HSANZ NG News Jun 2012

Volume 6, Issue 1

HAEMATOLOGY SOCIETY OF AUSTRALIA AND NEW ZEALAND NURSES GROUP

HSANZ NG News Volume 6 Issue 1

Haematology Nursing

From the president

Autumn 2012

Dear members and colleagues,

This edition of Haematology News is truly a bumper addition. Our new editors, Tracy King and Allan Hayward have been working like media magnates to continue to develop the News. Of course, this isn't possible without your input . As your work continues to develop in all kinds of innovative ways, your publications (in the News and elsewhere) share your work and sustains and develops best practice across all areas of haematology nursing.

In this issue we have a breadth and depth of exciting content. There are comprehensive conference reports from both the Tandem BMT and the EBMT meetings where our very own Tracy King won 'Best Abstract Prize' for '*The Devils Tic Tac's' – Understanding the adverse events of steroid therapy associated with the treatment of multiple myeloma'* There are updates from the Leukaemia and Blood Cancer Foundation NZ; EdCan; activities in Gosford, NSW with regard to their support group; and, of course, updates from the regions. I am very excited to be able to announce our two new sections; Haemophilia Focus – where we are happy to be able to include two excellent articles by Claire Bell and Grainne Dunne - as well as Paediatric Focus – where Grainne shares her expertise and insights into the complex issue of transition for long term paediatric haematology patients. This edition we also have an excellent clinical update about cutaneous T Cell lymphoma by Odette Blewitt.

We have also included a piece about the 'how to of abstract writing'. The call for abstracts has gone out for HAA 2012 to be held in exciting and sunny Melbourne – so start thinking about that, if you haven't already.

My term as president comes to an end later this year – I have thoroughly enjoyed the challenges, opportunities and privilege in being able to be a founding member and president of our group and look forward to a great future for us as Tracy King takes the reins as president from October. Of importance, this means that *elections for the position of vice president and treasurer will be held this year* so chat to any one on the exec committee if you have even a vague interest – it is a great experience and you will be supported by other members of the committee. Plus it looks great on your CV!

If you have not yet gotten around to joining the HSANZ Nurses Group – you can download a copy of the membership form from the HSANZ website:

http://www.hsanz.org.au/join/documents/2012HSANZ_MemForm_001.pdf

– it really is great value for $55 a year, but more importantly, I believe that your membership of this, the only professional organisation for haematology nurses, says something about you as an expert and specialist and, by having a strong membership, says a lot about haematology nursing as a discrete specialty - so stand up and join up!!

Moira Stephens

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This edition compiled and edited by Tracy King and Allan Hayward

HAA 2012—Melbourne

NB: ABSTRACTS OPEN for HAA 2012 Melbourne VIC DEADLINE 2ND JULY.

http://www.fcconventions.com.au/HAA2012/

In preparation for HAA 2013 and to offer some helpful advice to those of you thinking about submitting an abstract, we are re printing the short article below.

HOW DO I WRITE AN ABSTRACT?

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

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

The title should be short and give an accurate indication of what you will talk about. The reader should be able to read the title and decide if the abstract is of interest to them.

The introduction provides a brief background and explains what you looked at and why you did it. In essence, use the introduction to detail why you did the work.

Methods: What did you do? Use one or two sentences to explain what you did or how you tested your question.

Results: What did you find? The key part of the abstract. This section provides any data obtained in its analysed form. As a rule of thumb, the layout of the results section parallels that of the methods section.

Conclusions: What does it mean? The hard bit! The abstract should end with a concluding sentence / paragraph pointing out any potential significance of the findings to clinical practice or more specifically, the field of interest.

SOME FURTHER TIPS

Make sure your abstract is clear.
Always read and follow the conference abstract submission guidelines – this is what your abstract is marked against.
Ask someone with experience to help you write your first one. Any of the committee members would be happy to help.

Four criteria to think about:

Originality: abstracts containing significant new findings or that present innovative practice will be given higher scores than those that describe updates or modifications to older findings

Quality: abstracts that contribute to the knowledge of haematology nursing practice and /or /patient care and demonstrate the use of sound scientific (qualitative or quantitative) methodology or evaluation will be given higher scores.

Importance: abstracts that present new information about practice or care, or that add relevance to the broader context framed by the subject heading, will receive higher scores.

Presentation: higher scores will be awarded to abstracts that clearly state the specific objectives to be attained, the methods used, the main results, and provide a concise interpretation of the findings or discussion.

ANF Online CPD Site: IFOLIO

CPD FOR NURSES AND MIDWIVES: AUSTRALIAN NURSING FEDERATION ONLINE SITE – IFOLIO

The iFolio has been specially designed to assist nurses and midwives to maintain a professional portfolio and to continue professional development in order to retain their nursing registration. With this in mind the iFolio presents a number of features that can be used to satisfy an audit and maintain evidence of necessary training, experience and learning.

What can I do with my iFolio?

- ✔ Take quizzes and read the related clinical updates
- ✔ Watch video tutorials covering a variety of subjects
- ✔ Create, print and manage your curriculum vitae
- ✔ Print and manage your achievement certificates
- ✔ Store important files required for an audit
- ✔ Prepare and submit your iFolio for audit

Keep up to date with E-Alerts

E-ALERTS: AN EASY WAY TO KEEP UP TO DATE WITH THE LATEST NURSING AND SUPPORTIVE CARE RESEARCH

A fast and simple way of staying on top of the latest research is to get the table of contents from top journals delivered directly to your inbox. To do this, simply go to the journal website and sign up for e-alerts. You may need to register first, which is free and usually just requires your email, name, a username and a password.

European Journal of Oncology Nursing: Go to http://www.ejoncologynursing.com/ and go to Journal info tab and Sign up for e-alerts. (Free registration required)

Cancer Nursing: Go to http://journals.lww.com/cancernursingonline/pages/default.aspx and go to eTOC. (Email address required)

Supportive Care in Cancer: Go to http://www.springer.com/medicine/oncology/journal/520 and go to Alerts for this journal. (Email address required)

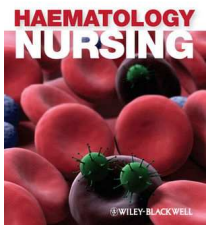
Journal of Pediatric Oncology Nursing: Go to http://jpo.sagepub.com/ and go to Email alerts. (Free registration required)

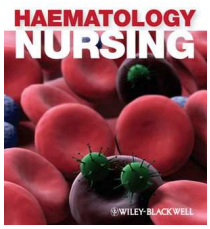
Blood: Go to http://bloodjournal.hematologylibrary.org/cgi/alerts (Email address required)

Collegian: Go to http://www.collegianjournal.com/ go to Journal info tab and go to Sign up for e-alerts. (Free registration required)

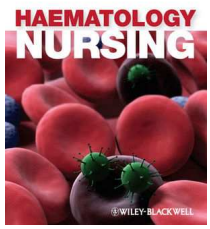
Jessica Roydhouse, Senior Research Officer, Cancer Nursing Research Unit (CNRU), The University of Sydney.

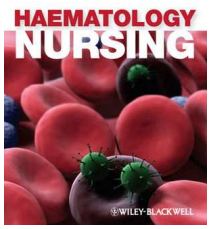
New Haematology Nursing Text





Marvelle Brown & Tracy Cutler UK (editors)
ISBN: 978-1-4051-6996-7
Available through Wiley-Blackwell
http://au.wiley.com/WileyCDA/WileyTitle/productCd-1405169966.html





EdCaN: Cancer Education

Hello again, newsletter readers. For those who don't know me, I am lucky enough to work for EdCaN as a Nurse Educator. EdCaN is funded by Cancer Australia as part of their Strengthening Cancer Care initiative. The project provides a set of competency standards and a suite of learning resources targeted at building capacity in the nursing workforce, with the ultimate aim of improving health outcomes for people affected by cancer. All nurses, no matter where they work, may be called on to look after people with cancer. This means that all nurses need information on quality Continuing Professional Development (CPD) opportunities in order to develop the skills they need to provide safe and effective care to these people. To this end, the EdCaN team recently presented at the Australian Practice Nurse Association annual conference in Melbourne, and it was fantastic to talk to our practice nurse colleagues about their experiences in cancer care.

On a personal level, it was a real eye opener to the kinds of issues nurses in different specialties face— for a Specialist Cancer Nurse, primary care is like a different world! But it was also a great lesson in communication. I would encourage everyone to think about the nurses that work around you— perhaps in surgical wards, or day units, or, indeed, at a GP clinic— and what their learning needs might be, in terms of caring for a person with cancer. The EdCaN learning resources are designed to support the CPD needs of all nurses in cancer care regardless of experience or setting.

Regular newsletter readers will know that EdCaN has a number of learning resources that may help to inform the practice of nurses working with people who have a haematological malignancy. Specifically, there is a supporting module that gives an overview of the Fundamentals of haematopoietic stem cell transplantation as well as two haematology-specific case-based learning resources: Ellie, a 4-year old with acute lymphoblastic leukaemia, and Arthur, an 84-year old with Non-Hodgkin's Lymphoma.

