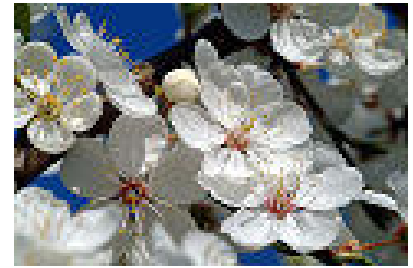




# From the president



Dear members and colleagues,

As you read this the winter is passing and the annual meeting is fast approaching. Isn't that lovely – the HAA meeting signals Spring is in progress and Summer is nearly here!

Once again this year we have received a high number of excellent abstracts despite the GFC and extra effort required to cross the Tasman. As usual, three travel awards are to be granted for best abstracts and these will be announced in the first session of the nurses meeting.

The Annual General Meeting of the Nurses Group will take place on Monday 18 October in the Lunchtime Break – so please come along, hear what is happening and contribute your voice to your organisation.

This year we have continued to hold quarterly national teleconference meetings with representatives from all states, territories and New Zealand. The plans for the next twelve months are to continue to develop local groups, increase nurse membership of HSANZ as well as continue to build and develop the nurse's section on the HSANZ website.

The Nurse's council will meet together in Auckland on the day before the conference to workshop a number of items as we did last year. Getting together for four hours enabled us to achieve concrete and practical outcomes which we have been working on this year.

One of those outcomes was an educational needs survey of members. If you haven't yet had a chance to take the survey please do, it doesn't take long and will really help us to steer the HSANZ NG in the right direction.

So, to those of you going to or at the conference, have a fabulous meeting and enjoy the weather provided, along with a great programme by Rosie Howard and the local organizing committee, and, to those unable to attend this year—have a great October and plan for Sydney in 2011!

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 – 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!!

Moir Stephens  
August 2010

## Inside this edition

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# HAA 2010—Auckland, NZ

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Planning for the nursing stream for the HAA conference here in Auckland 2010 is all slotting together, it has not been the smoothest of journeys and has at times tested my powers of diplomacy, but I am pleased to be able to report that it all appears to be on the final run; with abstracts being reviewed currently.

I am delighted that we have Shelley Dolan as our key note speaker. Shelley is the Chief Nurse for the Royal Marsden Hospital in London. Her clinical background is within ITU, but as Chief Nurse has a wealth of management experience, I am planning that we can utilise both Shelley's ITU background and her management experience working in large cancer hospital in the National Health System.

Other speakers include both local and overseas Nursing, Medical and Allied Health Professionals offering a range of haematology topics with the focus being on malignant Haematology Nursing this year. We have received a good number of abstracts and those that have submitted abstracts will hear back as soon as the reviewing has been completed.

The local organising committee has been hard at work not just putting together their relevant streams but also the evening entertainment and sampling food – unfortunately, due to work pressure, I missed out on the tasting session!

I have to ask myself what have I learnt from organising this conference so far, apart from enhanced diplomacy skills!, I have done an awful lot of networking and getting to know people both locally and nationally – which was great as I was new to NZ and I now feel I have some good contacts in NZ and Australia, it has been enjoyable at times especially when things slot together; juggling work and conference co-ordination has proved stretching, particularly as my work load increased by a third in the last two years but I guess nurses are used to multi tasking! So I am looking forward to seeing the completed programme finalised and then enjoying attending the conference –the only think that I am unable to plan is the weather! I can only hope it is clear blue skies so every one can enjoy the beautiful city and surrounding areas of Auckland.

Rosie Howard



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## HSANZNG Member notifications

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### Educational Needs Survey

We have developed an educational needs survey to understand better what members would like from HSANZ nurses group members with regard to education and resources. We would be most grateful if you could find time to complete this short survey which will help to guide us with developing appropriate resources. Closing date is 1st October 2010.

Please click here <http://www.surveymonkey.com/s/PNZ5CSH>

### Associate Nurse Member Contact Details

A plea to please ensure that your contact details are up to date on our database or you may miss out on important news. Please could you notify Lexy Harris ([hsanz@hsanz.org.au](mailto:hsanz@hsanz.org.au)) if your contact details change—this includes your email address in this age of trying to conserve paper.

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## BMT Network NSW News

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We have just announced our education programme for the second half of the year. The main event will be our Annual Scientific Forum that will be held at Novotel Olympic Park Thursday September 23. The day will have presentations covering many aspects of BMT with a number of members of the Network presenting results of their research.

Our two-day "Introduction to BMT Nursing Course" will be held for the second time this year in November. This course gives nurses the background enabling them to care for patients under going Transplant.

December will see our Forum for those nurses who have more experience in BMT; further details of this will be announced in September. For further information please contact David Collins or visit our website.

Remember, any nurse can register with our website, giving you access to our study days, Webcasts, and Nurses forum where you can exchange ideas with colleagues. Just log on to [www.bmtnsw.com.au](http://www.bmtnsw.com.au) and click on become a member.

*David Collins*

The Haematology Nurses of  
Sydney South West Area Health  
invite you to attend the:  
**Haematology Nurses Day**  
“Plasma Cell Disorders -  
Myeloma and More”  
**Wednesday**  
**22nd September 2010**

**COST FREE EVENT**

Kerry Packer Education Centre  
Royal Prince Alfred Hospital  
Camperdown - Sydney

**9.00am - 4.30pm**

Kindly



JANSSEN-CILAG

# Clinical Practice Corner

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**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?**



## **From Research to Practice: my experience of implementing changes to CVAD care within the South Island Bone Marrow Transplant Unit**

The South Island Bone Marrow Transplant Unit is a 15 bedded unit which provides treatment for both malignant and non-malignant haematological disorders.

