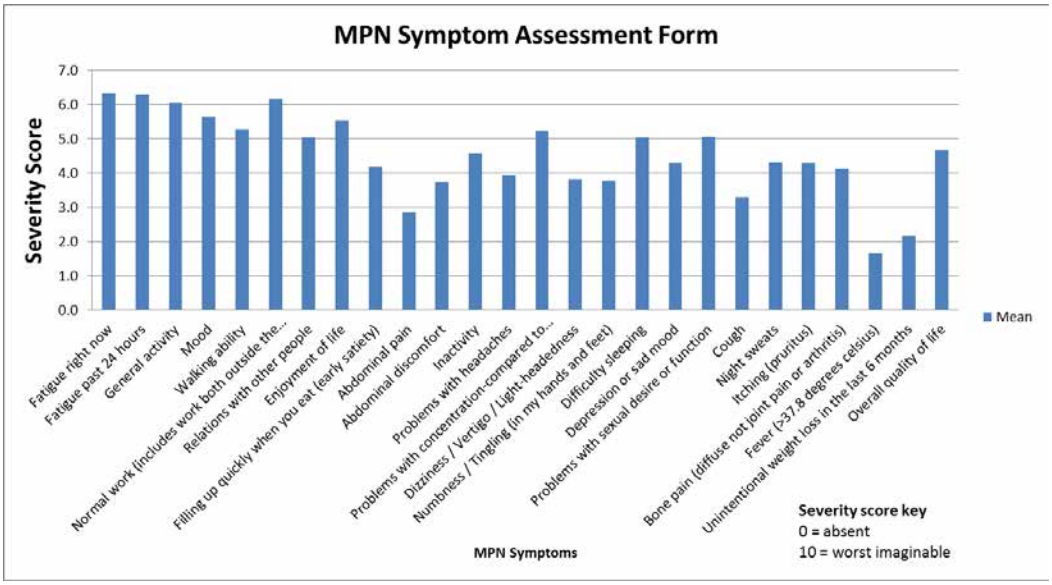
When considering the effects of an MPN diagnosis, 63% of people thought about their MPN often (42%) or always (21%). Additionally, 42% of people reported losing sleep over their MPN diagnosis. Almost 1 in 2 people (48%) felt isolated living with their MPN diagnosis.



The survey also incorporated a validated tool which was used to collect data and provide a snapshot of the symptom burden of people living with a MPN in Australia. The tool that was used was the 27 item, Myeloproliferative Neoplasm Symptom Assessment Form, developed by Scherber et al 2011. A score of 4 or more was considered as having a significant impact on a person's life. Overall, people who participated in the survey reported a mean severity score of 4 or more for fatigue, general activity, mood, walking ability, normal work (includes work outside the home and daily chores), relations with other people, enjoyment of life, early satiety (feeling of fullness in the stomach), inactivity, problems with concentration (compared to prior having an MPN), difficulty sleeping, depression or sad mood, problems with sexual desire or function, night sweats, itching, bone pain and overall quality of life. These results depict the debilitating impact that the symptom burden has on the lives of people living with a MPN in Australia.

This is the first insight and documented evidence of the disease experiences and impact that the disease burden has on the lives of people affected by these MPN subtypes in Australia.

The findings of this research study give the Leukaemia Foundation a platform on which to guide and improve its support services for people with a MPN.



Inherited Bone Marrow Failure Syndromes

Dr P M Barbaro, BMedSci , MBBS, FRACP FRCPA.
Haematologist, The Children's Hospital at Westmead, Dept Haematology, Children's Medical Research Institute

Introduction

Inherited bone marrow failure syndromes (IBMFS) are a group of rare, distinct disorders where one or more blood cell lines fail to be developed appropriately. IBMFS are usually diagnosed in childhood, however there is increasing recognition of these disorders in adult patients, and many children with IBMFS are now living into adulthood, thus it is likely that all people working in the haematology field will encounter a patient with an IBMFS in their career. These disorders have variable clinical presentations, however they share some haematological characteristics and in many conditions the ultimate cure can only be made through Haematopoietic stem cell transplantation (HSCT). Many of these conditions are associated with non-haematological congenital anomalies such as musculoskeletal, renal and cardiac defects, which can impact on the health of the patient, and have implications for treatment. These conditions are also associated with an increased risk of developing cancers, both haematological cancers (usually Acute Myeloid Leukaemia) and non-haematological solid tumours. Table 1 lists the most common IBMFS, and summarises the clinical, genetic and pathophysiology of each condition.