These learning resources contain a number of learning activities, as well as links to other interesting information. The case-based learning resources also include a number of videos which are designed to illustrate some of the issues faced by the person with cancer, and their family and friends. If you would like to learn more about using EdCaN to inform CPD opportunities, you can contact the team on edcanpsgc@qut.edu.au. Or, feel free to contact me directly on s.pike@qut.edu.au. We've also recently launched a Feedback button on the EdCAN website, which you can use for any questions or comments you might like to make.

Shannon Pike Nurse Educator s.pike@qut.edu.au Ph 07 3138 0135

Leukaemia & Blood Cancer NZ

leukaemia & blood cancer new zealand
our mission is to care, our vision is to cure

In January this year, the Leukaemia & Blood Foundation (LBF) became Leukaemia & Blood Cancer New Zealand (LBC).

The decision to change our name came about after conducting extensive market research with the help of brand experts. We asked our patients, supporters and the general public what they thought about our organisation, and understood of our brand. We were surprised and concerned by some of the results, for example:

Close to 30% of respondents thought the 'blood' part of our name meant that we screened or processed blood donations.

Only 12% of the general public realised we work on behalf of New Zealanders living with lymphoma, and only 19% of respondents realised we supported myeloma patients and their families.

The strong recommendation was that we introduce the word **cancer** into our name to help increase awareness.

We have heard of so many examples where patients living with leukaemia, lymphoma and myeloma are not aware of the fact they have a form of cancer. This is also a challenge that is faced by many of our international counterparts, several of whom are also changing their names to help socialise the term 'blood cancer', thus ensuring patients and families are aware of the seriousness of the condition.

However, we realise many patients and families we support are not living with conditions that are blood cancers. Our service remains the same and we continue to support people affected by non-malignant blood conditions, as we have always done.

In 2011, LBC's Support Services team celebrated our tenth anniversary of providing support to patients and families in New Zealand. In ten years, we have gone from having one part-time staff member, to now having five full-time Support Services Coordinators around the country.

Our team are kept busy, providing support in a myriad of different ways. As well as receiving referrals from hospital and community health professionals alike, we operate a freephone number for self-referrals and enquiries; visit patients in hospitals and at home; run support groups; moderate an online support forum website; respond to email enquiries and write a range of patient information booklets.

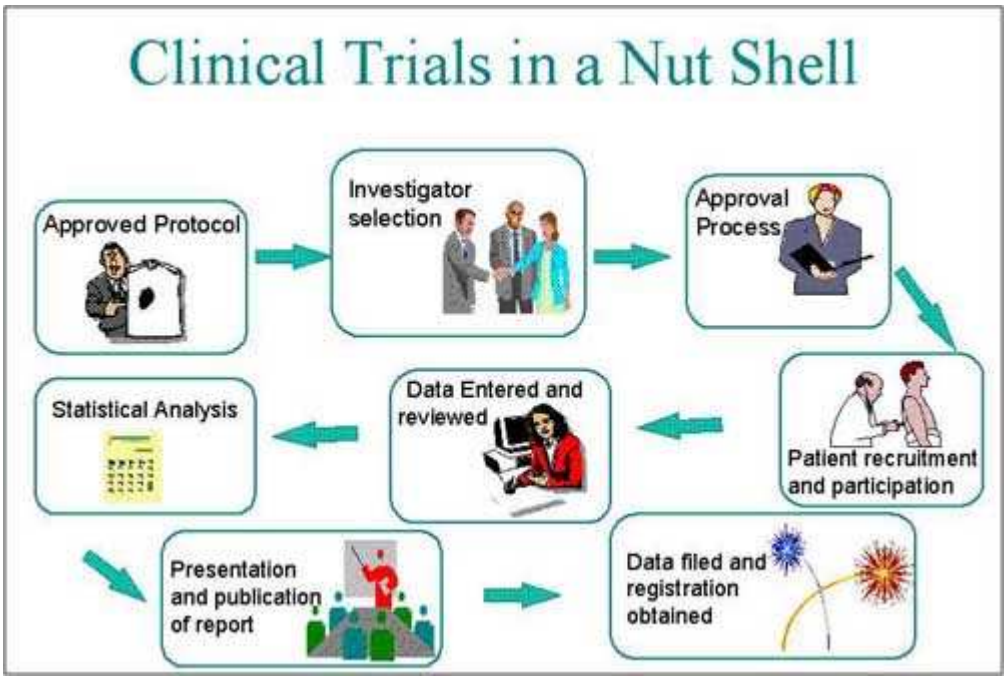
This year we have several special events coming up. The annual Winter Workshop, an evening for health professionals, tours the country in July; and the second Blood Cancer Patient Forum, a conference for patients and families, is happening in Auckland on September 15th.

If you'd like to know more about our team and what we do, please feel free to contact your local Support Services Coordinator on 0800 15 10 15, or email info@leukaemia.org.nz.

NEW – Clincial Trials Focus

Let's start at the very beginning...a very good place to start. Now, if only the world of clinical trials were as easy to explain as teaching curtain clad kids to sing!

I've decided to open this new and exciting edition to the newsletter with a brief and basic overview of clinical trials and then give a snapshot of a current study. We all have a responsibility to deliver evidenced based health care, the foundation of which is the implementation of the findings of clinical research. Having a broader understanding of the what, why and when, of clinical trials can help us all, in particular your clinical trials teams!



So what is a clinical trial?
In broad terms clinical trials are designed to answer a question. It is a research study that tests new treatment options and approaches.
For example:
Is this new treatment safe?
Is it effective?
Is it any better than the one's we already have?
What is the incidence and severity of the side effects?
How does the new treatment impact on patients QOL?
Often the trial sets out to answer all of these questions.

Before a new drug even makes it to a clinical trial it has been through a comprehensive range of laboratory based testing (pre-clinical). Progressing to clinical trial involving our patients on the wards and clinics takes a lot of time and is incredibly expensive. A new drug that progresses to the point of being tested in humans (and the majority don't make it this far) – then begins a series of stages of further testing. These stages are termed the 'phases' of clinical trials.

What are the different phases and type's of clinical trials?
Clinical trials are categorised into different phases.

Phase 1*:* Researchers trial a drug in a very small cohort of participants to assess its safety, side effect profile and safe dosing range. The main aim of a trial in this phase is to look at safety not efficacy.
Phase 2*:* The trial drug is given to a larger group of patients to see if it is effective and to further assess side effects.
Phase 3*:* Trial drug is given to a larger number of participants to further confirm effectiveness and side effect profile. The trial drug is often compared to current best standard therapy / regimen.
Phase 4*:* Post approval studies

A trial can be either sponsored by a pharmaceutical company often called '*industry*' '*sponsored*' or '*commercial*' studies or led directly by the investigator with no influence from pharmaceutical companies, often termed '*investigator initiated study*'.

NSW Myeloma Support Group

March 29th 2012 the Central Coast Myeloma Support Group held their annual Movie night fundraiser. Raised funds were to be split between M2 inpatient ward at Gosford hospital and MFA. $3050 was raised on a lovely last Thursday of daylight savings to a sell out crowd of 260 people. The movie 'Best Exotic Marigold Hotel' was enjoyed by all with many people going on to book into Indian retirement villages!
The money raised for the ward will extend our IT equipment (notebooks) to allow our long stay patients internet/skype access.
To find out more about the Central Coast Myeloma Support Group please contact me.
Jacqui Jagger
Haematology Cancer Care Coordinator
jjagger@nsccahs.health.nsw.gov.au

Clinical Trials focus continued

Randomised Controlled Trials (RCT) are often considered to be the gold standard of clinical research methodologies. Treatment is assigned to the participants randomly like tossing a coin to decide (it is actually much more detailed than that!)

Open or blinded: Open label trials are those where the participant and the researcher know which treatment is being given. Blinded trials are where the participant and sometimes the investigator do not know which treatment the patient is receiving in an attempt to decrease bias.

How are trials run?

A clinical trial must be reviewed and approved by an human ethics and research committee (HREC) before any participants are enrolled. All trials must be conducted according to the approved protocol and this ensures that there is uniformity. In addition to this clinical trials must be conducted according to the strict principles of Good Clinical Practice (GCP) to ensure that the rights and safety of participants are protected and that the data produced is credible.

How do I find out what trials are available for my patients?

For clinical trials to be successful they need participants. Although trials do not normally have direct benefits for the patients on them, they can offer earlier access to new drugs and the findings are likely to benefit others in the future. It is widely believed also that patients who are on a clinical trial have better outcomes, perhaps in part because they receive more care and attention from a wider health team including the direct coordination by a clinical trials nurse.

There are many ways to find out what is happening in the land of clinical trials. You could approach your trials team and ask them what is available or new? Investigators and sponsors are encouraged to register their clinical trials on a registry. See below for a few links that might be useful.

