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HSANZ NG News Jul 2011

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Haematology Nursing



From the president



Dear members and colleagues,

As you read this, the sun is out, the spring has (nearly) sprung and the annual meeting is just around the corner. I have just sent out invitations to the abstract review committee and we anticipate a bumper crop this year as the meeting will be combined with the Asia-Pacific BMT group.

A couple of notes for your diaries

- The Annual General Meeting of the Nurses Group will take place on Monday 31st October in the Lunchtime Break – so please come along, hear what is happening and contribute your say to your organisation.
- We are holding a Haematology Nurses' Study Day on the Saturday preceding the conference

 Saturday 30th October, in Sydney more details inside.

Our membership continues to grow and local activities in the States and Islands (NZ that is) continue to blossom.

The executive committee have decided to put the launch of the Journal "Haematology Nursing' on hold for the present time but we are very keen to pursue this in the future. In the meantime, this gives us the opportunity to continue to develop this version of Haematology Nursing as our news/mini-journal.

If you have not yet got around to joining the HSANZ NG – pick up a membership form from the HSANZ stand or from the website (http://www.hsanz.org.au/join/fees.cfm) – 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!!

Two exciting news announcements are; the launch of the Cancer Nursing Research Unit, 2 members of which are haematology nurses and HSANZ committee members, myself and Tracy King; and Tracy's award of a Clinical Fellowship. These are both important steps in the battle to recognise haematology nursing as an area of specialised practice and research.

Moira Stephens July 2011

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Cancer Nursing Research Unit

The launch of a new Cancer Nursing Research Unit (CNRU)

The central role of specialist cancer and haematology nurses in the delivery of quality cancer services in New South Wales was recognised at the launch of the Cancer Nursing Research Unit this May 2011.

The Cancer Nursing Research Unit is an innovative collaboration between Sydney Nursing School at the University of Sydney, the Cancer Institute of New South Wales and the Sydney Cancer Centre, Royal Prince Alfred Hospital. It combines Sydney Nursing School's strength in cancer, haematology and palliative care research and the Sydney Cancer Centre's excellence in clinical cancer care to develop and support nursing clinicians across NSW.



According to Professor Kate White, Professor of Cancer Nursing, "With the number of cases of cancer continuing to grow the Cancer Nursing Research Unit is helping to meet the needs of people in NSW by expanding the contribution of cancer nurses to quality cancer services, including the extended role of nurses in both clinical and community sectors."

Professor Kate White's appointment as Professor of Cancer Nursing is NSW's first Academic Chair in Cancer Nursing and is jointly funded by the Cancer Institute NSW and the University of Sydney. Under her leadership the Cancer Nursing Research Unit provides support in areas of cancer and haematology nursing research, education, models of service provision and is working to optimise state-wide cancer nursing services.

"Specialist nurses have a central role in the delivery of quality cancer services. In NSW, where there are over 2000 cancer, haematology and palliative care nurses, they are the largest professional group involved in cancer care. They have high level expertise in coordinating, supporting and managing the patient through diagnosis, treatment and recovery in both acute care and community settings.

Their specialised knowledge enables them to provide better care which ultimately improves patient outcomes," Professor White said.

The Cancer Nursing Research Unit launch showcased research being led by both cancer nurses and the Sydney Nursing School across NSW, including:

- Improving the delivery of care for patients with head and neck cancer
- Improving the management of adverse effects of steroid therapy associated with the treatment of multiple myeloma
- Improving nutrition care for women after gynaecological cancer
- Fast-track surgery for women with gynaecological cancer Information resources on breast reconstruction for women after breast cancer

These research studies demonstrate the important role of cancer nurses in supporting their patients and their role in decision making about future trends in treatment, patient care and disease prevention.

We welcome the opportunity to support nurses in NSW to achieve their research and educational goals. Please contact the CNRU if you want to discuss the development of a research study, need research advice, or would like information on educational or research opportunities for cancer nursing. Please contact Professor Kate White: Email: kate.white@sydney.edu.au



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CI NSW Clinical Training Fellowship

Tracy King RN MN

Cancer Institute NSW, Clinical Training Fellow (Haematology)

Myeloma Clinical Nurse Consultant, Royal Prince Alfred Hospital, Sydney.

Tracy King RN MN was recently awarded a Cancer Institute NSW Clinical Training Fellowship to undertake research on the adverse effects of high dose steroids in those undergoing treatment for myeloma. This study is being undertaken in collaboration with Professor Kate White and Moira Stephens from the Cancer Nursing Research Unit (CNRU). The findings from Tracy's research will be used to improve current best practice in the management of adverse effects associated with steroid therapy.

Tracy King is a registered nurse with over 18 years experience in the field of malignant haematology



and blood and marrow transplantation. Trained in the UK she gained her clinical experience at the Hammersmith hospital BMT unit where she undertook specialist training in advanced haematology nursing. As a member of the board of directors of the International Myeloma Foundation (IMF) UK, she further specialised in the care and support of those affected by multiple myeloma. Moving to Australia Tracy continued her specialist interest in myeloma working as support services manager for Myeloma Foundation of Australia and Myeloma CNC, RPAH Sydney. Tracy is an active member of a range of professional groups including the Cancer Institute NSWOG Haematology. She is also the co-founder and Vice President of the Haematology Society of Australia and New Zealand Nurses Group (HSANZ NG). Further information please contact: Tracy.king@sswahs.nsw.gov.au

Myeloma Academy launched

Myeloma UK launches the Myeloma AcademyTM an innovative online educational resource for healthcare professionals (HCPs) involved in the treatment and care of myeloma patients.

The Academy aims to improve patient treatment and care by providing HCPs with knowledge of the latest advances in myeloma research and clinical practice, as well as tools to understand the holistic care needs of patients and to navigate the changing health policy environment.

The free, online programme contains designated materials for both hospital doctors and nurses, offering a series of relevant and tailored learning opportunities designed to fit around busy schedules. In the second phase the Academy will be rolled out to General Practitioners and Allied Healthcare Professionals.

The Academy also contains a comprehensive library of key clinical guidelines and published papers, and information on upcoming events, conferences and latest news.

Eric Low, Myeloma UK Chief Executive commented:

"The Myeloma Academy will be a fantastic educational resource. Its online format makes it very accessible and easy to keep up with the pace of change in myeloma. Incorporating the holistic needs of patients as well as policy issues into the educational paradigm is a novel approach, but one we believe will bring significant benefits to patient outcomes."