Clinical Presentation and diagnosis

Most IBMFS present with signs and symptoms of cytopenias (bruising/bleeding, anaemia, infections) along with a FBC which highlights the cytopenias. Occasionally they will present with congenital anomalies or due to a known family history of the particular disorder. Clinical examination may give clues to the underlying diagnosis, such as café-au-lait spots in Fanconi Anaemia (FA), nail, skin and oral changes in Dyskeratosis Congenita (DC), or the classical tri-phalangeal thumb of Diamond Blackfan anaemia (DBA).

In many cases, there is no obvious clinical signs, and the diagnosis in made through laboratory investigation. Usually one or more cell lines will be effected on the FBC, and more often than not, the patient is macrocytic and has a raised foetal haemoglobin, both non-specific sign of bone marrow failure. A bone marrow biopsy may show marked hypocellularity as in FA, DC, Shwachman Diamond Syndrome (SDS), or it may show a distinct lack of one particular cell type as in DBA, Severe Congenital Neutropenia (SCN) or Congenital Amegakaryocytic Thrombocytopenia (CAMT). Screening diagnostic testing is helpful in many of these disorders (see Table 1), and many of these tests are now being performed on all patients who present with Aplastic Anaemia, as the finding of an IBMFS changes the treatment options for these patients.

Ultimately many of these patients will have their diagnosis confirmed with genetic testing, however a mutation in one of several genes can cause many of these conditions, and thus multiple genes need to be sequenced to make that diagnosis. It is now possible, through Next Generation Sequencing, to analyse many genes at the one time, speeding up this process.

Treatment Options

There are specific treatments for specific types of IBMFS. For patients with FA and DC, male hormone therapy in the form of Androgens, are effective in raising the blood counts. These have unwanted side effects, such as masculinisation and liver defects, which can limit their usefulness. Patients with DBA will often respond to corticosteroids such as Prednisolone, with increase in reticulocyte counts and haemoglobin. Again, long-term use of these medications can impact on health and endocrine function, so the lowest possible dose to maintain an adequate haemoglobin should be used. Granulocyte Colony stimulating factor (GCSF) is effective in increasing neutrophil counts in patients with SCN and SDS, however long term risk of AML has been an issue, although there is no clear evidence of this being the case. Again, the lowest dose required to raise the neutrophil count, and reduce infections should be used to limit these potential side effects.

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When these specific therapies fail, or when there is a contraindication to them, transfusion therapy can be used to support haemoglobin and platelet counts, and at this stage HSCT can also be considered. HSCT is potentially a cure for the haematological manifestations of these conditions, however does little for the other congenital anomalies seen. Often, the conditioning regimes used for HSCT in patients with IBMFS need to be modified, as these patients can have a higher rate of side effects from standard conditioning regimes.

Long Term complications

Patients with IBMFS can have multiple problems either from the therapy they receive (eg HSCT) or due to the underlying disorder, and often require input from multiple subspecialties. Many IBMFS have a higher rate of haematological and non-haematological malignancies, and these need to be monitored for throughout their life time. Specific organ defects are associated with the IBMFS, for example patients with DC can develop lung fibrosis, avascular necrosis of bones and liver cirrhosis, all of which may be accelerated after HSCT. SDS patients require gastroenterology input to manage pancreatic insufficiency. Bony defects in FA and DBA often require orthopaedic surgical procedures to correct and also increase function of the thumbs and hands.