The Australian New Zealand Clinical Trials Registry (ANZCTR), which is where researchers are encouraged to register their trial before conducting research in Australia www.anzctr.org.au/

The *clinical trials registry in the USA* www.clinicaltrials.gov/

The *National Cancer Institute* website in the United States: www.cancer.gov/clinicaltrials

The *Cancer Research UK* website: www.cancerhelp.org.uk

The Australasian Leukaemia and Lymphoma Group (ALLG)

The ALLG is the only not for profit organisation designing and delivering investigator initiated (i.e. free of pharmaceutical company influence) clinical trial research into blood cancers. Comprised of clinicians from almost all Australian and New Zealand public health institutions involved in the treatment of blood cancer patients, our trials are underpinned by high calibre scientific hypotheses and incorporate laboratory based research. Many ALLG trials are multidisciplinary and involve collaborations with other national collaborative cancer groups and researchers particularly Nurses, Pathologists and Cytogeneticists.

The ALLG hosts a range of meetings annually. To find out more visit their website.
http://www1.petermac.org/allg/NewSite/

Spotlight on a trial

Name of trial: 'NIMBUS - A Phase 3, Multicenter, Randomized, Open-Label Study to Compare the Efficacy and Safety of Pomalidomide in Combination With Low-Dose Dexamethasone Versus High-Dose Dexamethasone in Subjects With Refractory Multiple Myeloma or Relapsed and Refractory Multiple Myeloma'

Primary Objective: To evaluate the efficacy of pomalidamide plus low dose dexamethasone Vs High dose dexamethasone monotherapy and evaluate the efficacy of pomalidamide monotherapy following discontinuation of high dose dexamethasone monotherapy due to disease progression.

This trial is part of a larger International study and is being conducted at various sites across Australia. To find out if the study is open at your site, ask your clinical trials team.

To help your patients learn more about what a clinical trials involves and to see if they would be interested in taking part, the Cancer Council has a great booklet. You can order copies or download it directly from their website.
www.cancercouncil.com.au

Alternatively you can sign post people to 'Australian Cancer Trials'.
http://www.australiancancertrials.gov.au/about-clinical-trials.aspx

Next edition we'll be joined by a trials coordinator from another trials unit around Australia. If you have something you would like to contribute to this section or would like us to cover, please get in touch.

Rebecca Meti
Clinical Trials Nurse-Haematology, RPA, Sydney
rebecca.meti@sswahs.nsw.gov.au

Jenelle Peppin
Clinical Haematology & BMT Research Nurse, Royal Melbourne Hospital.
Jenelle.Peppin@mh.org.au

Conference Reports

If you've attended a meeting or conference at home or away, why not write a short summary for the newsletter so we can all learn from your experiences?

TANDEM BMT MEETINGS SAN DIEGO USA FEBRUARY 2012

Catherine Wood, BMT Coordinator Wellington Hospital NZ summarises aspects of a recent international BMT conference. Haploidentical Transplantation & Survivorship issues lead the way.

I was very fortunate to be able to attend the Tandem Bone Marrow Transplant (BMT) Meetings in San Diego. This is a combined meeting with a number of disciplines focussing on the care and treatment of patients undergoing both autologous and allogeneic stem cell transplantation. The meetings consisted of the following combined conferences:

- Medical and Scientific conference
- BMT nurses conference
- BMT pharmacy conference
- Advanced practitioners conference
- Training and education meeting for data managers contributing BMT data to the international bone marrow transplant registry.

The data manager meeting started before the others and was two days of intensive training and education. I have a dual role in that I coordinate bone marrow transplants in our centre and also submit data about our allogeneic stem cell transplants to the International Bone Marrow Transplant Registry. We are one of over *550 BMT* centres worldwide that does this and there is now data in this registry for hundreds of thousands of patients. This informs us about treatment outcomes for particular diseases, best treatment practises and allows us to benchmark ourselves against the rest of the world.

The other conferences ran concurrently and I selected the most appropriate talks from each session to attend. One of the big topics of the whole meeting was *haploidentical transplantation.* There are many patients who don't have matched brothers or sisters to be donors for them and up to a third of these patients also do not have a fully matched unrelated donor (either adult donor or cord blood) available to them on the world registries. In this situation, a transplant can be done using a family donor that is partially matched. This is a high-risk transplant and should only be used in patients with high-risk disease. There were some good education sessions about which donors are best, the type of conditioning regimen that should be used, the best patients for this kind of procedure, the potential problems and the current survival data. It is likely that there is going to be a significant rise in these kinds of transplants over the next few years so this was timely education.

There was also an emphasis on survivorship and the needs of the post BMT patient. There were excellent sessions on:

- Late effects that BMT patients experience (secondary malignancies, heart disease, obesity, sexuality and fertility problems, quality of life issues etc).
- Screening guidelines for secondary malignancies and other late effects. There are new consensus guidelines being published in March. There will also be patient information published about this so that patients are aware of the type of follow-up they should be receiving in the post transplant period.
- Treatment and treatment outcomes for secondary malignancies.
- Service provision for long-term survivors such as late effects clinics, consensus guidelines about screening, support for survivors and survivorship care plans.
- Cause of death of long-term survivors. Most commonly this is unfortunately through disease relapse. Chronic GVHD also increases the risk of mortality.

Other topics covered included:

Graft versus Host Disease (GVHD) – good updates were given about this most common of allogeneic BMT complications. There have not been many advances in the prevention and treatment of GVHD in the past few years.

Fukushima nuclear accident – Haematologists from Tokyo gave a very interesting presentation about the "Fukushima 50", the nuclear power workers who went back to the nuclear power station after the tsunami and explosions to try and make it safe. These workers were exposed to radiation during this time. The Japanese haematology community proposed that these workers have their stem cells collected and cryopreserved prior to returning to Fukushima so that if they developed radiation toxicity, marrow failure or malignancies post their exposure, there were autologous stem cells saved for them. One hundred and seven haematology units were on standby so that this could be achieved. The Japanese government refused, saying that there was no need for this to be done and that they could not afford to give the workers the five to seven days off required for the mobilisation and collection of adequate numbers of stem cells. Many workers wanted to have cells collected but the haematology community had their hands tied because the government forbade them to do this. The haematology community developed a quick mobilisation schedule using G-CSF and Plerixafor – mobilisation and collection of stem cells was achieved within 24 – 48 hours. This was done on two of the workers successfully before the government stepped in to prevent this.

Germ cell tumours - good sessions about tandem and triple autologous transplantation for patients with relapsed germ cell tumours.

Bone marrow transplantation *(BMT) in the elderly* – there were a number of sessions about this due to the increasingly aging population and the highest number of malignancies are diagnosed in this age group. There was talk about the potential problems with transplanting patients over 65, the kinds of conditioning regimens that should be used and what kind of screening should be done to ensure that the right patients are being taken to transplant so that mortality and morbidity are not too high. There was one poster on display about this and their oldest patient was 76 years of age and he had an unrelated donor transplant. It wasn't very many years ago that the age limit for an unrelated donor transplant was 45.

Conference Reports continued

Stem cell *mobilisation in the era of Plerixafor*. Some transplant centres in the USA were using this very expensive drug as first line mobilisation treatment. Most were however using standard mobilisation techniques (G-CSF alone or in combination with chemotherapy) and reserving Plerixafor for failed mobilisations. There is a clinical trial underway looking at the use of Plerixafor alone to mobilise volunteer stem cell donors – at this stage this is only for sibling donors. There doesn't appear to be much use of pegylated G-CSF for stem cell mobilisation when US centres were polled.

This was a very valuable meeting and I am very grateful that I was able to attend. It educated and informed about many aspects of bone marrow transplantation.

To find out more about next year's Tandem Meetings, go to their website.

http://www.cibmtr.org/Meetings/Tandem/Pages/index.aspx

AMERICAN SOCIETY of APHERESIS (ASFA) CONFERENCE, APRIL 2012

ASFA held their annual conference in Atlanta, Georgia last month. This brought together many experts in the field of apheresis such as apheresis nurses, doctors, scientists and technicians.

For me, this was my first year to attend ASFA's international conference. Whilst indeed it is an international conference I was a little surprised at the small numbers attending from outside the United States. As well as Europe, South America and Canada, a few clinicians attended from Australia to represent their great land down-under. The conference had approximately 300-400 people in attendance and went from April 11th-14th with a pre-conference 'TTP Consensus Conference' on the 10th.

I started the conference on the 11th by attending the FACT workshop. For those who have not yet experienced sleepless nights by a looming FACT accreditation, FACT (Foundation for the Accreditation of Cellular Products) is an accreditation body for the collection of cellular products and bone marrow transplantation. While the organisation is American based, accreditation can be gained by many centres outside the United States. Having gone through the accreditation inspection at Sydney Children's Hospital, I can confirm it is not an easy inspection to pass and standards for collection, transplantation and laboratory practice are maintained at a very high and strict level. As such this workshop was an amazing experience and a great refresher course for me. The workshop alone justified my trip across the long waters to Atlanta. It went through how a centre should apply for accreditation, what is needed to achieve accreditation, the process of inspection and further more how your centre can prove they are maintaining and improving upon standards already achieved. FACT is about building a service where only the highest standards of practice are acceptable to facilitate the best patient outcome.

The workshop was also FACT's first workshop carried out through their new 'FACTweb' on line system. FACTweb could be considered a steep learning curve for all levels of expertise within the FACT organisation, simply because it is a new way of doing things. Earlier this year, the FACT accreditation system moved from using the paper system to an online electronic system. As such all accreditations will now be applied for and performed through the online FACTweb system i.e. applications, accreditations, on site assessments and communication will only be electronically recorded. Therefore, each FACT centre must register their organisation through the on line FACTweb and must become familiar with the new online system. Despite my initial reservations, I was pleasantly surprised at how well the FACTweb operates and how user friendly the system seems to be.