To find out more or to register for the Academy please go to:

www.myeloma-academy.org.uk



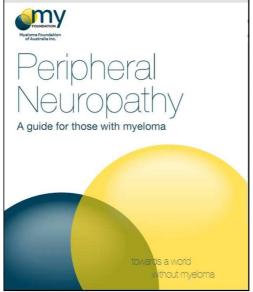
Peripheral Neuropathy Patient Guide

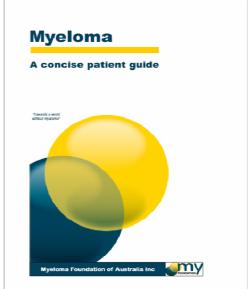
Myeloma Foundation of Australia has a new patient guide to help people understand and manage the troubling and not uncommon toxicity of peripheral neuropathy. Peripheral neuropathy can be caused by a variety of factors including the underlying disease but more commonly by neurotoxic agents commonly used to manage myeloma including Thalidomide and Bortezomib.

Recognising that some people require more in depth information about their disease Myeloma Foundation of Australia also has "Myeloma – a concise patient guide" available for download from the website. It is developed to supplement the information available in the standard patient guide and to offer people greater choice. You can obtain copies of the guide's from Myeloma Foundation of Australia (1800 693 566) or as a download from the Myeloma Foundation of Australia website

www.myeloma.org.au

Hayley King Myeloma Support Nurse VIC Hayley.king@myeloma.org.au 1800 693 566





New Lymphoma Book for children

The Leukaemia Foundation has published an illustrated book for children diagnosed with lymphoma, called *Tom Has Lymphoma*.

The 32-page picture book is based on a general story of a child with Hodgkin lymphoma.

Tom is 10 years old and lives with his large blended family and dog, Mutley. When Tom discovers a lump on his neck, he tells his mum and they go to see their family doctor.

The story clearly explains what is wrong with Tom and what happens to him as he has a series of tests and is treated 'to make Tom's lymphoma go away' in a child-friendly manner.

At the end of the book, there's a section called 'What these words mean' with simple explanations for the 'strange new words' children are likely to hear when they are going through the lymphoma experience.

Copies of *Tom Has Lymphoma* are available free from the Leukaemia Foundation (call 1800 620 420), at many treatment centres and hospitals where children are treated, and can be downloaded from the Foundation's website: www.leukaemia.org.au (About the diseases > Information booklets).

Tom Has Lymphoma has been republished by the Foundation in association with Caring for Children With Cancer and Lymphoma Association, both in the UK.

World Lymphoma Awareness Day

World Lymphoma Awareness Day is on September 15th and the Leukaemia Foundation is planning to hold events in all capital cities and many regional centres across Australia.

This special day has three objectives:

- to promote lymphoma awareness
- to bring together people who are affected by lymphoma, to provide support, and
- to celebrate access to novel treatments for lymphoma in Australia and recognise current and future research into lymphoma.

Closer to the day, details about the range of awareness raising activities and education events for the lymphoma community will be listed on the Foundation's website: www.leukaemia.org.au. If you'd like to get involved and join the Leukaemia Foundation in promoting and recognising World Lymphoma Awareness Day by hosting your own event in your area, speaking at a Foundation event, or if you have any other suggestions, please contact

Jane Miles: lymphoma@leukaemia.org.au.



Conference Reports

THE TANDEM BMT MEETINGS, HAWAII, 2011



This meeting was held from 17 - 21 February and consisted of multiple conferences in one. The ones that I attended sessions in were:

- BMT Registry data management meeting
- The BMT nurses meeting
- The BMT pharmacy meeting
- The medical and scientific meeting
- The mid level practitioner meeting.

The first meeting I attended was the data management meeting. Our allogeneic stem cell transplant patients are all asked if they are willing to have their anonymous data submitted to a very large registry called the International Bone Marrow Transplant Registry. It has the data of hundreds of thousands of transplants and is an excellent resource that can be used to answer questions about transplant but also allows us to benchmark ourselves against the rest of the world. This was a three day meeting which provided teaching and education around the forms that are completed for our patients and also the upcoming changes to data collection. It also provided some excellent education sessions around some of the complications of transplant.

For the first time a Clinical Practice Forum was held. This day was for all allied health professionals to attend. It had some excellent sessions about acute graft versus host disease, post transplant relapse strategies and current infection disease management guidelines. There was also an interesting session from an unrelated stem cell donor telling what it meant for him to be a stem cell donor.

I attended a large number of sessions in the BMT nurses meeting. These covered such topics as sexuality and sexual dysfunction in the BMT population, food safety in BMT, cutaneous effects of BMT and BMT for elderly patients with AML. The calibre of the nursing programme was excellent and I look forward to being able to apply some of what I learnt into my practise and to update patient information with some new information.

The medical conference ran over four days, overlapping the other conferences. There were some excellent sessions in this conference as well, some of which will stimulate discussion amongst the Haematology team in Wellington.

Some of the highlights of the conference include:

- A couple of sessions about the re-vaccination post transplant of childhood vaccines. This has been a controversial area in BMT but more and more guidelines are coming out about what vaccines should be given and when in the post transplant period they should be administered. These were timely sessions as our post transplant vaccine schedule is due for review. There are a couple of additions which we probably need to make to the schedule in light of the information provided at the conference.
- A couple of excellent sessions about late effects post transplant. There was talk about the late effects that do occur and some data around these. There was also a session about the screening that needs to be done on patients post transplant the type of screening that needs to be done and the frequency. Once again, this is a topical subject in our unit so the information provided will be helpful in reviewing what we are currently doing and deciding on the structure of late effects review in the future.
- Tied in with late effects was an excellent session on sexuality post transplant. This is a topic that I am doing my thesis on so was great to get an update along with an excellent bibliography. The patient information that I give out to patients needs this section to be reviewed and updated so this was a timely session. Information was given about sexuality issues affecting both females and males post BMT and gave some practical suggestions on how to address these issues.
- A very good session about ABO incompatible transplants. This was an excellent education session for me personally but I will be able to use the information provided in the BMT study days I run for nurses.
- There were a couple of good sessions about transplanting elderly patients (> 60 years) and the co-morbidities associated with this. This was a very relevant session because we are transplanting far more "elderly" people than we used to. One of the sessions gave good information about the BMT co-morbidity score which can be used to help identify who will do well post transplant and those who won't.

All in all the conference was very worthwhile and I am very grateful for the opportunity to attend. There was a good mixture of things to think about with respect to the care we provide in Wellington and reassurance that we provide a good service for our patients. There were also a number of titbits to bring back to discuss about whether incorporating these into our protocols is something that we want to do.