Conclusion

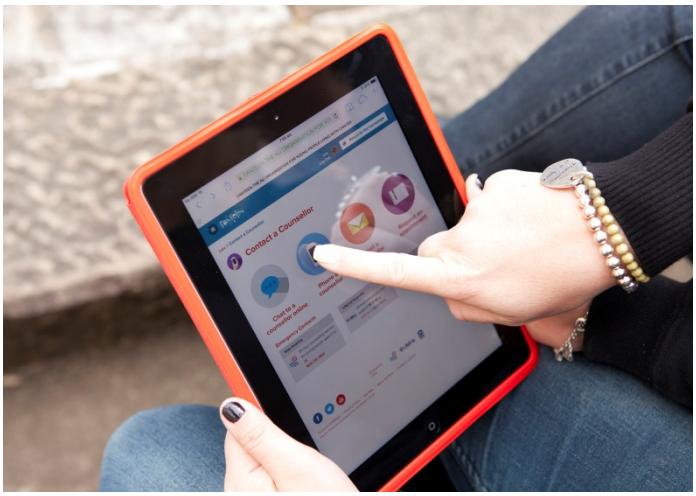
IBMFS are rare, however the needs of these patients are often great due to congenital anomalies, organ defects and increased risk of malignancy. These syndromes require specific therapies, and, although being rare, should be considered in the differential diagnosis in patients presenting with cytopenias.

Table 1. Characteristics of the most common Inherited Bone Marrow Failure Syndromes.

AML – Acute Myeloid Leukaemia; HSCT – Haematopoietic Stem Cell Transplantation; GCSF – Granulocyte colony stimulating factor.

Name	Haematological Manifestations	Other clinical associations	Screening Test	Pathophysiology	Number of Genes Involved	Predispoition to Cancer	Haematological Treatment options
Fanconi Anaemia	Pancytopenia, Hypocellular bone marrow	Abnormal face, Café-au-lait spots, Forearm and thumb abnormalities, Poor growth, renal and cardiac defects	Chromosome Breakage studies	DNA double strand break repair defect	16	Yes - AML, Solid Tumours (Squamous Cell Carcinomas)	Androgens, HSCT
Diamond Blackfan Anaemia	Anaemia, lack of red cell precursors in marrow	Craniofacial abnormalities, thumb abnormalities, renal and cardiac abnormalities	Red Cell ADA	Ribosome defect	> 10	Yes - AML, Solid Tumours (Osteogenic Sarcoma)	Steroids, Transfusions, HSCT
Severe Congenital Neutropenia	Neutropenia, lack of mature neutrophils in marrow	Usually none, however, congenital neutropenia may be associated with other syndromic diagnosis.		Abnormal protein leads to cell death	> 4 in Non-sydnromic	Yes - AML	GCSF, HSCT
Dyskeratosis Congenita	Pancytopenia, Hypocellular bone marrow	Skin and nail changes. Oral cavity lesions. Lung and liver disease.	Telomere length analysis	Short telomeres lead to cell death	10	Yes - Solid Tumours (Squamous Cell Carcinomas), AML	Androgens, HSCT
Amegakaryocytic Thrombocytopenia	Thrombocytopenia / Pancytopenia, lack of megakaryocytes in marrow			Thrombopoietin Receptor dysfunction	1 - *C-MPL*	Yes - AML	Transfusions, HSCT
Shwachman Diamond Syndrome	Neutropenia / Pancytopenia, hypocellular marrow	Short stature, Pancreatic insufficiency, musculoskeletal abnormalities	Fecal elastase, Plasma isoamylase	Ribosome / Mitosis defect	1 - *SBDS*	Yes - AML	GCSF, HSCT

WORLD FIRST WEBSITE FOR YOUNG PEOPLE AFFECTED BY CANCER

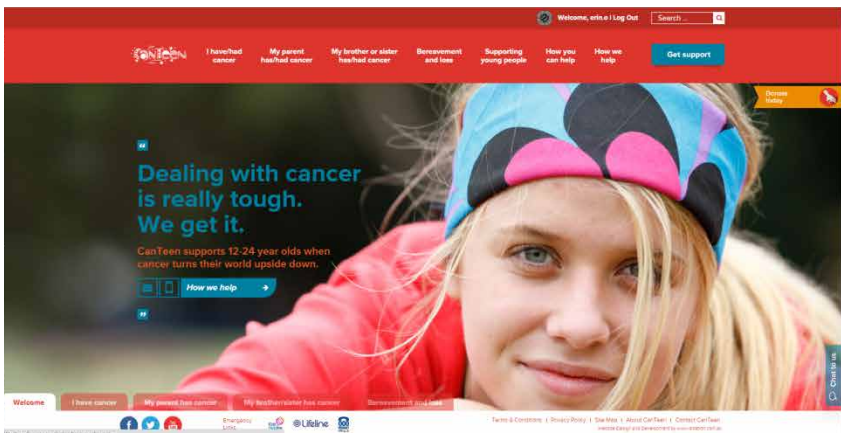


A groundbreaking new website has been launched to support young people affected by cancer, whether they're dealing with their own or an immediate family member's cancer (or death from cancer).