Following the workshop we joined up with everyone else in the main conference. I have learnt that in any conference you should always aim to come home with at least 1 meaningful message to your colleagues. A striking message I came away with was realising what good apheresis work we are doing here in Australia! Networking with some of our American colleagues allowed me to see that in Australia we are lucky that we can simply get on with the procedures without the challenges of health insurance; we have access to the latest software on the Spectra Optia machines e.g. PBSCC, white cell depletions, extracorporeal filtering all of which is an advantage we shouldn't take for granted. I also believe as a smaller apheresis community we avail of the resources we have to learn from each other. In addition to this, having to manage the ethical issues surrounding stem cell collections sold purely for research was one I never really had to think about before attending the conference.

The conference presentations included many discussions on TTP and discussed the difficulty along with the importance of differentiating between TTP and HUS, including atypical HUS in the absence of ADAMTS13. Use of Eculizumab can be helpful in atypical HUS. It was also pointed out not to rush into renal transplant planning in HUS as this may not always be necessary. A European group from Vienna presented on Spectra Optia Stem Cell Collections in children and young adults. I found this interesting to the degree that it confirmed their results were really no different to our results here in Australia. Again reminding me that here in Australia we're doing a good job and perhaps in some areas we may be doing better than other centres around the world.

Australian apheresis nursing was also represented at the meeting by a poster presentation on 'White Cell depletion - challenges in a 17kg patient'.

ASFA enlightened me on what is happening in the northern hemisphere and where Australian apheresis might be looking on the international league of Apheresis. The next ASFA conference will be held next year in Denver May 22nd - 25th.

Gráinne Dunne, CNC Apheresis/Haematology, Sydney Children's Hospital.

Conference Reports continued

EUROPEAN GROUP FOR BLOOD AND MARROW TRANSPLANTATION (EBMT) APRIL 2012

The following reports from EBT come from three nurses who attended, each reporting on a different aspect from conference. All three had poster or oral abstracts accepted for presentation and tell us about their work.

Jenelle Peppin
Clinical Haematology & BMT Research Nurse, Royal Melbourne Hospital Jenelle.Peppin@mh.org.au

I was thrilled to attend EBMT to present interim results on novel research of which I was the primary nurse and study coordinator. Our clinical study evaluated chronic graft-versus-host disease, which is known to be the major cause of non-relapse mortality in patients surviving beyond 100 days after an allograft stem cell transplant.

With an interest in late effects and sexual health, I attended the EBMT Patient and Family Day, which is now in its 6th year and focused on the obstacles of life after transplantation – both autologous and allogeneic.

As autologous and allogeneic transplant patients are confronted with many challenges after transplantation, patient and family-related topics have become an integral part of EBMTs activities. The topics that were presented and discussed were:

- The decision to consent to an autologous transplant – a patient's perspective
- Living with graft-versus-host disease (GVHD) – a patient's perspective
- GVHD
- Infection risks and what can be done:
  - Pets
  - Live vaccines
  - Food
- Practical issues:
  - Travelling
  - Vaccinations
  - Caring for children and pets
  - Intimacy
  - Sexuality
  - Fertility

The program and copy of all presentations from the 6th EBMT Patient and Family Day can be accessed by using the following link: http://www.congrex.ch/ebmt2012/patient-family-day/programme-presentations.html

The topic of late effects was also discussed at length during the general meeting. The EBMT Late Effects Working Party identified the following:

- In patients who received reduced intensity conditioning (RIC) regimens, there is an increased prominence of fatigue, insomnia and pain after transplantation.
- Genital GVHD is under-diagnosed and under-treated in women.
- The median time of confirmation of gynaecological GVHD is 13 months.
- A literature search identified only 6 cases of male genital GVHD worldwide
- When asked, 61% of males confirmed that they were dissatisfied with their sexual life after their transplant.
- Erectile dysfunction was the most common issue raised by men after their transplant.
- Suicide is more prominent in males than females after an allogeneic transplant.
- 46% of suicides occur 1 year after transplantation.
- GVHD increases the risk of suicide.

In regard to sexual health communication, the following was identified:

- 20% - 30% of males and 40% - 45% of women have sexual dysfunction in the general population.
- For women, sexual function drops initially in the first year after transplantation, then starts to recover within 2-3 years. By 5 years, there is an improvement in sexual function, however, it is not to the level that was experienced prior to transplantation.
- For men, sexual function initially drops after transplantation, however, within 2 years it usually recovers to the level that was experienced prior to transplantation.

Attendance at the EBMT Conference and associated Patient and Family Day was invaluable. It allowed me the opportunity to present our research findings to a global audience, as well as advance my knowledge, understanding, and clinical expertise in the areas of haematological malignancies and bone marrow transplantation.

Julija Sipavicius
BMT Coordiantor, Royal Melb Hospital
Julija.sipavicius@mh.org.au

Several sessions were dominated by recent advances in the use of intravenous busulphan. Standard therapy in most conditioning regimes utilises the intravenous form, however various discussions took place addressing the possible new roles of oral busulphan, particularly in the use of low dose therapy in the elderly.

Many sessions of interest included the common themes and challenges of BMT that have dominated large international meetings over the years, namely

- Overcoming the challenges of *GVHD*
  - emphasis is shifting towards aiming to gain a better understanding of the pathophysiology of GVHD – perhaps if we understand the pathophysiology than we could treat GVHD more successfully
  - *Targeted therapy* towards interleukins and t-cells is now forming important research in the aim to better understand and manage GVHD, using various new immunomodulating drugs
  - Initial consensus in managing GVHD is treatment with methylprednisolone, however treatment for patients with steroid resistant disease truly remains a trial and error see-saw and varies greatly.
- Tryosine-kinase inhibitor (TKI) therapy in CML. The introduction of TKIs has dramatically changed the prognosis for the majority of this patient group. My medical colleague (Professor Jeff Szer) and I submitted an abstract titled "Clinical characteristics and outcomes of patients relapsing 2 years or more following allogeneic stem cell transplantation

Conference Reports continued

for chronic myeloid leukaemia", which was nominated for best abstract in the medical stream. This retrospective analysis demonstrated the success of TKI therapy following relapse after BMT, though how long patients require TKI remains questionable among the haematology community. Other presentations discussed how effectively to treat a sizable majority who fail TKI therapy including the role of BMT.

- *Infection:* Although infection prophylaxis and management of infectious complications post BMT has improved dramatically in the last decade, infections remain a main cause of morbidity and mortality in patients undergoing HSCT. Many presentations addressed the challenges of infection prophylaxis and management with a large focus on the need for more accurate and detailed monitoring and management of viral infections (mainly CMV) after engraftment particularly in patients who are immunosuppressed.

Other sessions addressed specific disease types including the more common malignancies:

Acute Leukaemia

- The role of autogolous transplant remains questionable in AL, though one presentation from the EBMT AL party presented a strong case of autografts in ALL.
- Starting to consider maintenance treatment post BMT

The *German lymphoma group* recently undertook treating patients with lymphoma using tandem autografts with good preliminary outcomes.

Reduced intensity conditioned (RIC) transplant remains a hot topic, and various sessions discussed the different uses and varying drugs that may have benefit in RIC regimes.

An interesting presentation from Scotland highlighted the challenges of *long term follow-up post BMT* for patients who live in remote areas, (who require treatment and follow-up in metropolitan areas). They had shown that patient compliance with treatment and/or follow-up review was suboptimal and requires other ways managing patients who live outside of major centres.

Interesting session on *nuclear accident* (whether by natural causes or terrorism) and various views of clinicians were presented on how governments and healthcare professionals should prepare for such an event if a large number of individuals become marrow suppressed at the one time. Resources, not surprisingly played a role, and learning from the Japanese experience (following Fukashima), not all individuals will have access to life-saving treatment if such an event occurred.

Lastly, given that *haploidentical transplantation* has dominated 2 recent large meetings in the US, it was surprising very little discussion took place at EBMT around this topic.

Tracy King

Myeloma CNC, Research Fellow, RPAH Sydney

With permission from the EBMT Nurses Group I include a copy of the article that will appear in the EBMT post conference publication of the EBMT nurse's group newsletter.

'The Devils Tic Tac's' – Understanding the adverse events of steroid therapy associated with the treatment of multiple myeloma.

T King[1, 2], K White[1], L Acret[1], M Stephens[1], N D'Abrew[1], N Ferrar[2], T Lindsay,[2]

Sydney Nursing School, Cancer Nursing Research Unit, University of Sydney[1]; Institute of Haematology, Royal Prince Alfred Hospital[2]; Psycho-Oncology Service, Royal Prince Alfred Hospital[2]

As recipient of the 'Best Abstract EBMT 2012' I am delighted to be in a position to write this summary of our research looking at the experience of people affected by myeloma undertaking high dose corticosteroid therapy. This project represents my first major piece of nursing research which I have undertaken as part of a Clinical Training Fellowship awarded by the Cancer Institute NSW here in Australia. The Fellowship has been an invaluable opportunity for me to work under the supervision of experienced nurse researchers whilst remaining in the clinical area. A model, I believe, that is essential to build future clinical cancer nurse researchers. My supervisor is Professor Kate White who heads the Cancer Nursing Research Unit (CNRU) affiliated with Sydney Cancer Centre and the University of Sydney.