Catherine Wood

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Conference Reports continued

THE INTERNATIONAL MYELOMA WORKSHOP PARIS 2011





The International Myeloma Workshop (IMW) hosts a bi annual 4 day meeting which this year was attended by the largest number of clinicians reflecting the progress and interest in the field of myeloma. Or was it that the conference was in Paris, venue being the conference centre below the Louvre? Whatever the draw card was, 2,485 delegates from 67 countries came together for an intensive 4 days of meetings and presentations. Although there was not a separate nursing symposium, I had the great fortune of catching up with many of my UK myeloma nursing colleagues and also met nurses from around the world who were in attendance. The focus of the meeting was to hear updates form the large myeloma research and trials groups, who together are working towards answering some important questions in how best to manage myeloma. The various myeloma advocacy groups were exceptional in providing summaries of presentations and themes discussed via live webcasts and summaries hosted on their websites. In particular I suggest you review the following sites to obtain further summaries and reports from IMW:

The International Myeloma Foundation

www.myeloma.org

Special webcasts from IMW can be found by following this link.

 $\underline{\text{http://myeloma.org/IndexPage.action?tabId=222\&menuId=291\&indexPageId=319\&parentMenuItemId=291\&categoryId=0}$

The International Myeloma Working Group (IMWG) produces a range of consensus statements and guidelines that can be found online by following this link. Several statements have been updated post IMW and the reports will be made available soon via these links.

http://myeloma.org/PortalPage.action?tabld=8&menuId=125&portalPageId=8

The IMF nurse leadership board have also published consensus statements available online, including the recent 'Long term care guidelines for patients with myeloma' presented at IMW this year and soon to be available via the IMF website.

http://myeloma.org/PortalPage.action?tabld=8&menuId=201&portalPageId=7

The Multiple Myeloma Research Foundation

www.themmrf.org

A range of CNE accredited webcasts, reports and resources including comprehensive information on the research of sequencing the myeloma genome.

Areas worthy of mention from IMW include the following:

Molecular pathways and genetics.

Increased understanding of myeloma at a molecular and genetic level is fuelling the rapid progress in terms of improvement in patient outcomes. Myeloma is characterised by significant heterogeneity at multiple levels and it is increasingly recognised that this heterogeneity is mainly related to the characteristics of the tumour clone (Avet-Loiseau et al 2011). It is also recognised that these chromosomal abnormalities impact clinical outcomes with high risk chromosomal abnormalities being identified as t(4:14), t(14,16) and del 17p. In March 2011, researchers published a landmark study in *Nature* analyzing 38 multiple myeloma genome sequences, the largest such data set ever published in multiple myeloma (Chapman, Lawrence, Keats, et al 2011). It is expected that a greater understanding of the molecular and genetic pathways in myeloma will assist in a risk adapted approach to therapy and provide targets for the developments of new agents to treat myeloma.

New drugs and therapeutic approaches

Optimum treatment approaches for the management of younger fit myeloma patients and those not suitable for high dose therapy and stem cell rescue were presented by a variety of research groups. Although there remains the need for longer term follow up and greater understanding of high risk and low risk groups, some common themes did emerge. A) Achieving maximum response with upfront therapy is an important goal and seems to confer improved PFS and OS. B) Induction, high dose therapy followed by consolidation then maintenance therapy is a common schema. C) The role of allografting in myeloma remains contentious in terms of where to place the therapy and who it should be offered to. Although TRM is improving it remains at around 15% and without a clear OS benefit seen it is not generally recommended in the upfront setting. There remains a potential benefit in the high risk patient with ISS III and del 17p.

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Conference Reports continued

D) Improvements in supportive care include new agents and imaging techniques in the management of myeloma bone disease and a focus on managing the common toxicities of therapy in particular neuropathies and risk of thrombotic events. Guidelines for supportive care in myeloma

have recently been published by the British Committee for Standards in Haematology in conjunction with the UK Myeloma Forum and provide a valuable resource to have on hand. You can find a copy at www.bcshguidelines.com.

New agents currently being investigated in clinical trials include new generation proteasome inhibitors (Carfilzomib, Salinosporide, MLN9708 (oral), CEP18770, ONX0912); IMiDs (Pomalidomide); Histone deacetylase inhibitors (HiDAC) panabinostat, vorinostat, romidepsin, tubacin, givinostat – most often used in conjunction with Bortezomib); Monoclonal antibodies (Elotuzimab); Heat shock protein 90 inhibitors and many more.

Secondary malignancy in myeloma - an emerging issue?

A symposium was dedicated to the results from a variety of large studies looking at the possible rise in secondary primary malignancies in those with myeloma, in particular after being exposed to IMiDs (Lenalidomide). A demonstrated increased incidence (3-4%) in second primary malignancy (SPM) after prolonged (>24months) lenalidomide therapy is a recent finding (Attal, Oliver et al 2011; McCarthy, Owzar, Anderson et al 2011; Palumbo, Bringen, Zweegman et al 2011). Risk of SPM in MM is multifactorial (myeloma related, treatment related, environmental, host related factors, behavioural factors). Mechanism of the IMiD are thought to contribute to the increased risk of SPM and include the effects of being oncogenic; mutagenic; cause chronic stimulation; impair immune surveillance and post therapy immune reconstruction. The important take home message was that the slight increased risk of SPM needs to be viewed in the context of clear benefits of improved survival.

Overall the IMW supported the view of a recent editorial comment - "Nowhere in medical oncology has progress over the past decade been more rewarding than in the treatment of multiple myeloma..." Susan E Bates, deputy editor CCR Focus National Cancer Institute USA . Clin Can Res 17(6) 2011.

I look forward to attending the next IMW in Japan in 2013 and reporting back to you on further improvements in the management of those with myeloma including continued improved survival.

Tracy King RN MN

Tracy.king@sswahs.nsw.gov.au

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Chapman, M., Lawrence, M., Keats, J. et al. (2011). Initial genome sequencing and analysis of multiple myeloma. *Nature*. 471.467-471. McCarthy, P., Owzar, K., Anderson, K. (2010). Phase III intergroup study of lenalidomide versus placebo maintenance therapy following single autologous stem cell transplant for multiple myeloma. CALGB 100104. *Journal of Clinical Oncology*. 28:577s.

Palumbo, A, Brinchen, S., Zweegman, S. et al. (2011). Secondary malignancies in elderly myeloma patients. Haematologica 96 supplement. S22.