I started working on the BMTU at the beginning of 2007 and noticed that CVAD infections were reasonably common. Not long after I started, another nurse also started who was passionate about central line care, her name is Elizabeth Culverwell. We discussed strategies for managing these lines and decided a review of practice was required and this is where my story begins.....

We spent time off and on over the next six months reviewing literature, bench marking current practice throughout the world and thought about how we could change practice. There were a couple of strong themes that came through the literature, one was the use of positive displacement devices and the other was flushing of these lines without heparin. So with these two themes in mind we set about working on a plan to implement changes in CVAD care.

Our plan was to go from 2x/day flushing of these lines with heparin to weekly flushing of these lines with saline only, using a positive displacement device. First we took the results of our literature review and our plan to a departmental meeting to get sign off and then we initiated education sessions for all our staff about the changes in care. We used an American model of care bundles which is when you group best practice interventions, which individually improve care but, when applied together, result in a significantly greater improvement.

The positive displacement device that we decided to use was the Smart Site Plus®. We chose this product because it rated well in an independent product evaluation audit and we both had had prior experience with using Smart Site® products.

An implementation date was also set and we worked hard with our supply department to ensure that all the new products were available before this date. When this date arrived we took all the old products off the shelves and replaced them with the new products. We also worked with our Emergency department so they knew how to use these products before our patients presented there.

So, what happened next? Well it is all a bit of a blur really. There was some confusion about the process and using the products and lack of communication at times. This was all sorted out and a few months down the track this initiative became embedded into the Unit.

That was two years ago and the results have been very positive. Our CVAD infection rate is slightly lower despite almost a double in patient numbers having CVAD's inserted. Again, the occlusion rate is much the same but as already alluded to, the patient numbers have increased. The bean counters are also happy because there was a saving of over \$20 000. This was mostly due to not buying heparin.

What I didn't anticipate was the implications of this change on both the wider hospital and the community nursing service. This took a bit of working through. Now the whole hospital has adopted these changes, as has the community nursing service. Elizabeth has now moved on and has a role as the CVAD educator for the Health Board.

As for me, I am still working on the BMTU. I am proud of our achievement and believe we have enhanced patient care and outcomes through best practice.

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## Rituximab Maintenance: One step closer to Cure in Follicular Lymphoma

It's hard to imagine the world of Lymphoma without "rituximab" and yet despite its success, Follicular Lymphoma (FL) remains incurable.

Many of you will remember the PRIMA study, a clinical trial designed to assess the effectiveness of rituximab as primary maintenance therapy in FL.

Well the results are out and indeed promising. In fact 50% more promising in that the risk of relapse is halved for those receiving maintenance Rituximab therapy, after Rituximab induction in combination with chemotherapy.

Concord Hospital was a PRIMA trial centre and in total enrolled 10 eligible candidates. 5 were randomised to receive Rituximab maintenance, 4 were randomised to the Observation Arm and 1 patient failed to randomise due to disease progression.

One of those patients was \*Jack. Jack was first diagnosed with FL in 2005 at the age of 68. With Stage IV disease and splenic involvement, he more than fit the criteria for a PRIMA candidate.

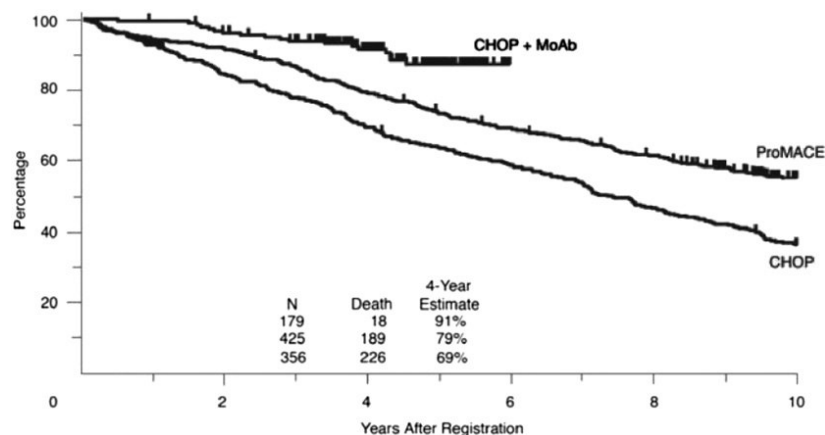
With faith in his specialist and far from dissuaded by a potential 3 year treatment regimen, he signed on to participate in the study and received 8 x cycles of R-CVP followed by randomisation of Rituximab maintenance which looking back at now he refers to as 'a breeze'.

Overall patients enrolled on PRIMA tolerated Rituximab maintenance quite well with no impact on quality of life and minimal toxicity. The most commonly reported adverse effects were infections (37% in the rituximab arm and 22% in the observation group). Jack was fortunate to not have experienced any side effects while on treatment.

The results achieved at Concord were inline with the results of the PRIMA Interim Analysis where for patients who received Rituximab Maintenance, 82% at 24 months follow up were still in Complete Response compared to 66% of those in the Observation Arm.