Why did we undertake this chosen piece of research?

Despite recent advances in the management of myeloma, including increased overall survival, myeloma remains an incurable blood malignancy. Myeloma is characterised by a range of debilitating morbidities which includes bone disease, renal insufficiency and myelosuppression. The treatments to manage myeloma often involve triplet combinations of an alkylating agent, immunomodulator or proteasome inhibitor (thalomid, lenalidomide or bortezomib) and a corticosteroid. The common pathway for people living with myeloma is following a remitting and relapsing state with one line of therapy often following direct on from another. Toxicities relating to anti-myeloma treatments are predictable and can be dose limiting. They include peripheral neuropathy, thrombotic events and complications relating to myelosuppression. These toxicities are well described in the literature and validated assessment and grading tools exist to help manage them. Although toxicities related to steroids are known there is a paucity of evidence regarding the incidence and management of steroid specific toxicities in the myeloma literature.

Anecdotally as a myeloma nurse specialist with over 15years experience specifically in the field of myeloma, I have spent more time guiding patients in the management of the toxicities of high dose steroids than any other toxicity associated with their treatment.

What I have found to be most troubling for people affected by myeloma are the psychological sequelae of high dose steroids. These effects can be high and low moods, irritation, distress, lack of ability to operationalise and the combination of being 'on edge' while being physically exhausted. These less tangible, hard to describe effects are often not fully disclosed by health professionals as we concentrate on toxicities of the newer more high profile agents such as peripheral neuropathy and thrombotic events. The degree to which oral, low cost, more common drugs are seen to be less troublesome and we spend less time discussing them with our patients? This is perhaps compounded by a lack a reliable, evidenced base language to describe the way high dose steroids effect cognition, psychological and physical states. We saw an opportunity - we believed that having a greater understanding of the experience of AEs related to steroids and their management can enhance patient education and supportive care measures.

Conference Reports continued

It came as quite a surprise to us that recruitment for the study was instant, rapid and somewhat overwhelming – a unique and fortunate situation for any researcher. With only basic advertisement of the study, participants used every conceivable mode of communication to contact me to register to take part. People were keen to contribute to our better understanding and management of those with myeloma, but this perhaps highlighted the first opportunity for these patients to "tell it like it is". We stopped recruiting to the study after three weeks as the methodology of interviews and diary keeping could, and did generate vast amounts of qualitative data for us to analyse. Forty seven participants participated in the focus group interviews and 22 participants took part in in-depth individual interviews completing a total of 126 weekly diaries.

Major themes identified in our analysis of the patient and carer interviews and diary keeping included:

Experience of side effects & consequences of
Self management skills
Coping

An overriding theme of people 'being constantly attuned to and monitoring of an altered self' whilst on steroids was impacted by the chronicity of their disease.

Where to from here?

Work is underway to complete the analysis of all phases of the study and compare data across the study. We are comparing data from the patients and carers with the literature and interviews of clinicians. Shortly we will begin the task of writing up the study in its entirety for publication.

Not surprisingly more questions have come from this piece of work than answers – often the way. Our study team is keen to build upon what we have learnt and work towards the development of tools to help assess steroid effects in this population in the clinical setting.

We would like to take this opportunity to thank EBMT nurses group for the honour of being awarded best abstract at EBMT 2012. We are grateful for the recognition of our work and look forward to continuing our research, perhaps in collaboration with some haematology nurse researchers we met at conference in Geneva. Attending conference not only gave me the opportunity to present our work but also to learn from others, network and catch up with old friends.

The next EBMT will be the 7th to the 10th April 2013 London UK
http://www.congrex.ch/ebmt2013

Survivorship

Survivorship is a hot topic at many cancer conferences these days and EBMT is no exception. We heard from Diana Greenfield a MacMillan nurse from Sheffield UK. She was able to inform us of the National Cancer Survival Initiative (NCSI) which is a partnership between the Department of Health, Macmillan Cancer Support and is supported by NHS Improvement.

The aim of the NCSI is to ensure that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible. The NCSI is made up of a range of project groups including**:** Assessment and Care Planning – Health and Wellbeing Clinics **–** Managing Active and Advanced Disease – Supported Self Management **–** Consequences of Cancer and its Treatment – Survivors of Childhood and Young People's Cancers – Work and Finance – Vocational Rehabilitation **–** Physical Activity.

For more information see the following websites:

National Cancer Survival Initiative UK www.ncsi.org.uk
www.cancerconsequences.org

For Australian perspective please go to: Australian Cancer Survivorship Centre www.petermac.org/cancersurvivorship

For an American perspective please go to: National Coalition for Cancer Survivorship www.canceradvocacy.org

The abstract book from the EBMT conference is available as a supplement to the Bone Marrow Transplantation, the official journal of EBMT. Search for it via the EBMT website.

EBMT Abstract book. Volume 47 Supplement 1 April 2012. Bone Marrow Transplantation.
Pages: S1-S528

For a range of useful resources available on line to download see the EBMT Nurses Group website. Of particular note is the new booklet on 'Adherence to Oral Anti-tumour Therapies and new slide sets on the management of MDS. Navigate via the EBMT website to 'Education' and then 'Nursing Education' and then 'Materials'.

http://www.ebmt.org/Contents/Education/Nursingeducation/Materials/Pages/Materials.aspx

Can't get to the conference?

Many conferences these days, particularly those in the USA, make available online conference abstracts, summaries and even copies of slides for your to read. For example, the Oncology Nurses Society (ONS) recent conference just this month has many interesting Haematology specific sessions available to view. Follow this link to find navigate the program and read a range of sessions that includes:

Multiple myeloma clinical updates
Outcomes of CAM
T-Cell Lymphoma – testing your knowledge and management skills
MDS – challenges and strategies for effective outpatient management
Survivorship care

http://congress.ons.org/education/sessions.shtml

From ONS 2011 Congress you can access the online supplement – 'Spotlight on Symposia' where you will find a series of clinical updates and interesting articles with a Haematology focus – 'Emerging Treatments for Hematologic Disorders'. To download the supplement, navigate via the ONS website via the link below.

Clinical Update—Lymphoma

In this section we hear from nurses undertaking quality improvement work or clinical disease summaries from local educational sessions. Odette updates us on Cutaneous T Cell Lymphoma with a focus on best practice around skin care in this patient group.
If you have a piece of clinical work or a disease or clinical practice update you would like to share with the group, please get in touch with the editor.

THE DILEMMAS OF SKIN LYMPHOMA AND SCRATCHING THE ITCH

Odette Blewitt
Odette.blewitt@petermac.org
Skin Lymphoma Nurse Consultant- Nurse Practitioner Candidate
Peter Mac Callum Cancer Centre

The Cutaneous (skin) system is the largest organ of the body. Cutaneous T Cell Lymphoma is a rare and incurable blood condition manifesting as patches, plaques or visible tumours in the skin. It affects 0.3- 1% of people in every 100,000 (Prince, McCormack, Ryan, O'Keefe, Seymour & Baker, 2003). Patients diagnosed with Cutaneous T Cell Lymphoma (CTCL) comprise of 75% of this group of patients whilst the other 25% patients diagnosed represent those diagnosed with Cutaneous B Cell Lymphomas (CBCL) (Prince et al, 2003).

Certainly the diagnosis, prognosis and long term implications of CBCL and CTCL are varied. CTCL is an incurable, indolent disease. Patients may live with the disease for up to 20 years after initially being diagnosed in the 40-60 age bracket.

CTCL may masquerade as other disorders such as eczema or psoriasis. The average diagnosis time is three years from onset of symptoms to diagnosis. Patients are frequently frustrated by the delayed time they receive the diagnosis of CTCL, even though seeing multiple experts, due to the difficulty diagnosis the disease.

Progressive or refractory disease often leads to multiple hospitalisations and treatment-related complications. The impact on quality of life is insurmountable.
Manifestations and complications of the disease are numerous. They can include pruritus, infection resulting from direct skin involvement and psychological impairment related to the often disfiguring nature of the disease. Over time the disease can "transform" or become more aggressive. Chronic, refractory skin disease brings with it an increased risk of disease transformation and infection. Transformation has the ability to dramatically reduce overall survival.

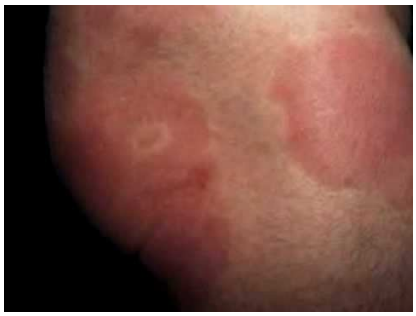
Conversely, those diagnosed with CBCL generally have a prognosis comparable to the general population. 97% of patients with Follicle centre cell lymphoma and marginal zone lymphoma are cured with radiotherapy alone (Prince et al, 2003). Thus, the needs of this patient group are consequently quite different to patients with CTCL.