2011/2012 dates for your diary

National/Trans-Tasman Conferences/Meetings

25-30 Oct: ANZCHOG 2011, Auckland, New Zealand

http://www.anzchog.org/

29 Oct: Haematology Nurses Pre HAA Study Day, Sydney, Australia

Further enquiries or to register interest: tracy.king@sswahs.nsw.gov.au 30 Oct-2 Nov: HAA 2011, Sydney, Australia

http://www.haa-ap2011.org/

8-11 Nov: ALLG, Brisbane, Australia

http://www.allg.org.au/

15-18 May 2012: ALLG, Sydney, Australia

http://www.allg.org.au/





International Conferences

4-6 Nov 2011: EHA Annual Congress Highlights, Bangalore, India http://www.ehaweb.org/Congress/Highlights-of-the-16th-Congress

9-13 Dec 2011: ASH, San Diego, USA

h ttp://www.hematology.org/Meetings/

1-4 Apr 2012: EBMT, Geneva, Switzerland

http://www.congrex.ch/ebmt2012

14-17 Jun 2012: EHA 17th Congress, Amsterdam, The Netherlands http://eha.eurocongres.com/17th/

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Clinical Practice Corner

This is the space where you can share your practice, your bright ideas and innovative ways; everybody is at it, so why not share it?

'A LIGHT BULB MOMENT' – reflections of a haematology nurse.



Christiana Guthrie is an experienced haematology nurse who has recently commenced working in Concord Repatriation General Hospital clinical trials unit after working in the inpatient haematology/oncology/palliative care unit for six years. After attending an Australasian Leukaemia & Lymphoma Group education and scientific meeting and the Lymphoma Education day for nurses at CRGH, Chris was contemplating what she should report back about these two events. Our trials unit manager prompted Chris with: "Was there a light bulb moment?" This is part of Chris' amazing response.

When Susie told me that I had to talk about the ALLG conference to all of you, my first thought was oh my god, what can I possibly tell you that you do not already know. My second thought was I hate speaking in front of people!

So I asked Susie what on earth I was going to talk about. One of Susie's responses was, was there a 'light bulb moment'? Did something happen that changed your thinking or taught you something that you didn't know before? What did you take away from the conference?

When I sat back and reflected on the conference, lots of things were said at the conference that changed my thinking, and I certainly learnt a lot about AML and MDS, however for me the light bulb moment came after the conference, when I realized how pessimistic and defeatist I had become. The previous 6 years I have spent constantly treating and caring for especially sick patient's, who were full of hope of a cure, watching them spend month after month on the ward and, rarely getting the opportunity to go home. Ultimately dying from their disease or as it often felt the treatment we were administering.

My mindset had become such that I felt that the treatment was worse than the disease, and why did the specialist promise so much hope, everyone knows that these patients can't be cured. We just make their last months of life a misery. This is the general feeling on the ward because you do not get to see the patient's that are cured, or have their treatment in HACU and go home. Once they leave the ward the nurses have no idea about what has happened to them. I had even told my children that should I be diagnosed with cancer I would not have treatment I would just enjoy what time I had left.

The ALLG conference and Lymphoma Nursing Day made me stop and think about patients that I had nursed with acute promyelocytic leukaemia that are alive and well, one with a three year old son, another recently returned from her honeymoon. If I was still working on the ward, I would not have met them again and seen how successful their treatment has been.

Listening to the specialists at the conference and all of you talk about the trials that they and you are working on and the passion that resounds in all of your voice's, couldn't help but make me believe that cures are possible and you can't help but be swept up by everyone's positivity.

So what did I take away from this conference and the lymphoma day?

A re-invigorative thirst to know more, it has renewed my love of haematology nursing, and most importantly it has made me positive about the future.

I feel that the last 5 months that I have spent in clinical trials has been one great big light bulb moment. I appreciate being given the opportunity to attend the ALLG conference, the lymphoma day, and every education session that I attend. I feel that I can be much more positive about the future in haematology nursing and more importantly feeling positive about our patient's futures.

Ultimately I hope to pass on what I have learnt and what I will learn in the future. Chris.

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News from the regional groups

New Zealand (North Island)

The lower North Island continues to have a successful 2011 with running education evenings. The plan is to have six sessions this year split between Wellington and Palmerston North. We have had one session so far in Palmerston North talking about Haemophilia and one session in Wellington talking about apheresis and stem cell mobilisation. There continues to be an enthusiastic response to these meetings with an average of around 25 attendees coming along on each evening. The next evening is being held on



the 22nd June in Palmerston North and is oversubscribed already. They are popular so you need to be in quick if you want to attend! The education evenings wouldn't be possible without sponsorship. Bayer HealthCare and Genzyme have very kindly sponsored the first two sessions and Roche is sponsoring the next meeting.

Upcoming education evenings for 2011 are as follows:

Date	Location	Topic
22 nd June	Palmerston North	Lymphoma
17 th Au- gust	Wellington	AYA
19 th Octo- ber	Palmerston North	Palliative Care in Hae- matology
30 th No- vember	Wellington	Blood Transfusion

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@ccdhb.org.nz

Catherine Wood

Western Australia

This year the WA Nurses Group committee has decided to offer a malignant and a non malignant topic at each of our clinical meetings. This we hope will attract nurses from the whole of haematology. The group had its first clinical meeting for the year in April. Our topics were "Hot MabThera" and new anticoagulants and the meeting was very well attended, thank you to all those who came. Thank you to Janeece and Robyn for organising the speakers, and Janeece for organising the venue.

Our next meeting is going to be July 12th at Sir Charles Gardiner Hospital. Our topics will be Cyroglobulinaemia and Waldensroms Macroglobulinaemia. Thank you to Lynne who has organised this meeting so well, speakers, venue and a sponsorship contact.

We are looking forward to seeing both our regular members and new members.

Our meetings are free and open to all nurses so we would love you to spread the word and invite your colleagues to come along and support this group.

Any WA Haematology nurses who are interested in joining HSANZ or would like to be more involved in the planning and committee, or if you have any topics you would like covered or you would love to share your knowledge then I'd love to hear from you. Please get in touch with me via the email below.

Karen Taylor WA Chair Karen.Taylor@health.wa.gov.au

Victoria

The Victorian Nurses group has had a very active year. We have had 2 successful educational evenings with impressive attendance of up to 70 participants from all over the state. As always we are working on increasing our membership and providing support and education to Victorian Haematology Nurses.

In March we enjoyed an educational evening on MDS. Sandra Kurtin. NP, from the Arizona Cancer Centre and Michael Dickson. MD, from Peter Mac gave us a detailed insight to current treatment for MDS and optimal approaches to patient care.

Recently in June, Odette Blewitt. NPc, Skin Lymphoma CNC pro-

vided us with a fascinating and very practical approach to management of cutaneous T-cell Lymphoma. Odette has considerable experience in skin lymphoma so was able to take us on a journey of discovery in caring for patients with various stages and symptoms of this illness.



Upcoming educational opportunities include:

8th of September, Insights into PNH. Speakers: Michael Brown, Research Nurse, RMH and Prof. Jeff Szer, RMH.

22nd November – Topic to be confirmed.

We are in the process of arranging our first rural HSANZ Victorian Nurse group educational evening. This will be in Traralgon – Gippsland region of Victoria. The topics will be MDS and Multiple Myeloma. Date to be confirmed.