Fast forward a couple of years later and our local results for those who received Rituximab Maintenance are still great with 60% still in a CR. What Jack would love to know now is—for how much longer?

Undoubtedly Rituximab has been pivotal in the success of treatment for FL. Take for example the median survival of 8-10 years in the pre-Rituximab era and then a median survival of 14years with Rituximab. But now with the Interim results of PRIMA and the addition of Rituximab maintenance, is a median survival of 20 years perhaps a little beyond our reach or is it? Only time will tell.



4 Year estimated Overall survival pre Rituximab (CHOP arm) and in the Rituximab era (CHOP + MoAB)  
(Marcus et al, 2008)

For now Jack continues with follow up. As for the PRIMA results, well they have definitely provided hope for a disease no longer referred to as incurable, but can now be regarded as a chronic illness.

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A special thanks to Trish Lawler (Roche) for providing the PRIMA Interim Analysis.

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## Female Sexuality and Haematopoietic Stem Cell Transplantation

The diagnosis and treatment of cancer is a potentially life-threatening event. There has been a presumption that once a person has been diagnosed with such a disease they will lose interest in sexuality as all thoughts and energy will be focused on fighting the disease. The likelihood of long-term survival and cure is now higher with improved cancer therapies and supportive care. Improved patient outcomes have resulted in an increase in emphasis on quality of life (QOL) issues including sexuality.

Problems with sexuality and sexual function are one of the most common QOL concerns for survivors of HSCT. Both males and females are affected but it appears women are more impacted by this post transplant complication with up to 80% of women reporting long-term sexual problems compared with 50% of male survivors. Despite sexuality issues impacting on patients QOL, medical and nursing teams very seldom talk about sexuality and sexual function with their patients. Reasons for this reluctance include personal discomfort, fear of appearing intrusive into private matters and health care professionals not feeling adequately educated. Often the emphasis of care may be so focussed on cure or alleviation of symptoms that sexuality and sexual function is ignored meaning that patients are not receiving holistic care. Patients are also reluctant raise these issues with medical staff due to fear, embarrassment or feelings of vulnerability. They are often relieved and happy to talk about them if the issue has been first raised by the medical team.

The concept of sexuality has been variously defined and debated in the literature with some feeling that definitions of sexuality are too narrow and tend to focus solely on the act of sexual intercourse. The World Health Organization (WHO) offers a broad working definition of sexuality that was developed through a consultative process. This definition has often been quoted in the literature about sexuality post cancer treatment however most of this literature still tends to focus on genital or functional sexuality. The definition states:

“Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors”.

Defining sexuality is however very individualised with sexuality meaning different things for different people. Southard and Keller (2009) conducted a study where they asked participants to define what sexuality meant to them. Definitions were varied but women in particular defined sexuality around themes such as body image, remaining desirable to partners despite body changes that may have occurred, the ability to be a woman, maintaining femininity, love, sex and intimacy. There has been a move away from viewing sexuality in a functional and genital way to recognising a woman's sexuality as a broad, individualised experience that shifts and changes over a woman's lifetime.

During an allogeneic HSCT, high doses of therapy are given causing symptoms such as nausea and vomiting, pain, fatigue, premature ovarian failure, skin changes, alopecia and mucositis. GVHD and its treatments also causes changes in skin, genitalia, bowels, GI tract and eyes. These physical changes impact on body image and also cause psychological changes such as anxiety, loss of self-esteem, relationship stress, role changes and uncertainty. All these changes impact on a woman's sexuality by altering her ability to maintain femininity, feel desirable, be able to share intimately with her partner, to communicate effectively and be passionate and sexy.

The impact of HSCT on a woman's sexuality is something that needs to be discussed with patients by nursing and medical staff both pre and post HSCT. The sexual response cycle as developed by Masters and Johnson in 1966 is one tool used in evaluating sexual function but unfortunately this does tend to focus very much on the sexual act rather than concepts such as body image, intimacy, touch, communication and love which describe sexuality as a whole. The Sexual Response Cycle consists of four phases: excitement, plateau, orgasm and resolution. This model appears to be more descriptive of sexual function in men rather than in women and implies that women progress through the sexual act in a linear fashion. Research and self reporting from women has shown that desire does not always precede arousal and that for example; stimulation of the breast and genitalia may be unwelcome prior to arousal but become desirable afterwards. Basson (2001) went on to develop her own sexual response cycle for women that is more circular and intimacy based. Though organs such as the vagina, clitoris, labia and vulva are important for women during sex, the central nervous system and a number of areas of the brain are also important, as are sex steroids and hormones.

The causes of sexual dysfunction are multi-factorial therefore assessment needs to be multi-pronged encompassing physiological,

sociological and psychological factors. Yi and Syrjala (2009) stress that for the post HSCT patient reporting sexual difficulties, a full medical examination should be done as there are many frequently occurring complications such as hypothyroidism, diabetes, loss of muscle mass due to steroids that may impact on sexual function.

Assessment of sexuality and sexual function however should not wait until problems exist. It is important that a pre transplant baseline sexual function assessment be done with both the transplant recipient and their partner. There are advantages of talking about these issues prior to transplant – it emphasises to the patient and their significant other that sexuality is an important issue and that the treating team is interested in them as a whole not just as a person with a disease. It also legitimises the topic, allowing it to be talked about at future visits. Talking about sexuality early on may prevent some sexual difficulties by just providing some information about the potential problems that might be experienced throughout treatment. It also means that any changes can be tracked over time and that timely and appropriate treatment can be instituted.