The common theme amongst patients with Cutaneous Lymphoma, regardless of T Cell or B Cell status, is the importance of symptom management. Managements related to skin care, dressings, pain, psychological distress, and pruritus are all symptoms we as health professionals have the ability to address. It is imperative to empower patients to manage independently providing adequate supports are in place.

Hygiene, skin care, dressings (wet or otherwise), and symptom management are all important components in the care of those with Cutaneous Lymphoma. Alterations in the patient or carer's ability to carry the above out must be addressed. Hospital admissions may be required in order to improve skin care, infection management or disease management directly related to impaired skin integrity. These symptoms directly impact psychological distress experienced in this group of patients.
Acknowledging symptoms particularly when they are difficult to control, is the first step in empowering patients to help themselves. Once patients are unable to optimally manage their symptoms in the community it is imperative for us as health professionals to step in and guide them.
Cleansing of the skin is important in patients with Cutaneous Lymphoma in order to reduce the infective load on the skin and also to hydrate the skin. Adequate hydration of the skin can also significantly reduce pruritus if directly related to dry skin. Once a patient is unable to have a bath or shower address this. Pain and Palliative Care Services are a resource which often requires utilisation in order to address difficult to control symptoms such as itch and skin neuralgia.

Product choice of moisturisation for patients is also important. Products range from very greasy (Paraffin based products) to less greasy (Sorbolene based products). Skin dryness assists in determining the most appropriate level of skin hydration for patients.
Topical steroids and skin directed treatments are frequently used in this patient group. Steroid choice is often gauged by patient tolerance, compliance, and skin integrity. Impairments or improvements in the condition of the skin often require the regimen to be altered.

It is imperative to address the goal of care for each individual patient and their family. Care is tailored to patient needs and wishes. Scratching the itch is all too easy. Skin care may have the ability to reduce this.



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Paediatric Focus—Transition

PAEDIATRIC FOCUS

Transition for Long Term Paediatric Haematology Patients - Making that move from the children's hospital.

Gráinne Dunne
CNC Apheresis/ Haematology , Sydney Children's Hospital
Grainne.Dunne@sesiahs.health.nsw.gov.au

Change is often a difficult or daunting process for everyone! Whether it's changing how we do things, changing where we live or changes in our work.

For our long term paediatric patients, changing hospitals is inevitable once the patient is old enough to move on to the 'adult' world of health care. For these 'young adults' such a transition involves 'changing how they do things' as well as 'changing their hospital location'.

Over the past few years, our haematology department at Sydney Children's Hospital has worked hard to improve how we manage these important life changes for our teenage patients. Most of these patients have thalassaemia, haemophilia, sickle cell anaemia or other blood disorders where they have been reliant on the children's hospital for as far back as they can remember.

To reward these patients for their long years spent at Sydney Children's Hospital and to celebrate their transition to adult healthcare, Sydney Children's Hospital hosts a Graduation Ceremony twice a year.

Below are photographs of our haematology graduates at Sydney Children's Hospital's most recent ceremony held in May. All patients graduated to The Prince of Wales Hospital, Randwick.

The graduation ceremony was a beautiful way to say goodbye to the old and to greet the new. The ceremony was hosted by Sydney Children's Hospital Director of Clinical Operations Michael Brydon together with 'Captain Starlight' and 'Captain Sidepony'. All three provided enough humour to lift everyone's spirits if not the ceiling itself. The invited celebrity speaker was amazing as he congratulated the graduates on their wonderful achievements and provided great motivation and encouragement to live their future lives with dignity and pride.

After the 3 hour ceremony the graduates and their families were pampered for another few hours. This time sailing Sydney harbour aboard a luxury yacht kindly donated to the hospital specifically for the graduates, who worked hard in their healthcare over the years to reach this point.

Our ultimate goal in transition care is to enable the patient to take greater ownership for the management of their own medical condition - in collaboration with their old and new medical teams.

Each patient will achieve a different level of success with the challenges surrounding transition.

It is therefore important to build the adolescence's confidence and show them that they can gradually become independent and responsible for their own medical needs.

For a few patients this is a great opportunity to finally take over the reins from mum or dad. For most however it may be a scary concept. As such, ongoing reassurance and encouragement is very important, from both the medical team and from the family.

Last year Sydney Children's Hospital introduced their first transition clinic whereby the haematology patients were reviewed by their paediatric team alongside their new adult team. Altogether discussing and planning the individual's healthcare needs.

The adolescent slowly builds their self confidence as they start to take on some new responsibilities i.e. speaking for themselves in clinic review, asking the doctor/nurse the questions rather than mum or dad asking, trouble shooting problems themselves with the team and managing their own medications. This can begin as early as 13 or 14 years of age so as to facilitate a gradual process.

Of course we always encourage the patient's family to continue giving support, care and guidance regardless of age. At the same time it is hoped that when the young adult moves to their new hospital, they will be more able to manage their needs and are prepared for the challenges that a new hospital, new staff, new routines can bring along.

Clinical Update - Haemophilia

In this section we hear a personal perspective from Claire Bell, Haemophilia Nurse Practitioner who tells us about her role and scope of practice including opportunities she has embraced to truly engage with the wider Haemophilia community in WA and Nationally. We then have a clinical update from Grainne Dunne in NSW who updates us to a change in product being used to manage Haemophilia. If you work in the area of Haemophilia or Haemoglobanopathies and would like to contribute to this newsletter, we'd love to hear from you.

Haemophilia nursing – a sub-specialty within haematology

Claire Bell
Haemophilia Nurse Practitioner, Royal Perth Hospital
Claire.bell@health.wa.gov.au

Six years ago when I was asked if I would like to see what it was like to be the Haemophilia Clinical Nurse Consultant I could not have imagined the opportunities it has offered me and where it has taken me.

Haemophilia is a term used to group a number of inherited bleeding disorders, which includes haemophilia A and B, von Willebrands disease, platelet function disorders and rare bleeding disorders. Within Australia each state (and most territories) have at least one adult and one paediatric Haemophilia Treatment Centre. Some centre's are small and are often combined with general haematology; however some, like the one I work in, are dedicated Haemophilia Comprehensive Care Centres. This means that within Western Australia our centre sees most of the adults and is the state referral service. We offer a drop-in service, dental care, physiotherapy, dedicated social work/counselling service and in doing so aim to meet the needs of the community. Currently there are about 600 adults with inherited bleeding disorders registered to our centre. We also see patients from the smaller centres for dental procedures and some surgical procedures.

So when I started in a leave relieving position I had heard of haemophilia, but I had not even heard of von Willebrands disease – the most common inherited bleeding disorder! Certainly learning the various clotting mechanisms and how each deficiency or dysfunction contributes to an increased risk of bleeding or a prolongation of bleeding was a steep learning curve. The management is relatively simple – replace what is missing or dysfunctional, but just when you think you understand it all something new pops up, like a patient with more than one bleeding disorder!

The role of the haemophilia nurse is evolving as the treatment available to those affected improves. The primary role, I believe, is education – for patients, families, other health care professionals. Being an inherited disorder it is sometimes assumed that patients and families know what they're doing and pass down information, however it is naïve to assume that patients are managing their disorder correctly and that families pass down accurate and up-to-date information. Families are also influenced by past experiences that have occurred which can have a huge impact on decision making. Education is frequently informal but education sessions are provided to specific interest groups, health care professionals both within our hospital and in the community.

The treatment of inherited bleeding disorders has traditionally been the administration of plasma derived products, including factor concentrates, FFP and cryoprecipitate. In the 1980's the haemophilia population was devastated by the discovery of hepatitis C and HIV. A vast number of patients were affected, particularly those with haemophilia A who received non-heat treated factor concentrate. That sparked the pharma companies to invest in the production of recombinant products, which are now available for those affected by haemophilia A and B. Currently these products, within Australia, are available to patients at no cost. Even though they are not considered a blood product, as they use recombinant technology to produce the specific factor required, they are not PBS listed either. Instead these products are provided to patients, funded by the National Blood Authority through Health Departments. As such, pharma companies must tender for their product to be used.

As a health care professional this tender process has increased my opportunities to gain new education and to present to other health care professionals. As part of the tender there is an education fund component. This has allowed me to attend national meetings, such as the 2011 Haemophilia, ASTH and HSANZ (nurses) meetings. It also provided funding for me to attend the 2011 ISTH Conference in Japan at which I was presenting a poster. This year I have received funding for the 2012 World Federation of Haemophilia Conference in Paris, for which I have submitted two abstracts. I could never have afforded to do this myself and so I am very grateful for these opportunities to present at a world forum.

I have also had the opportunity to participate in the organizing of a number of workshops and am currently on an Australian/New Zealand panel organizing a Haemophilia Nurses Workshop later this year in Wellington, NZ. I have assisted pharma companies with the creation of patient education materials and have reviewed information pamphlets with other haemophilia nurses for the Haemophilia Foundation of Australia.

Within WA I feel part of the haemophilia community. I work closely with the *Haemophilia Foundation of WA* and have performed a number of education workshops, created a self infusion DVD alongside other members of the centre, and this weekend I have been invited to the Haemophilia Foundation of WA Family Camp – along with my daughter! This partnership between the patient group and treatment centre is vital as it promotes the dissemination of current and accurate information, improves attendance at the treatment centre and promotes a sense of "community" which has given these patients such a powerful voice in the past.