"Opportunity to attend HAA for Victorian nurses – Pfizer Travel Grant for 2011"

The Victorian chapter of the HSANZ Nurses Group with the generosity of Pfizer, Australia is excited to be able to invite applications for sponsorship to attend the HAA conference in Sydney, 2011.

Who can apply?

Sponsorship will be offered to one Haematology Nurse who fulfils the following criteria:

Haematology Nurse with less than 5 years experience in Haematology (Melbourne based or regional) <u>OR</u> a Haematology Nurse from Regional Victoria

What does the travel grant include?

Due to the generosity of Pfizer, Australia and their support of Haematology Nurses, sponsorship will include full registration to HAA, Sydney 2011, return airfare to Sydney and accommodation during the conference.

The HSANZ Victorian Nurses Group will provide the successful applicant with assistance and support at HAA, Sydney 2011 to navigate the conference process.

How do I apply?

Applicants must submit a written piece of 200 words or less describing why you should be chosen as the successful applicant. Please include your contact details, place of employment and years in Haematology.

The Victorian chapter of the HSANZ Nurses Group with the Please send applications (or if you have any questions regarding educational evenings or membership) to me at the email below.

yvonne.panek-hudson@petermac.org

Yvonne Panek-Hudson

News from the regional groups







2011 JOINT SCIENTIFIC MEETING 30 OCTOBER - 2 NOVEMBER 2011 Sydney Convention & Exhibition Centre, Darling Harbour, Sydney, Australia

<u>Tasmania</u>

I recently felt privileged to be invited by the Cancer Council, along with other Cancer Care Coordinators from the Royal Hobart Hospital (RHH) to speak to the community of Bothwell. We were invited to speak about our area of specialty, the services available and the role of nurses in assisting patients and their families. What a treat to leave the city behind on a sunny winter day, wend our way along country roads and enjoy a hearty lunch in front of an open fire with friendly locals.

The Bone Marrow Transplant Service at the RHH has been established as a statewide service after years of quietly getting on with the job. This has led to an increase in our profile. In 2010 we won an 'Innovations in Practice' award for our efforts in concurrently implementing both the statewide structure and NATA standards in a streamlined, patient-focussed way. Cancer Nurses are taking an interest in haematology/transplant nursing as a discrete specialty. It is now a popular request for graduate and other nurses to spend a day in the service gaining insight into transplant nursing. In response to so much interest, a questionnaire regarding learning needs of local nurses is soon to be circulated with a view to establishing regular study days in haematology to be held at the Royal Hobart Hospital.

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Gill Sheldon-Collins

South Australia/Northern Territory

It's hard to believe that it is nearly August already. Saying that we have had a fairly busy time of it in SA with two education events and we finally got to provide an education day in Darwin, NT!

March saw an evening education session on Thalassaemia Major and Myelodysplastic Syndromes. It was a well attended event with 55 people there to hear from Paediatric Haematologist/Oncologist Heather Tapp about Thalassaemia Major and Clinical Services Coordinator Michael Fitzgerald discuss MDS – from Flinders Medical Centre (with an Adult perspective). We were lucky to be supported by Amgen, Gilead, Novartis and Roche for this event.

The local HSANZ Nurses Group again combined forces with the Adelaide Regional Group of the Cancer Nurses Society of Australia to provide a whole day of education to haematology and oncology nurses. 41 Nurses from regional SA as well as public and private metro nurses attended the day. The programme included presentations on cancer cell biology, haematopoietic stem cells, safer chemotherapy practices (from prescribing to administration) and nurse practitioner presentations on survivorship and patient assessment. Our thanks to Amgen for their support.

Finally we also got to head North to provide some education in the NT when we went to Darwin in July. And what a perfect time of the year to go, 30 degrees every day, a very welcome escape from the cold SA winter – It was also noted that the low overnight temperature in Darwin was a good 5 degrees higher than the "high's" we were having in SA! The day was well attended with 20 people from paediatric nursing, ambulatory nursing and also included registrars

and consultants who dropped in to listen to presentations. The Alan Walker Cancer Care Centre was a great venue and the day started off with a presentation on haemopoiesis, followed by disease specific talks on acute leukaemia, chronic leukaemia, myeloma and lymphoma. Some the challenges facing adolescents and young adults with cancer were also presented by AYA Consultant Michael Osborn. Other speakers included Allan Hayward and Dr Pratyush Giri from Adelaide, Dr Andrew Wei from Melbourne and Dr Akash Kalro from Darwin. Overall, a great event and something that we are looking forward to repeating in the future. Our thanks to Gilead and the Leukaemia Foundation for their support.

Look out for a couple more education evenings before the end of the year!

allan.hayward@health.sa.gov.au

Allan Hayward

New South Wales

NSW continues to enjoy regular educational events for nurses around the State. The recent Sydney dinner meeting attended by 60 nurses was lucky enough to hear summary reports from 2 International Haematology conferences. David Collins (CNC BMT Network) feedback findings from European Haematology Association meeting and Lucy Maurice (CNC Paediatric BMT SCH) reported with a paediatric perspective from the recent EBMT meeting. It was fascinating to hear the paediatric perspective and both speakers gave comprehensive and interesting reports from their respective conferences.

"Hold the date – Saturday 29th October 2011 – Haematology Education Day Sydney"

The local NSW organising committee has began work on the program for the pre HAA conference nurse's educational day in Sydney. This full study on Saturday 29th October aims to make use of senior Haematology nurses coming to town to present to local nurses. The day is open to all haematology nurses and is to be hosted at a central Sydney venue (to be confirmed). The day will be free of charge and provide attendees with RCNA CPD points. Speakers will include Liz Pirie who is the international key note speaker for the nurse/s stream at HAA. Liz Pirie is an education specialist for the Scottish National Blood Transfusion Service and the nurses group is delighted she has agreed to arrange her travel to accommodate joining us at the pre conference educational event.

Remaining educational events for 2011:

18 th August 2011	Sydney
29 th October 2011 Pre HAA study day	Sydney
17 th November 2011	Sydney
TBA Haematology nurses day	Orange
Late September Haematology nurses day	Can- berra

For more information or to register your interest in attending, please feel free to contact me.

Tracy.king@sswahs.nsw.gov.au





2011 JOINT SCIENTIFIC MEETING 30 OCTOBER - 2 NOVEMBER 2011 Sydney Convention & Exhibition Centre, Darling Harbour, Sydney, Australia

Research News - a short trip around some recent journals

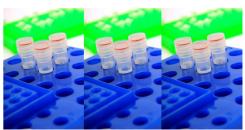
A review of pathophysiology and current treatment for neonatal alloimmune thrombocytopenia (NAIT) and introducing the Australian NAIT registry.