There are several assessment tools that can be helpful for the assessment of sexual function/dysfunction:

ALARM	A	Activity (status or level of current sexual activity)
	L	Libido/desire ( level or existence of desire or libido)
	A	Arousal/orgasm (the ability to achieve orgasm)
	R	Resolution/release/relaxation (ability to achieve)
	M	Medical information (current and past health, medications, co- morbidities)
PLISSIT	P	Permission (to have sexual feelings & relationships and to participate in sex)
	LI	Limited information (about impact treatment and disease on sexuality)
	SS	Specific Suggestions (to manage identified sexual side effects)
	IT	Intensive Therapy (referral to a sex therapy or counsellor)
BETTER	B	Bring up issues of sexuality/sexual function
	E	Explain that sexuality is integral to QOL and important to discuss
	T	Tell patients about available resources and assist them to get these
	T	Timing is crucial – discussions should be facilitated as patient/partner desires
	E	Educate patient/partner about any expected or potential alterations in sexuality or sexual functioning
	R	Record important aspects of any discussions, assessments, interventions and outcomes in the patient's notes

Treatment for sexuality issues or sexual dysfunction needs to encompass both physiological symptoms and psychological conditions. Counselling and behavioural strategies may be very beneficial however sometimes just the sympathetic understanding of a patient's problems may be therapeutic in itself. Medical treatment may involve hormone therapy and the involvement of other disciplines such as gynaecology and endocrinology. Considering other ways that people can increase their sexual satisfaction beyond traditional intercourse is also important as is the use of regular exercise, erotica, masturbation and or vibrators.

In summary, problems with sexuality and sexual function are important post transplant complications for many women. It may be caused by a variety of physical and psychological factors. It is very important that sexuality issues are talked about with the patient and their partner prior to transplant and that this conversation continues post transplant. Patients find it difficult to raise the issue of sex and sexuality issues so it is important that nurses and doctors enquire after a patient's sexual health.

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# Clinical Practice Corner cont'd

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## What do Blogs reveal about people's experience whilst being treated for Myeloma with novel agents?

### Internet and illness experience

This short paper formed the basis of a poster presented at HSNZ meeting in Perth 2008. Understanding how patients and carers access and use resources for information can improve clinical practice and facilitate the delivery of relevant and contextual patient-centred education.

### Background

As of December 2007 75.9% of the Australian population— 15,504,532 people - use the internet ([www.internetworldstats.com/](http://www.internetworldstats.com/)), however, there are barriers to internet usage, one of which is the "digital divide" (Kontos et al 2007). People in a higher socioeconomic position (SEP) demonstrate a greater access and usage compared to those in a lower SEP. Broadband access has also been shown to influence health seeking internet usage (Cline & Haynes 2001) and as of December 2007, only 23% of the Australian population had Broadband access ([www.internetworldstats.com/](http://www.internetworldstats.com/)) and therefore, a significant proportion of the population are not in a position to be "Web 2.0 Natives" .

A new kind of patient, the e-patient (Ferguson et al 2007) has been proposed, mediated by the rapid growth of web-based health-related information and the possibility of establishing or joining online trans-geographic communities of people with the same disease or the same problem (Ayme et al 2008). Patients use the internet "to gain, maintain and display familiarity with a remarkable body of medical and experiential knowledge about their illness" (Ziebland et al 2004). This enables them to be able to be technically proficient and discriminating users of medical information and medical services, covertly questioning their doctors advice (Ziebland et al 2004) further undermining a paternalism in health care. So powerful is this notion that it has prompted discussion of implications for the control of medical knowledge, which is no longer the sole preserve of doctors, and the de-professionalisation of medicine (Hardey 1999, Blumenthal 2002, Muir Gray 2002).

One emerging area of internet use is the blog. **Blog** is an abridgement of **web log**. A blog is a website, usually maintained by an individual, with regular entries of commentary, descriptions of events, or other material such as graphics or video. Entries are commonly displayed in reverse chronological order. "Blog" can also be used as a verb, meaning to maintain or add content to a blog. An emerging field of study examines how blogs are used by people with cancer. Chung & Kim (2008) found that blogs were used four ways: for prevention and care, problem-solving, emotion management, and information-sharing. Frost & Massagli (2008) found three functions of comments on blogs: targeted questions to others with shared experiences; advice and recommendations and; forming and solidifying relationships based on similarity. The importance of blogs is evidenced in the efforts of Pharmaceutical and other industries with financial interests in health to exploit them, including Google's tying of it's AdSense products to individual blogs. (Hsu & Lin 2007). What is apparent is that people with serious illness use the internet, including chat sites, support groups, informational sites and blogs, to help them to be more active partners in their own health care. This paper focuses on the significance of blogs in that transition.

### Methodology

This exploratory study examined four blogs written by people with multiple myeloma. All were in the public domain and not requir-



ing any password access. The impact of novel agents on the experience of living with myeloma was of specific interest and so all were searched using key words “Velcade”, “Revlimid”, “Lenolidamide” and “novel agent”.