The future of haemophilia nursing is a mixed bag – as treatments improve with long acting products, currently in phase III studies, the traditional role of the nurse as the treater of bleeding episodes will decrease and encouraging patients to keep attending the treatment centre will be a battle, as is already seen in other countries. But this holistic approach to managing people with inherited bleeding disorders is proven to reduce morbidity and mortality and therefore it is vital these specialist services are continued. I am currently completing the Master of Nursing (Nurse

Haemophilia continued

Practitioner) degree with the final unit to go. Whilst the change to a Nurse Practitioner will largely legitimize what we already do, it will hopefully open the door to some exciting changes to the way we deliver health care to this unique population.

www.haemophilia.org.au

HAEMOPHILIA FACTOR VIII CONCENTRATES - CLINICAL UPDATE

Haemophilia, a genetic bleeding disorder characterised by the absence or reduced production for factor VIII & Factor IX clotting factors. Here in Australia we are very privileged to have factor concentrates provided to our haemophilia patients free of charge, funded by the Australian government. There are many countries throughout the world where factor concentrates are either not available at all or must be paid for by the patient themselves. This is due to the very high cost of factor concentrates.

During the 1990's, recombinant factor concentrates first became available for use in Australia. Initiating this programme was a government directive stating that all Australian haemophilia children requiring factor concentrates must receive recombinant products as a 1st choice of therapy. Recombinant factor then became available to the haemophilia adult community soon after this. Recombinant products are synthetically manufactured and thus contain little or no animal/human proteins. This has been a great step forward especially for the younger generation of haemophilia patients growing up in a world where regular factor is provided without the fear of contamination by viruses such as HIV and Hepatitis C.

In Australia, supply of haemophilia factor concentrate is controlled by the National Blood Authority (NBA). This is a government statutory agency established to improve the management of blood and plasma products within Australia. The NBA holds contracts with each haemophilia pharmaceutical company who supply factor to the Australian market. These contracts operate through a national tender process. As of July 2011 the new tender for haemophilia factor concentrates was released which will be continuing for the next 3-5 years.

What does this recent tender mean for Australian factor VIII concentrates?

Great changes have occurred since last July due to this tender release, pertaining to the supply of recombinant factor VIII products. Prior to July 2011 there were 3 FVIII recombinant products available here in Australia.

Advate
Recombinate
Xyntha

As of July 2011 'Advate' and 'Recombinate' FVIII concentrates (both manufactured by Baxter) have been removed from the Australian tender and replaced by 'Kogenate FS' (manufactured by Bayer). As such, we will now have 2 recombinant FVIII products available for our Australian haemophilia patients which are 'Kogenate FS' and 'Xyntha' (manufactured by Pfizer). The latter had already been on the previous Australian tender along with the 2 Baxter FVIII products. The NBA issued a time period of 1 year to complete this switch over process, which ends June 2012.

Why is this product switch an issue?

Switching from one brand of factor concentrate to another is not as easy as it sounds. The body's immune system can be very sensitive to such product switching and in some people it is believed product switching can result in the body producing an antibody to the new factor which is known as a "haemophilia Inhibitor". This would have a devastating effect on any haemophilia patient and needs to be avoided where possible. Other situations which contribute to the development of inhibitor formation are surgery, infection, trauma and sustaining a large bleed requiring large factor dosing. Factor brand switching is therefore a process to be carried out with careful monitoring and the process is often feared by many patients/carers. Development of a haemophilia inhibitor is life changing, traumatic and scary for a patient because their usual FVIII product is no longer effective in the stopping of a bleed.

During the 2012 haemophilia product switch, the patient will be reviewed by their haematologist in the haemophilia clinic, a decision is made as to which factor they will switch to (Kogenate FS or Xyntha) and blood screening will commence for haemophilia inhibitors. This latter screening will occur prior to the switch, then 1, 3, 6 and 12 months following the product switch.

For those patients previously using Xyntha FVIII, no additional screening will be required as they will remain on their usual product.

If you are unsure or concerned about patients prescribed FVIII therapy, please contact the patient's haemophilia centre.

Xyntha (Dual Chamber)

Gráinne Dunne CNC Haematology/Apheresis, Sydney Children's Hospital
Grainne.Dunne@sesiahs.health.nsw.gov.au

News from the regional groups

Nursing program HAA 2013 - Melbourne

With the finishing touches being added to the programme the Nurses stream of the annual joint scientific meeting of HSANZ/ ANZSBT & ASTH conference is shaping up to be a huge success. The conference is in Melbourne from the *28th – 31st of October 2012*.

There are a variety of topics and speakers covering many aspects of Haematology including Paediatrics, Apheresis, Adolescent & Young Adult issues, Palliative care and Survivorship. We are excited by the addition of a number of joint nursing and medical symposia on topics including multiple myeloma and palliative care.

Nurses Key Note Speaker

Our international invited speaker is *Dr. Karen Syrjala from the Fred Hutchison Cancer Centre* in Seattle USA. Karen is the Director of bio-behavioural sciences and co-director of the survivorship program at the FHCRC. Her work focuses on survivorship and symptom management including non-pharmacological methods to improve symptoms and survivorship. Karen has a strong belief in helping people recognize their strengths and taking charge of their health during treatment and long term survival. Karen will be presenting 2 plenary sessions, participating in a panel discussion and facilitating a master class.

Abstracts Now Open

Invitation for abstract submission is now open and I encourage you to participate and share the wonderful work you are doing with the haematology community. If you've done some research or are involved in a project, I urge you to get together with your colleagues and put together an abstract for either a poster or oral presentation. If it's your first time speak to someone who has presented before and ask them to help you with abstract submission, presentation structure, poster development and oral skills.

Looking forward to reading all the abstracts…

Please go to the HSANZ website @: www.hsanz.com.au for more details and instructions on abstract submission, conference registration, venue details and accommodation.

Don't forget that spring in Melbourne is lovely and we have the added bonus of the spring racing carnival that will be a theme at the conference…

New Zealand (North Island)

The lower North Island continues to have a successful 2012 with nursing education evenings. The plan is to once again have six sessions this year split between Wellington and Palmerston North. We have had one session so far in Palmerston North talking about Multiple Myeloma and one session in Wellington talking about bleeding disorders in women. There continues to be an enthusiastic response to these meetings with an average of around 25 attendees coming along for each presentation. Some hospitals are cutting the education hours available to nurses in order to save money so these education evenings are becoming more valuable. Remember that attending these presentations counts towards your education hours for your practising certificate. The next evening is being held on the 20th June in Wellington. There are limited spaces available so you need to be in quick if you want to attend! The education evenings would not be possible without sponsorship. Bayer HealthCare

2012 dates for your diary

National/Trans-Tasman Conferences/Meetings

26 – 28 July 2012 Cancer Nursing Society of Australia CNSA
Hobart TAS Australia
https://www.dcconferences.com.au/cnsa2012/home

7 September 2012 Cancer Institute NSW – Innovations in Cancer Control Conference.
http://www.cancerinstitute.org.au/events/i/innovations-in-cancer-control-nsw-conference-2012

28 – 31 October 2012 HAA Melbourne VIC Aus
http://www.fcconventions.com.au/HAA2012/

13 – 15 Nov 2012 COSA – IPOS Conference. Impact through Translation: Cancer Research Informing Practice. Brisbane QLD
http://www.cosa.org.au/asm/asm.html

International Conferences

14 – 17 June 2012 17th Congress of European Haematology Association (EHA). Amsterdam, Netherlands
www.ehaweb.org

28 – 30 June Multinational Association of Supportive Care in Cancer MASCC New York USA
http://www2.kenes.com/mascc/pages/home.aspx

9 – 13 Sept 2012 International Society of Nurses in Cancer Care ISNCC Prague, Czech Republic
www.isncc.org/conference/17th_ICCN

8—11 Dec 2012 American Society of Haematology (ASH) Atlanta USA.
http://www.hematology.org/Meetings/Annual-Meeting/7077.aspx

News from the regional groups

and Janssen have very kindly sponsored the first two sessions for 2012. Upcoming education evenings for 2012 are as follows:

Date	Location	Topic
20th June	Wellington	ALL
22nd August	Palmerston North	Myelodysplasia
24th October	Wellington	Lymphoma
28th November	Palmerston North	New Oral Anticoagulants

There are still no education sessions like these available for the upper North Island. If anyone would like to be involved in organising some, please feel free to get in touch with me.
If anybody would like further information about any of these meetings or would like to attend then please feel free to get in touch with me.