<u>Aust N Z J Obstet Gynaecol.</u> 2011 Jun;51 (3):191-198. doi: 10.1111/j.1479-828X.2010.01270.x. Epub 2011 Feb 14.

McQuilten ZK, Wood EM, Savoia H, Cole S.

Abstract

Fetomaternal or neonatal alloimmune thrombocytopenia (NAIT) is a rare but serious condition associated with significant fetal and neonatal morbidity and mortality. The most useful predictor of severe disease is a history of a sibling with an antenatal intracranial haemorrhage. However, NAIT can occur during the first pregnancy and may not be diagnosed until the neonatal period. Antenatal treatment options include maternal intravenous immunoglobulin (IVIG) and corticosteroid treatment, fetal blood sampling (FBS) and intrauterine platelet transfusion (IUT) and early delivery. FBS (with or without IUT) can be used to direct and monitor response to therapy, and to inform mode and timing of delivery. However, this procedure is associated with significant risks, including fetal death, and is generally now reserved for high-risk pregnancies. This review highlights the current understanding of the epidemiology and pathophysiology of NAIT and summarises current approaches to investigation and management. It also introduces the newly established Australian NAIT registry. Owing to the relative rarity of NAIT, accruing sufficient patient numbers for studies and clinical trials at an institutional level is difficult. This national registry will provide an opportunity to collect valuable information and inform future research on this condition.





2011 JOINT SCIENTIFIC MEETING 30 OCTOBER - 2 NOVEMBER 2011 Sydney Convention & Exhibition Centre, Darling Harbour, Sydney, Australia



Invitation to Sydney, Australia, for HAA-ISHAPD 2011

Abstracts due 1 July 2011

Notification of abstract acceptance mid August 2011

Registration brochure available late May/early June 2011

Accommodation bookings close 31 August 2011

Early Bird registration closes 12 September 2011

We wish to extend a warm invitation to all haematologists, scientists, nurses and members of industry, especially those in the Asia-Pacific region, to participate in a special 2011 meeting of the Haematology Society of Australia and New Zealand (HSANZ), the Australian & New Zealand Society of Blood Transfusion (ANZSBT) and the Australasian Society of Thrombosis and Haemostasis (ASTH) - the HAA.

This year, the Annual Scientific Meeting and Trade Exhibition of the HAA will be held jointly with meetings of several other societies. These are:

- the XIIth Congress of the ISHAPD (International Society of Hematology, Asia-Pacific Division)
- the 16th Congress of the APBMT (Asia-Pacific Blood and Bone Marrow Transplantation Group)
- the ISCTA (International Society for Cellular Therapy: Australia)
- the BMTSANZ (Bone Marrow Transplant Society of Australia and New Zealand)
- the BMTSAA (Bone Marrow Transplant Scientists Association of Australasia)

Darling Harbour, Sydney from 30 October to 2 November 2011. The conference venue is in a prime Sydney harbour location within easy walking distance of hotels and the city centre.

The programme comprises top quality international and local speakers addressing a comprehensive range of topics on malignant and non-malignant haematological disorders, stem cell transplantation, transfusion medicine, haemostasis and thrombosis and laboratory haematology.

We are excited about the scientific quality of the meeting as well as the excellent opportunities for scientific and social interactions and look forward to welcoming you to Sydney

Michael Harvey For HSANZ David Ma

For APBMT

Peta Dennington For ANZSBT

John Rasko

For ISCTA

Chris Ward For ASTH Vicki Antonenas For BMTSAA

Moira Stephens Nurses' Programme

Szu Hee Lee



Research News - continued

Managing multiple myeloma in the elderly: Speksnijder HT, Mank AP, van Achterberg T. are we making progress?

Expert Rev Hematol. 2011 Jun;4(3):301-15.

Quach H, Prince HM, Spencer A.

Source

Department of Clinical Hematology, Faculty of Medicine, Nursing & Health Sciences, Monash University, Victoria, Australia.



Abstract

Treatment of multiple myeloma has evolved rapidly over the last decade due to novel therapeutic agents. Improved upfront and salvage options have resulted in enhanced survival; however, this has been less pronounced in elderly patients compared with their younger counterparts. Indeed, treatment-related toxicities in older patients may have subverted the survival benefit made by newer treatment modalities. However, owing to the immaturity of current published data, the true survival impact made by novel agents in the elderly patient subgroup is far from being fully appreciated. Improved responses, along with increased salvage options, imply that progress for elderly patients is being made. The current challenge to improve survival for elderly patients not only rests with continued research into tolerable novel treatment regimens, but also, scrupulous supportive care and the judicious use of current novel agents in appropriate dosing, combinations and sequence. Here, we review the outcomes of elderly patients with multiple myeloma over recent years and focus on the current treatment options available for this group.

Nursing diagnoses (NANDA-I) in hematology-oncology: a Delphi-study.

Int J Nurs Terminol Classif. 2011 Apr-Jun;22 (2):77-91. doi: 10.1111/j.1744-618X.2011.01183.x.

Abstract

PURPOSE:

To identify NANDA-I diagnoses that are most relevant to hematology-oncology nursing in Europe.

METHODS:

In a two-round, electronic, quantitative Delphi study, 28 experts from nine European countries assessed the relevance of NANDA-I diagnoses and health problems.

FINDINGS:

This study identified 64 relevant diagnoses and three health problems. All experts listed 11 diagnoses: "imbalanced nutrition: less than body requirements,""diarrhea,""fatigue,""risk for bleeding,""risk for infection,""impaired oral mucous membrane,""risk for impaired skin integrity,""impaired skin integrity,""hyperthermia,""nausea,""acute pain," and the health problem "pruritis."

CONCLUSIONS AND IMPLICATIONS FOR PRAC-TICE:

The "NANDA-I classification 2009-2011" describes, in almost all disease- and treatmentrelated problems, nursing diagnoses as relevant to the adult patient with hematological malignancy. These diagnoses are therefore recommended.

Pain severity, satisfaction with pain management, and patient-related barriers to pain management in patients with cancer in Israel.

Oncol Nurs Forum. 2011 Jul 1;38(4):E305-13.

Naveh P, Leshem R, Dror YF, Musgrave CF.