10 to 80 entries were found in each blog with up to 5 comments by other people, per entry. These were analysed to determine how peers affected by myeloma communicated via blogs. Consent was given by the bloggee to publish comments, graphs and pictures in the poster and in this paper.

## Results

This study found 2 major ways that people used their blogs ; as an information resource (evaluating treatment choices; reporting complications and biomedical data; publishing news and reports; sharing advice and recommendations) ;and as a source of unicity ( story telling; supportive comments; acknowledgment).

### Blogs as an Information Source

**Treatment choice evaluation** was based on up to date biomedical data and included discussion of; treatment efficacy; availability of clinical trials; side effect profiles; drug cost and; drug availability following trials. Medical care facilities & specific doctor’s skills and expertise were included in discussion about treatment choices. People’s own experience with side effects and response to treatments were also key discussion points. Bloggees were informed and understood about the choices available to them. This, combined with their experiential knowledge made them experts in their field. These comments below are typical of treatment choice discussions :

*“There are 2 trials I’m thinking about. One is the monoclonal antibody for IL-6 that I’ve spoken about before. The other is a Velcade vs. Velcade + Doxil trial. “*

*“I haven’t been complying with treatment this month. Revlimid makes me feel pretty terrible, and I wanted to be able to help my mom through her surgeries and whatever other tx is needed. I do feel better in most ways, now that I’ve been off Revlimid for a month. I’m afraid to say that I didn’t tell anyone I was doing this. If I need to, I’ll go back on it in September. I don’t think it was doing much for me though. Just making me feel sick”*

*“Since I feel that the CNTO 328 trial is not working for me, I’ve been thinking about my next treatment step. I’m almost 100% sure that I want to enrol in the Multicenter, Open-Label, Single-Arm, Expanded Access Program For Lenalidomide Plus Dexamethasone In Previously Treated Subjects With Multiple Myeloma. It involves high dose dex, which isn’t very appealing to me “*

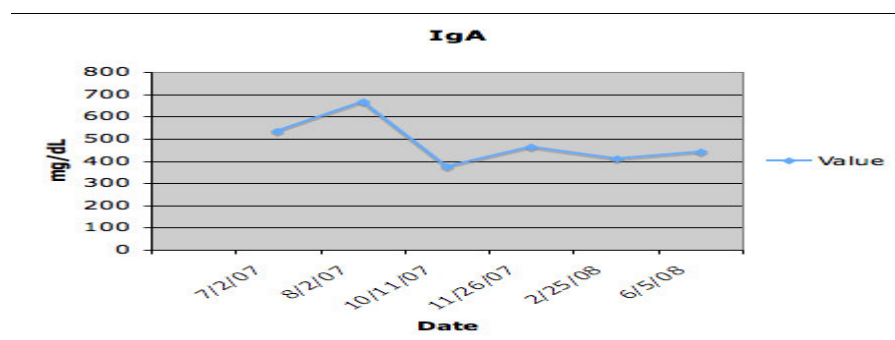
**Reporting complications and biomedical data** involved sharing experiences and offering advice. Bloggees used both their own experience and information both from health care professionals and from alternative sources. One bloggee’s hospital had the facility of online access to her ‘labs’ which was important for her to manage her myeloma. Reporting side effects and events also served as a vent, a resource for catharsis and unicity.

*“This week I just had Zometa, which I learned from others never to have on the same day as Velcade. They reported severe flu-like symptoms”*

*“Here’s a new picture of what the rash looks like. Don’t click on the thumbnail if you don’t want to see it. I think it’s hideous. I try to stay in so that I don’t attract mobs of torch-wielding villagers out in front of the house.”*



*“IgA is pretty stable. This is a chart of my IgA values since before the SCT last summer. I stopped Velcade and Doxil in July, 2007 and the SCT took place at the end of August. This is quantitative serum IgA in mg/dL.”*



**What do Blogs reveal about people’s experience whilst being treated for Myeloma with novel agents? (cont’d)**

**about people’s**

# Clinical Practice Corner (cont'd)

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**Press Releases** from news media, pharmaceutical companies and journals were posted as biomedical updates and included links and information about new resources and 'treatment results and breakthroughs'. In addition to reporting the bloggers discussed drug costs, availability & lobbying. Pharma and news media sources, such as CNN, were emailed and updates reported.

*"MMSupport.net unveils "Ask the Expert", featuring Multiple Myeloma physician and scientist, James Berenson M.D."*

*"Those of us in the trials get the drug at no cost to ourselves, but when it's approved for use with MM, we'll have to pay (one way or another). I'm going to start an email campaign to let the media know about this. So far, I've only written to CNN and had no response."*

*"Have not heard what the latest is from Celgene, FDA or anywhere else. anyone know what's the current state?"*

## **A source of Unicity**

Unicity is the condition of being united; quality of the unique; unification. (Lat 13cen) These blogs offered a space where people could identify with each other as having a fairly rare and incurable illness and share accumulated empirical knowledge gained both through their illness experience and their acquired medical knowledge. They offered each other not only empathy in their shared experience, but an empowerment and an alliance.

**Story Telling.** Blogs were structured around a chronological story, generally starting with an introduction to the blogger and their myeloma narrative. Commenters similarly introduced themselves by giving a short narrative about their own or their significant other's myeloma story. Particular similarities such as the same type of myeloma (Ig referenced) were noted in the discussion. Requests for information could be made directly or could be integrated within an overall story.