The CanTeen Online Support Platform sets an international benchmark with its world first combination of 7-day access to professional CanTeen counsellors and 24/7 access to youth-specific information and an interactive, personalised online peer support community.

Young people dealing with cancer are 5-6 times more likely to be at high risk of developing mental health issues like anxiety and depression. The instant peer and professional support offered through the CanTeen Online Support Platform will help combat the main triggers of psychological distress, including feelings of isolation and a lack of information.

If you know a family dealing with cancer, please send them the website link or encourage them to watch this short video. Alternatively, if you would like to order a promotional CanTeen USB key containing the video, please call 1800 835 932 or email support@canteen.org. au.



www.canteen.org.au/nowwhat

Introducing CanTeen's online support platform for 12-24 year olds. www.canteen.org.au/nowwhat

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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. ***Please note for three of the groups (NSW, VIC and TAS) will have a change of leadership in the coming months - See below.***

North Island, New Zealand

Catherine Wood

There have been four education meetings run in the lower North Island this year. Topics covered include NHL, ALL and bone marrow biopsies. The sessions have been split between Wellington and Palmerston North. We have had great speakers this year who have very generously given up some of their precious spare time to present to us. We have also had generous sponsorship from Gilead, Janssen and Roche – without their support these meetings would not be able to take place in their current format.

Planning for the 2015 programme is underway. We are currently reviewing the evaluations and topic suggestions from this year's sessions to formulate a programme for next year for the Wellington / Palmerston North region. Next year there will also be some education evenings for the upper North Island which is very exciting. Details for all sessions will be in the first newsletter in 2015.

If you have any suggestions for topics or would like more information about the education sessions, then please feel free to contact me at Catherine.Wood@ccdhb.org.nz I hope that you all have a safe and happy Christmas.

South Island, New Zealand

Jane Worsfold

The Christchurch HSANZ Nurses group hosted an education evening for Haematology & Oncology nurses at Christchurch Hospital. Satellite centres were invited to link in for tele-conferencing. The topic was "FISH Philosophy" which was enjoyed by the 20 attendees. Refreshments were kindly provided by Leukaemia and Blood Cancer NZ.

It is continuing to prove challenging to get staff & outlying centres to attend but we'd love to have more nurses join us. I would encourage any nurse interested in haematology on the South Island, to get in touch if they would like to be kept updated to our activities.

Victoria

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HSANZ nurses group – Victoria have had another productive year, with an interesting showcase of presentations and speakers, and continued excellent attendance at meetings. We are working really hard to recruit more members and campaign at each meeting. We are grateful to our sponsors who demonstrate commitment and interest in supporting haematology nurse education both in the metropolitan and regional areas. We were excited invite applications for grants to attend HAA Perth and awarded 3 this year – 2 to successful abstract submitters and 1 to a junior haematology nurse. All grant recipients will write a report for the next HSANZ nurse's group newsletter and the 2 presenters will speak at our final Victorian educational evening for 2014. **Hayley King will be taking over as Chair of the VIC group as of Feb 2015**. Hayley would welcome contact from VIC members Hayley.king@mh.org.au

We are looking forward to another fantastic year in 2015!!