Abstract

Purpose/Objectives: To examine pain severity, satisfaction with pain management, and patient-related barriers to pain management among patients with cancer in oncology units at a teaching hospital in Israel. Design: Descriptive, cross-sectional, correlational design.Setting: Oncology, hematology, and bone marrow trans-plantation (BMT) departments; oncology, hematology, and BMT daycare units; and a radiation department in an Israeli hospital.Sample: Nonprobability convenience sample (N = 144) of ambulatory (n = 76) and hospitalized (n = 68) patients experiencing pain in the past 24 hours. Methods: Patients who had experienced pain in the past 24 hours completed the Revised American Pain Society-Patient Outcome Questionnaire, the Barriers

Questionnaire-Short Form, and a demographic data questionnaire. Main Research Variables: Pain severity, satisfaction with pain management, and patient-related barriers to pain management. Findings: A significant inverse relationship was observed between patients' pain severity and their expectation of pain relief. Less-educated patients had significantly higher pain severity scores. Ambulatory patients waited longer for their pain medication than hospitalized patients. The greatest barriers to pain control were fear of addiction and the notion that medication should be saved in case the pain gets worse. In addition, ambulatory patients had higher pain barrier scores than hospitalized patients.Conclusions: The relationship between pain severity and the expectations of patients with cancer regarding pain relief indicate that patients' expected outcomes and barriers may impede optimal pain relief. This study also identified areas of possible weakness within the hospital's pain palliation program.Implications for Nursing: Nurses should assess for patients' expectations and barriers that could impede pain relief and provide appropriate interventions.

Immune modulation to prevent antibodymediated rejection after allogeneic hematopoietic stem cell transplantation.

Transpl Immunol. 2011 Jun 21. [Epub ahead of print]

Nordlander A, Uhlin M, Ringdén O, Kumlien G, Hauzenberger D, Mattsson J.

Abstract

It has been shown that antibodies to donor CD34+/VEGFR-2+ stem cells or antibodies against mismatched HLA are associated with graft rejection after hematopoietic stem cell transplantation (HSCT). CD34/VEGFR-2 positive stem cells have been implicated to play a major role in engraftment after HSCT. In this study we treated four patients with an imminent risk of antibody-mediated rejection with immune modulation, i.e. plasma exchange, intravenous immunoglobulin (IVIG), and rituximab before HSCT. Three of the patients had been previously transplanted and rejected their initial grafts after 12months, 1month, and less than 1month, respectively. The fourth patient was not transplanted previously but had HLA directed antibodies present against the graft. During the immune modulatory treatment we followed the pattern of antibodies in sera using FACS and microcytotoxicity assay. We could show that two patients had antibodies against donor CD34+/VEGFR-2+ cells while the other two

Research News - continued

had antibodies directed against HLA. All four patients tolerated the immune modulatory regimen without any side effects. In this preliminary study we show that immune modulatory treatment may be used to reduce antibody levels and to prevent rejection after HSCT. In two of the three patients which experienced previous rejections and had detectable anti-HLA or anti-CD34+/VEGFR-2+ antibodies, immune modulation resulted in engraftment. In the fourth patient with known anti-HLA-class I antibodies, the treatment also resulted in engraftment. Our results encourage further studies regarding this treatment regimen.



Preservation of fertility in females with haematological malignancy.

<u>Br J Haematol.</u> 2011 Jul;154(2):175-84. doi: 10.1111/j.1365-2141.2011.08723.x. Epub 2011 May 12.

Donnez J, Dolmans MM.

Abstract

Several options are currently available for the preservation of fertility in cancer patients: embryo cryopreservation, oocyte cryopreservation or ovarian tissue cryopreservation. The choice of the most suitable strategy for preserving fertility depends on different parameters: the type and timing of chemotherapy, the type of cancer, the patient's age and the partner status. Cryopreservation of ovarian tissue is the only option available for prepubertal girls and woman who cannot delay the start of chemotherapy. So far, 15 live births have been obtained after orthotopic transplantation of cryopreserved ovarian tissue.

Cytarabine Dose of 36 g/m2 Compared With 12 g/m2 Within First Consolidation in Acute Myeloid Leukemia: Results of Patients Enrolled Onto the Prospective Randomized AML96 Study.

<u>J Clin Oncol.</u> 2011 Jul 1;29(19):2696-702. Epub 2011 May 23.

Schaich M, Röllig C, Soucek S, Kramer M,

Thiede C, Mohr B, Oelschlaegel U, Schmitz N, Stuhlmann R, Wandt H, Schäfer-Eckart K, Aulitzky W, Kaufmann M, Bodenstein H, Tischler J, Ho A, Krämer A, Bornhäuser M, Schetelig J, Ehninger G.

Source

Medizinische Klinik und Poliklinik I, Universitätsklinikum Dresden, Fetscherstraße 74, 01307 Dresden, Germany; markus.schaich@uniklinikum-dresden.de.

Abstract

PURPOSE

To assess the optimal cumulative dose of cytarabine for treatment of young adults with acute myeloid leukemia (AML) within a prospective multicenter treatment trial. PATIENTS AND METHODS Between 1996 and 2003, 933 patients (median age, 47 years; range 15 to 60 years) with untreated AML were randomly assigned at diagnosis to receive cytarabine within the first consolidation therapy at either a intermediate-dose of 12 g/m(2) (I-MAC) or a high-dose of 36 g/m(2) (H-MAC) combined with mitoxantrone. Autologous hematopoietic stem-cell transplantation or intermediate-dose cytarabine (10 g/m(2)) were offered as second consolidation. Patients with a matched donor could receive an allogeneic transplantation in a risk-adapted manner. Results After double induction therapy including intermediate-dose cytarabine (10 g/m(2)), mitoxantrone, etoposide, and amsacrine, complete remission was achieved in 66% of patients. In the primary efficacy analysis population, a consolidation with either I-MAC or H-MAC did not result in significant differences in the 5-year overall (30% v 33%; P = .77) or disease-free survival (37% v 38%; P = .86) according to the intention-to-treat analysis. Besides a prolongation of neutropenia and higher transfusion demands in the H-MAC arm, rates of serious adverse events were comparable in the two groups. CONCLUSION In young adults with AML receiving intermediate-dose cytarabine induction, intensification of the cytarabine dose beyond 12 g/m(2) within first consolidation did not improve treatment outcome.

Sleep Disturbance in Hospitalized Recipients of Stem Cell Transplantation

<u>Clinical Journal of Oncology Nursing Volume</u> 15, Number 3 / June 2011

Laura Boonstra, BSN, RN, OCN®, Karen Harden, MS, RN, AOCNS®, Sarah Jarvis, BSN, RN, Stephanie Palmer, RN, Pam Kavanaugh-Carveth, RN, Joe Barnett, BS, RN and Christopher Friese, RN, PhD, AOCN®

Disrupted sleep is considered a patient out-

come sensitive to oncology nursing care and can lead to a variety of physical and psychologic dysfunctions, such as insomnia, chronic pain, respiratory distress, obesity, stress, and anxiety. Although sleep disturbances have been studied in recipients of hematopoietic stem cell transplantations (HSCTs), these studies have not examined the acute phase of transplantation. The current study aimed to identify the level of sleep disturbance in this patient population, identify factors contributing to decreased ability to sleep for hospitalized recipients of HSCT, and compare the differences in sleep disturbance between age, gender, type of transplantation, and initial stem cell transplantation versus readmission for transplantation-associated complications. Among the 69 patients studied, 26% reported clinical insomnia, as measured by the Insomnia Severity Index, and 74% had some degree of insomnia. Patient characteristics were not significantly associated with insomnia scores. Patients reported bathroom use as the most frequent reason for sleep disruption (85%). These findings suggest that sleep disturbances are common in hospitalized patients undergoing HSCT, and strategies to reduce disruptions are needed to improve patient outcomes.