*"How have you been? Did the Revlimid produce a durable response?"*

*"I have myeloma too. Your test results indicate IgA Lambda light chain disease and mine is IgG Lambda light chain disease. Very similar test results"*

## **Conclusion**

Patients use the internet in a variety of ways. Much of the clear benefit found by patients from this resource may be underestimated or unknown. What is clear, however, is that these bloggers have become experts in their illness, possessing both medical and empirical knowledge and that they believe that expertise in patienthood is an important tool in their healthcare management. Their blogging is a key tool and expression of this expertise.

Clinicians and information providers need to better understand the way patients and families use blogs, and the role blogs play in managing one's illness. Further research is warranted both to facilitate understanding the experience of patients outside of the clinical arena and to enable use of the resource to keep up with patient's needs and activities.

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\*Advanced Staff Only



# Bone Marrow and Haematopoietic Stem Cell Transplants

8.30 am - 5.00 pm  
Charles LaTrobe Theatre  
The Royal Melbourne Hospital  
Grattan St  
Parkville, VIC, 3052

## 16 & 17 November 2010

### About the Course

The Bone Marrow Transplant short course was developed to meet the learning needs of nurses caring for patients undergoing bone marrow or peripheral stem cell transplantation. In preparation of the program, we ask that you be familiar with the transplant process. To assist you with this please familiarise yourself with the pre readings attached to this flyer on the RMH Nursing Education Website

### Topics include

- Overview of Haemopoiesis and Immunosuppression
- The history of Bone Marrow Transplants
- Tissue Typing
- Clinical Indications and selection of BMT
- Infectious Disease Issues in BMT
- Complications of BMT including: Sexuality Issues, Symptom Management, Mucositis Management, Total Body Irradiation Management, Psychosocial/Ethical Issues, Nutrition Management, Fatigue and its Impact, Graft versus Host Disease (GVHD)
- From Cure to Palliation
- Going Home after a BMT/Role of the Ambulatory Day Care Centre
- Research in Bone Marrow Transplant field
- A Patients perspective of transplant

### To Register

Please complete the registration section below. Registrations close:  
**Friday, 05 November, 2010**

### Course fees

External Applicants: \$270.00  
Melbourne Health Employees: \$110.00  
Lunch and refreshments provided.

### For more information about the clinical content of this course, contact:

**Jo-Anne Martin**  
Clinical Nurse Educator  
Ph: 03 9342 7000 pager: 7343  
Email: joanne.martin@mh.org.au

### For registration and payment queries, contact: Short Course Administration

Ph: 03 9342 4981  
Fax: 03 9342 4970  
Email: shortcourse@mh.org.au

Conditions: Please make cheques/money orders payable to: 'Nursing Education Services, RMH'. The fee is not refundable and must be paid prior to course commencement. The Royal Melbourne Hospital reserve the right to cancel any course should attendee numbers be insufficient. A full refund will be given, should a course be cancelled. SEND REGISTRATION TO: Nursing Education Services. The Royal Melbourne Hospital, c/o Post Office, Parkville, VIC, 3050. telephone: 03 9342 4981 fax: 03 9342 4970 or email: shortcourse@mh.org.au. \*Please note: All correspondence regarding confirmations and course details will ONLY be communicated by email. Please ensure the email address provided is one that is checked regularly.

#### Registration Form - Please PRINT clearly.

Name: \_\_\_\_\_  
Tel (BH): \_\_\_\_\_  
Email address\*: \_\_\_\_\_  
Current employer: \_\_\_\_\_  
Ward/Unit: \_\_\_\_\_  
Melbourne Health employee: YES / NO (please circle)

#### Payment Method

Cheque  Money Order  Mastercard  Visa  Other  
**CASH IS NOT ACCEPTED**  
Amount: (please circle) \$110.00 \$270.00  
Credit card number: \_\_\_\_\_  
Cardholder name: \_\_\_\_\_  
Cardholder signature: \_\_\_\_\_  
Expiry date: \_\_\_\_ / \_\_\_\_ (mm/yyyy)

Nurse Unit Manager/Manager Approval (required for Melbourne Health employees only)

Course participation approved by: Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / 2010

## BONE MARROW TRANSPLANT 2010

The Royal Melbourne Hospital is part of Melbourne Health. ABN 73 802 706 972



# News from the regional groups

## New Zealand (North Island)

The lower North Island has held a further two successful education evenings since the last newsletter was published. We had the second education evening in Palmerston North in June following on from the inaugural meeting in March. There has been an enthusiastic response to these meetings from the Palmerston North nurses. We had 23 attendees come along for an update about Multiple Myeloma. The other education evening was held in Wellington very recently. This was another successful evening where 20 attendees learnt about Chronic Lymphocytic Leukaemia.

The education evenings have become sought after events. They would not be possible without our sponsors. We have had very generous support from Novo nordisk, Gilead and Novartis for these two education evenings.

There are only two education sessions left for the rest of the year as follows:

When	Where	Topic
6 Oct	Palmerston North	VTE prevention and treatment
1 Dec	Wellington	Apheresis

If anybody would like to attend any of these meetings or has further suggestions for education initiatives then please feel free to get in touch with me. I can be emailed at:

[Catherine.Wood@ccdhb.org.nz](mailto:Catherine.Wood@ccdhb.org.nz).