Catherine Wood
BMT Coordinator Wellington Hospital
catherine.Wood@ccdhb.org.nz

New Zealand (South Island)

Winter has come to the south, but before it did, we made the most of the balmy Indian summer with the HSANZ NZ Branch meeting held at the stunning Dunedin Art Gallery. A fantastic two-day meeting with interesting speakers and great discussion. Highlights of the Nursing programme included Professor Sanchia Aranda from NSW Cancer Institute, talking on the role of patients in self-care, Alan Burnett from the UK, talking on advances in AML treatment, and none of us who attended Professor Stewart Dunn's communication workshop are going to forget any of the lessons we learnt anytime soon. If you have the opportunity to hear any of these speakers, take it, they are worth it.
The Leukaemia & Blood Cancer New Zealand Winter Workshop series is coming up, to be held in Auckland, Wellington and Christchurch during July. Contact your local LBC nurse for details.
For the very organised amongst you, planning is underway for the 17th NZNO Cancer Nurses Section - Haematology and Oncology Conference, to be held in the beautiful southern city of Dunedin, 21-23 March 2013. An exciting line up of speakers is planned, with a particular focus on innovations in cancer nursing practice and the challenges the ever changing field of cancer nursing presents. So pencil this date into your diaries. Notification of opening dates for registration and submission of abstracts will be out shortly.

If you don't attend already, join other cancer nurses in South Island Cancer Nurse Network for monthly education sessions via videoconference from multiple sites across the South Island. For information on upcoming dates and speakers, or to find out where your nearest videoconference facilities are, contact – Emma Bell at the Southern Cancer Network on emma.bell@siapo.health.nz .

Christine Kerr
Support Services Coordinator, Southern Region, Leukaemia & Blood Cancer Foundation
christine.kerr@leukaemia.org.nz

Victoria

In addition to all the fantastic work the conference organising committee have been doing, we are also running our local educational sessions. The first for the year was on Haemostasis and Thrombosis. This was presented by Dr Kate Burbury, Consultant Haematologist at Peter Mac. Our next educational evening is on the 8th of May. The focus is of fertility considerations for the haematology patient and will be presented by Dr. Cathryn Stern, Reproductive biology specialist and gynae/obstetrician. We are already fully booked for this event and are expecting 60 members.
The Victorian group are heading regionally again this year. Trish Joyce from Peter Mac and Kaye Hose from the Leukaemia Foundation are presenting an overview of Multiple Myeloma and Nurse-led care post treatment for Multiple Myeloma, in Benalla on the 14th of May. The local group are thrilled to be collaborating with regional haematology nurses who have been travelling to Melbourne for our educational evenings. We hope to make this an annual event.
Odette Blewitt – Skin Lymphoma CNC, presented at an educational session last year and has kindly written up her presentation to share with you all. I hope you enjoy it as much as we did her presentation.
Any questions regarding the HSANZ Victorian Nurses group or the HSA conference in October 2012, please don't hesitate to contact me.
Looking forward to seeing you all in Fantastic Melbourne!!

Yvonne Panek-Hudson
Yvonne Panek-Hudson, Allograft Nurse Practitioner
Victorian rep – HSANZ Nurses group
yvonne.panek-hudson@petermac.org

Western Australia

The WA Nurses group has commenced its year with a presentation on CML by Andrew McQuillan. We were fortunate to also have a patient with CML talk with us about her experience. Haematology nurses are able to learn so much from our patients regarding their treatment, their feelings & their journey. The feedback from the session was positive.

News from the regional groups

We are conducting an evening session at Rockingham Hospital in July. This session will invite health professionals from Peel Health Campus and surrounding areas. The topics will be both malignant and non-malignant haematology with a community care focus.

A nursing membership drive is happening this month. Forms are available online but also from our education sessions. I'm updating the WA nursing database so if you would like to receive emails about upcoming education sessions please let me know @ cassi.lawrence@health.wa.gov.au

Cassi Lawrence
Cancer Nurse Coordinator – Haematology, WA Cancer & Palliative Care Network

Tasmania

A successful Dinner Meeting was held on 14th March at the Woolstore Hotel. Over 30 nurses attended and feedback was very positive. The audience enjoyed a dinner and two presentations, Plerixafor and Non Hodgkins Lymphoma. The event was kindly sponsored by Sanofi which enabled us to invite a guest speaker from Melbourne.

We now have a small volunteer Local Organising Committee which is working on the next event, hopefully to be held in August with local speakers. Ideas are always welcome for any speakers or venues so please be in touch.

Gillian Sheldon-Collins

BMT Coordinator, Royal Hobart Hospital
Gillian.sheldoncollins@dhhs.tas.gov.au

South Australia/Northern Territory

A two day paediatric study day was held at the Royal Darwin Hospital in late May. This was a collaboration between educators at the Women's and Children's Hospital in Adelaide and the Paediatric Oncology Unit at Royal Darwin Hospital as well as the HSANZ Nurses Group. Participants were able to learn more about paediatric / young adult cancers and their nursing management .
The 16th Annual HSANZ Blood Club Scientific Weekend Meeting will be including a nursing specific stream on the Saturday this year. The focus will be on fertility preservation and sexuality. The confirmed speakers are: Paula Scallion from Fertility SA—Fertility preservation in patients undergoing chemotherapy/bone marrow transplant and Yvonne Panek-Hudson, Allograft Nurse Practitioner—Sexuality and survivorship post donor transplant. This weekend event is being held 14-16 September 2012 at the McCracken Conference Centre at Victor Harbor. Please contact Allan Hayward for more details, registration forms and current program.
Dates for Adelaide sessions for the remainder of the year are yet to be set.
If anyone has an interest in assisting with the organisation of educational events in SA it would be great to hear from you.

Allan Hayward
allan.hayward@health.sa.gov.au

New South Wales

The annual Central Coast session of the HSANZ NG was held up at The Entrance on Thursday 12th April. Dr Cecily Forsyth gave an inspirational talk entitled 'Hodgkins Lymphoma - is more or less better?' 47 nurses attended from as far as Sydney and Newcastle. The focus of the session looked at those people with early stage disease but with poor prognostic indicators and those with advanced stage disease. Cecily very thoroughly dissected the topic and was really able to project the dilemma that haematologists have to face with choosing the appropriate treatment.
Decision making is not as straightforward as survival curves or disease free survival but encompasses fertility issues, organ damage & risk of secondary malignancy.
The presentation stimulated discussion on a range of issues including adolescent/young adult support, late effects and survivorship. As we are aware nursing leadership in the context of AYA and late effects are hot topics with colleagues driving forward nurse led initiatives all over the country.
The session was very well evaluated, as was the food and venue (albeit a little noisy). Our colleagues, Bowtie Steve form Amgen & Svetlana Varlamova from Pfizer organised the funding of the event with our grateful thanks.
Remaining Educational Events in NSW 2012.

Date	Location	Topic
14th June	Sydney	Complementary Therapies in Haematology
16th August	Wollongong	TBC
15th November	Sydney	AYA

For more information or to register your interest to attend any of the NSW educational meetings please don't hesitate to get in touch with me.

Jacqui Jagger
Haematology Cancer Nurse Coordinator Gosford Hospital
jjagger@nsccahs.health.nsw.gov.au

HSANZ – NG National Council Members

President **Moira Stephens**
Lecturer
School of Nursing, Midwifery & Indigenous Health
University of Wollongong
NSW
Phone: + 61 2 4221 5350
Mobile: +61 422 468 233
Email: moiras@uow.edu.au

NZ North Island **Catherine Wood**
BMT Coordinator
Wellington Hospital
Phone + 64 4 806 2091
Email: catherine.wood@ccdhb.org.nz

VIC **Yvonne Panek-Hudson**
Allograft Nurse Practitioner
Peter MacCallum Cancer Centre
Melbourne
Phone: +61 3 9656 1111 and page
Email: Yvonne.Panek-Hudson@petermac.org

WA **Cassi Lawrence**
Cancer Nurse Coordinator
Malignant Haematology
WA Cancer and Palliative Care Network
Mob: 0408 811 849
Email: cassi.lawrence@health.wa.gov.au

ANZSBT Rep **Bev Quested**
Transfusion Nurse Educator,
Transfusion Medicine Service,
ARCBS,Adelaide,
Phone: +61 8 84221372
Mobile: +61 439 30132
Email: BQuested@arcbs.redcross.org.au

Vice President NSW **Tracy King**
'Clinical Research Fellow" CNRU and Myeloma CNC
Royal Prince Alfred Hospital
Sydney
Phone: +61 2 9515 7310
Email: tracy.king@sswahs.nsw.gov.au

Secretary **Julija Sipavicius**
Bone Marrow Transplant Coordinator
The Royal Melbourne Hospital
Phone: +61 3 9342 7965
Email: julija.sipavicius@mh.org.au

SA / NT and Treasurer **Allan Hayward**
Program Manager, Youth Cancer Service SA/NT
c/o—Cancer Centre
Royal Adelaide Hospital
Phone: +61 8 8222 2804
Email: allan.hayward@health.sa.gov.au

QLD **Catherine Kirk**
Transplant Coordinator
Haematology and Oncology Clinics of Australia
Email: ckirk@hoca.com.au

NZ South Island **Christine Kerr**
Support Services Coordinator – Southern region
Leukaemia and Blood Foundation
Christchurch, NZ 8146
Phone: +64 3 365 0367
Mobile: +64 21 523 173
Email: christine.kerr@leukaemia.org.nz

TAS **Gillian Sheldon-Collins** BMT Coordinator
Royal Hobart Hospital
Email: Gillian.sheldoncollins@dhhs.tas.gov.au