New insights into the pathogenesis and treatment of Waldenstrom macroglobulinemia.

Curr Opin Hematol. 2011 Jul;18(4):260-5.

<u>Issa GC</u>, <u>Leblebjian H</u>, <u>Roccaro AM</u>, <u>Ghobrial IM</u>.

Abstract

PURPOSE OF REVIEW:

Waldenstrom macroglobulinemia is a distinct low-grade lymphoproliferative disease. There have been recent significant advances in understanding the underlying pathogenesis of this disease, including genetic and epigenetic regulators of tumor progression.

RECENT FINDINGS:

Current studies have shown that the tumor microenvironment plays a critical role in cell proliferation, dissemination, and drug resistance.

SUMMARY:

This review provides an update of the advances in the pathogenesis of factors both intrinsic (in the tumor clone) and extrinsic (in the bone marrow microenvironment) that regulate tumor progression in Walden-

Research News - continued

strom macroglobulinemia. We next discuss novel agents that have been recently tested in clinical trials based on the advances observed in the pathogenesis of Waldenstrom macroglobulinemia.

Prevalence of posterior subcapsular cataracts in volunteer cytapheresis donors.

<u>Transfusion.</u> 2011 May;51(5):921-8. doi: 10.1111/j.1537-2995.2010.02948.x. Epub 2010 Nov 23.

Clayton JA, Vitale S, Kim J, Conry-Cantilena C, Byrne P, Reed GF, Ferris FL 3rd, Leitman SF.

Abstract

BACKGROUND:

Granulocyte donors routinely receive dexamethasone orally before donation. Steroids may increase the risk of posterior subcapsular cataract (PSC) formation.

STUDY DESIGN AND METHODS:

We recruited 100 granulocyte donors (four or more granulocyte donations; any number of platelet [PLT] donations) and 100 age-and sex-matched PLT donors (zero to three granulocyte donations, any number of PLT donations) to examine the risk of PSC. PSC was assessed by a masked ophthalmologist and reading center lens photograph gradings or medical record documentation of PSC as the reason for cataract extraction.

RESIJITS:

Fourteen eyes of 10 granulocyte donors and five eyes of four PLT donors had PSCs (odds ratio [OR], 2.82; 95% confidence interval [CI], 0.83-9.61; p=0.10). Risk of PSC increased with number of granulocyte donations: compared to zero to three donations (4.0%), the risk for four to nine, 10 to 19, and 20 or more donations was 8.6% (OR, 2.25; 95% CI, 0.31-13.99; p=0.30), 9.5% (OR, 2.53; 95% CI, 0.44-14.20; p=0.21), and 13.0% (OR, 3.60; 95% CI, 0.48-22.81; p=0.11), respectively (p=0.06 for trend).

CONCLUSION:

We did not demonstrate a statistically significant increased risk of PSC associated with granulocyte donation. However, although this makes a large risk unlikely, we cannot rule out a small to moderate risk and there is biologic plausibility that the steroid administration associated with granulocyte donation could be associated with PSC formation. Transfusion medicine professionals should advise granulocyte apheresis donors

to maintain an appropriate frequency of eye examinations.

Informed consent and patient understanding of blood transfusion.

<u>Transfus Med.</u> 2011 Jun;21(3):183-9. doi: 10.1111/j.1365-3148.2011.01069.x. Epub 2011 Jan 27.

Court EL, Robinson JA, Hocken DB.

Source

Department of Surgery, The Great Western Hospital, Swindon SN3 6BB, UK. emma@ecourt.demon.co.uk

Abstract

BACKGROUND:

Obtaining separate informed consent for blood transfusion is mandatory in some countries. Although patients should be informed about risks and benefits of transfusion, studies suggest this does not happen routinely in the UK and the patient perspective is lacking in the current literature. Aim: To explore provision of information and the consent process for patients receiving blood transfusions at our hospital.

OBJECTIVES:

To assess patient recall of the consent process, information conveyed, ease in understanding discussions and perceived knowledge of transfusion afterwards.

METHODS:

All 342 adult patients for whom blood was cross-matched between 1 March 2008 and 30 April 2008 were sent postal questionnaires.

RESULTS:

One hundred and sixty-four questionnaires were returned. Overall, 59·1% of patients said someone explained they might need a transfusion; of those 86·7% felt the reason had been explained. Only 58·8% of patients felt informed of what transfusion involves, with 67·0% told of the benefits and 27·8% informed of risks. Overall, 51·5% of patients said this information was easy to understand, but only 26·8% were aware of a transfusion information leaflet. Of those receiving leaflets, all said they read it and had no questions. Despite this, 61·9% were satisfied overall with the information received.

CONCLUSION:

Information leaflets could increase the information available to patients, with minimal impact on health care professionals' time.

Leaflets are available, free of charge, from the National Health Service Blood and Transplant website. These have been introduced at each bedside, in pre-op packs and in outpatient clinics, with re-assessment planned in 6 months.

Pathophysiology, diagnosis and prevention of arthropathy in patients with haemophilia.

<u>Haemophilia.</u> 2011 Jul;17(4):571-8. doi: 10.1111/j.1365-2516.2010.02472.x. Epub 2011 Feb 22.

Dunn AL.

Source

Aflac Cancer Center and Blood Disorders Service/Children's Healthcare of Atlanta/ Emory University, Atlanta, GA, USA.

Abstract

Recurrent haemarthroses in Summary. patients with severe and moderate haemophilia can result in the development of one or more target joints and subsequent degenerative joint disease. This debilitating process is characterized by physical and physiological changes in articular cartilage, synovium and bone. Models of degenerative joint disease have been examined after the addition of whole blood or blood components to cell cultures or animal joints, or by monitoring biomarkers in individuals with and without haemophilia. Inhibition of cartilage-based proteoglycan synthesis and induction of proliferative synovitis are commonly observed in these models of degenerative joint disease. Clinical evaluation of joint disease includes use of specially designed physical examination and radiographic tools. Efforts to prevent or limit arthropathy include the use of prophylactic factor infusion regimens, surgical joint intervention or both.



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