The upper North Island as yet doesn't have any education being facilitated by the HZANZ NG. If anybody is willing to get something going for the Auckland/Waikato area then please get in touch with me at the above email address.

*Catherine Wood*



## New Zealand (South Island)

The education evening held at Christchurch public hospital on 18<sup>th</sup> May 2010 was attended by staff of the Bone Marrow Transplant Unit. Speakers were Deborah Kidner (RN) and Kim Clark (RN). Both had attended a course on implementation of the Liverpool care pathway

(LCP). The evening started with a presentation of the history of LCP, when to implement and the documentation. The evening was interesting and generated lots of discussion around timing of implementation and the benefits and pitfalls that may present with its use in the Bone Marrow Unit. The general opinion was that a case needed to be put forward to the Haematology business meeting for agreement to implement an audit of care of the dying and implementation of the care pathway. We will let you know how we get on with this.

### **Nurse led blood transfusion clinic**

Two registered nurses have now completed the adult assessment course with Otago University (NURX405). This will enable us to extend our current nurse led transfusion clinic. At present appointments are for Tuesdays only seeing up to 12 patients by one nurse

who then has to assess who will be transfused on the same day and who will come back another day. By having 2 nurses we are looking at moving the clinic out of the outpatient setting and having appointments through the week assessing and transfusing on the same day up to three patients within the day ward setting. This will mean less hospital visits for the patient, freeing up crowded out patient departments areas and the loss of one nurse out of clinic practice area.

*Sharron Ellis*



## Western Australia

Our first year of clinical meetings has been successful. The first clinical meeting for the year was titled "Childhood ALL". Despite wild weather forecasted for that afternoon and night there was a fairly good attendance by haematology nurses in Perth. Both presenters received great feedback, especially from the haematology nurses whose main remit is caring for adults.

"A Mixed Bag" was the theme of our June meeting. Multiple Myeloma and APLM were the topics presented. Once again our presenters received positive feedback. The topics were thought provoking and nurses' feedback indicated that they would like more presentations on diseases and topics based on the latest research and clinical trials in haematology.

Our final clinical meeting for the year is in November. We are hoping to have a presentation on 'Hot Mabthera' and the current clinical trial for mesenchymal stem cells.

We need to continue with the drive to attract more HZANZ members and haematology nurses to our clinical meetings. We have a WA committee meeting soon to discuss strategies to enable us to gain more momentum.

*Cassi Lawrence*

## Victoria

It's been an exciting first half of 2010 for Victorian Haematology Nurses. Interest in educational sessions and membership is flourishing. Our recent educational evening, generously supported by Pfizer, had an attendance number of 45 nurses from around metropolitan and regional Victoria, and Tasmania. The guest speaker was A/Prof David Ritchie who presented on "Novel Therapies in Lymphoma". For those of you who have had the pleasure of hearing Dave speak you will know he is not only a highly skilled speaker but also very engaging and interesting. Once the formalities were complete, the group enjoyed mingling with old and new friends, networking and sharing knowledge. There was an incredible buzz in the room and it was a pleasure to be a part of it.

The Department of Health as part of the Victorian Nurses Practitioner Project has just announced 2<sup>nd</sup> round funding for health services to develop Nurse Practitioner Models and

# News from the regional groups

support for Nurse Practitioner Candidates for the 2010-2011 period. This is a timely opportunity for Victorian health services to identify key areas where a Nurse Practitioner role would be appropriate and to support the preparation of a suitable candidate into the position. For more information please go to:

[www.health.vic.gov.au/nursing/furthering/practitioner](http://www.health.vic.gov.au/nursing/furthering/practitioner)

Our next educational evening is on Monday the 6<sup>th</sup> of September. We are looking forward to hearing the guest speaker, Dr. Chris Hogan presenting "An update on current issues in Transfusion Practice".

For further information about the educational evening and Victorian membership please contact me via email [yvonne.panek-hudson@petermac.org](mailto:yvonne.panek-hudson@petermac.org).

Looking forward to seeing you at HSA Auckland, 2010.

*Yvonne Panek-Hudson*

## South Australia/Northern Territory

In May a successful education day was held in Adelaide for Haematology and Oncology Nurses. This was a joint venture with input from HSA NZ Nurses Group and CNSA as well as the kind support of Roche and Amgen. More than 50 nurses were able to attend a full education day with topics such as interpreting biochemistry results, assessment and management of cancer related fatigue and mental health assessment in cancer patients. The afternoon was dedicated to hands-on practical workshops in clinical skills development for cardiovascular, gastrointestinal, respiratory and neurological patient assessment. Nurse practitioners ran the four workshops which was great to showcase the variety of areas they have specialised in. Hopefully we'll see more nurses inspired to become NP's in Cancer as a result. The feedback from the day was very positive with the afternoon clinical skills development workshops proving overwhelmingly popular.