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Tasmania

Gillian Sheldon-Collins

A successful educational dinner was held in Hobart on 7th November. Once again this was a successful collaboration with CNSA. 36 nurses attended and all the evaluations were very positive. The topic was "Cancer Incidence, Genetics and Screening in Tasmania". Tasmania has a relatively stable homogenous population so is an excellent environment for longitudinal population studies. We are also blessed with the University of Tasmania and the Menzies Research Centre. We invited 3 guest speakers who really engaged with the audience and each other to provide an enjoyable and interesting night. Our first speaker from the Tasmanian Cancer Registry informed us of the latest local cancer incidence data according to types of malignancy, gender, age and postcodes. Our next speaker described her ongoing longitudinal research, initiated by a previous generation, into familial haematological disorders. She was able to show us the family trees of those affected with CLL and NHL in particular, spanning several generations. Our third speaker presented Tasmanian cancer screening and genetics, honing in on the "Angelina Jolie Effect" on the increased demand for testing for the BRCA 1& 2 breast cancer genes, the hitherto unknown families this unearthed, and the challenges this knowledge poses for both the genetic counsellors and the young affected women without definitive medical evidence. A big thank-you to Amgen as our committed sponsor. We hope to expand and increase our educational dinners next year, enhance opportunities for state-wide engagement, researchers and speakers and provide videoconferencing for nurses in regional Tasmania.

Bronwen Neely will be taking over regional Chair for Tasmania. Bronwen.neely@dhhs.tas.gov.au

New South Wales/ ACT

Tracy King

Our local group have had a busy year hosting educational events. With the usual 3 in metro Sydney plus 1 in Gosford and 1 in Wollongong we also co-hosted a disease specific myeloma day in Sydney with co-hosts Celgene and supported a BMT focused day for nearly 100 nurses at RPA in Sydney. Kathlene Robson hosted a dinner meeting in Canberra and is working on hosting more in 2015. We were also very proud to have been able to support a HSANZ NG local member to attend HAA 2014 in Perth with a grant raised locally, to go towards costs. Prue Pendlebury from Sydney Children's Hospital Haem / Onc / BMT was the successful grant winner. With generous support from Amgen we were also able to award 2 local members sponsorship to attend the HAA conference through a competitive application process. Congratulations to Lesley Richardson from Gosford Hospital and Lindley Randel from Chris O'Brien Lifehouse. After 6 or more years working to host meetings and events in NSW / ACT I am stepping back from active participation in HSANZ NG locally, to take a back seat and concentrate on my studies. It has been a rewarding time for me but I look forward attending meetings rather than hosting them! David Collins takes over leading NSW / ACT chapter and Sally Taylor (Nurse Educator Haematology RPA) is joining the local organising committee. I would like to thank all haematology nurses for their participation and support over the years and in particular, Jacqui Jagger and Grainne Dunne for their support and friendship. The local team already have meetings for 2015 planned and will be continuing to host and support educational events for haematology nurses in the area. Please contact David Collins directly for any matters regarding NSW / ACT going ahead.

Over and out!

Please contact David Collins for NSW / ACT matters. David.collins@health.nsw.gov.au

Conference Calendar

Date	Conference	Details
February 2015		
6th – 7th February	**Flinders Survivorship Conference**	Adelaide, South Australia Abstract submission open: deadline 07.11.14 Registration open: closes 07.11.14 http://www.survivorship2015.org/registration/
11 – 15 February	**BMT Tandem Meeting**	San Diego, CA, USA Abstract submission open: deadline 09.10.14 Registration opens 01.08.14 http://www.cibmtr.org/Meetings/Tandem/Pages/index.aspx
March 2015		
18th March	**Rural Innovations Changing Healthcare**	Multiple venues across NSW – refer to event website for details. Abstract submission deadline 01.02.15 Registration open, deadline 10.03.15 http://www.aci.health.nsw.gov.au/networks/rural-health/about/rich
22th – 25th March	**EBMT**	Istanbul, Turkey. Abstract submission open Sept 2014 Registration opens: European autumn 2014 (no specific details yet) http://www.ebmt2015.org/
April 2015		
23 – 26 April	**Oncology Nursing Society Annual Conference**	Orlando, Florida. Registration opens 05.12.14 http://congress.ons.org/
May 2015		
6 – 9 May	**ALLG Meeting**	Melbourne, Australia http://www.allg.org.au/events.html
June 2015		
14 – 16 June	**CNSA 18th Winter Congress**	Perth, Australia Abstract submission: open, closes 06.02.15 Registration opens January 2015 http://www.cnsawintercongress.com.au/
July 2015		
8 – 11 July	**International Society of Nurses Conference**	Vancouver, Canada Abstract submission: closes 26.01.15 Registration open www.isncc.org

HSANZ

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