More recently we held an education evening at the Tennyson Cancer Centre in Adelaide. We had an enormous response with more than 70 nurses attending to hear (and participate) in two excellent presentations. Ann Canty from the ARCBS and Apheresis unit at the Royal Adelaide Hospital first discussed HLA platelets giving some basic information on what that means, why they are used, what sort of testing is needed as well as some of the challenges involved in coordinating donors, treating centres, blood results and so on. Our second presentation, from BloodSafe Transfusion Nurse Consultant Bev Quested at the ARCBS, was in the form of an interactive quiz show; "Spicks and Specks of Blood". Questions ranged from the serious: "What blood type is considered the universal donor?" to the more light-hearted: "Who would win? Zombies or

Vampires?" This proved to be an interesting presentation with challenging questions for nurses at all levels. Again, feedback was very positive. I would like to acknowledge our supporters for their generous contribution and assistance organising the evening: Amgen, Gilead, Novartis Oncology and Roche. I would also like to say a huge thanks to Kirsten Bubner who handles a lot of the organising behind the scenes with RSVP lists, collating evaluation reports as well as creating and printing attendance certificates for everyone. These certificates are an important addition to a nurse's professional portfolio as HSA NZ Nurses Group education activities attract RCNA Continuing Nurse Education points.

We are now looking forward to the HAA Annual Scientific Meeting in Auckland in October and hoping to see familiar and some new faces from around Australia and New Zealand!

*Allan Hayward*

## New South Wales

The local committee has met recently to plan next year's education programme and are pleased to announce that we will again be hosted by Wollongong and Gosford in addition to three Sydney evenings. Dates and venues are listed below for your diaries – the topics and speakers have yet to be confirmed.

I can, however, list the topic and date for our final meeting of 2010. It is Sickle Cell Anaemia with Grainne Dunne (CNC Haematology, Sydney Children's Hospital) to be held in Sydney on Thursday 18 November.

Thursday 17 February 2011	Sydney
Thursday 14 April 2011	Gosford
Thursday 16 June	Sydney
Thursday 18 August	Wollongong
Thursday 17 November	Sydney

Following this year's joint HSA NZNG, University of Sydney, Amgen & Novartis supported initiative to hold a study day in Dubbo on 15th November, we are in the early stages of planning a study day in Canberra in 2011.

Our committee's membership has changed over the past year and we gratefully acknowledge the enormous amount that Jacqui Jagger contributed before leaving us to deliver and look after the newest member of her family. David Collins (CNC BMT Network NSW) has joined Heather Mackay, Grainne Dunn and me.

Looking forward to seeing you sometime in the great world of haematology nursing,

*Moir Stephens*

## 2010/11 dates for your diary

### International Conferences

**1-4 Sep:** World Apheresis Association Congress, Interlaken, SWITZERLAND

**10-13 Oct:** International Society of Haematology, Jerusalem, ISRAEL

**4-7 Dec:** American Society for Hematology, Orlando, Florida, USA

### **2011**

**3-6 Apr:** EBMT, Paris, FRANCE

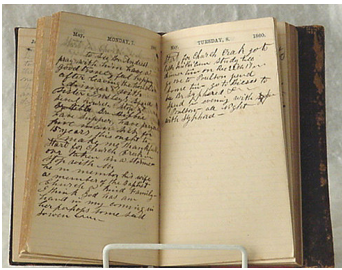
### National/Trans-Tasman Conferences/Meetings

**17-20 Oct:** HAA, Auckland

**9-12 Nov:** ALLG, Sydney



# Research News – a short trip around some recent journals



## Destined to die in hospital? Systematic review and meta-analysis of place of death in haematological malignancy

Howell DA, Roman E, Cox H, Smith AG, Patmore R, Garry AC, and Howard MR. [BMC Palliat Care](#). 2010; 9: 9. Published online 2010 June

### Background

Haematological malignancies are a common, heterogeneous and complex group of diseases that are often associated with poor outcomes despite intensive treatment. Research surrounding end-of-life issues, and particularly place of death, is therefore of paramount importance, yet place of death has not been formally reviewed in these patients.

### Methods

A systematic literature review and meta-analysis was undertaken using PubMed to identify all studies published between 1966 and 2010. Studies examining place of death in adult haematology patients, using routinely compiled morbidity and mortality data and providing results specific to this disease were included. 21 studies were identified with descriptive and/or risk-estimate data; 17 were included in a meta-analysis.

### Results

Compared to other cancer deaths, haematology patients were more than twice as likely to die in hospital (Odds Ratio 2.25 [95% Confidence Intervals, 2.07-2.44]).

### Conclusion

Home is generally considered the preferred place of death but haematology patients usually die in hospital. This has implications for patients who may not be dying where they wish, and also health commissioners who may be funding costly end-of-life care in inappropriate acute hospital settings. More

research is needed about preferred place of care for haematology patients, reasons for hospital deaths, and how these can be avoided if home death is preferred.

\*\*\*

## Patient satisfaction with nursing staff in bone marrow transplantation and hematology units.

Piras A, Poddighe M, Angelucci E.

[Transplant Proc](#). 2010 Jul-Aug;42(6):2257-63.

Several validated questionnaires for assessment of hospitalized patient satisfaction have been reported in the literature. Many have been designed specifically for patients with cancer. User satisfaction is one indicator of service quality and benefits. Thus, we conducted a small qualitative survey managed by nursing staff in our Bone Marrow Transplantation Unit and Acute Leukemia Unit, with the objectives of assessing patient satisfaction, determining critical existing problems, and developing required interventions. The sample was not probabilistic. A questionnaire was developed using the Delphi method in a pilot study with 30 patients. Analysis of the data suggested a good level of patient satisfaction with medical and nursing staffs (100%), but poor satisfaction with food (48%), services (38%), and amenities (31%). Limitations of the study were that the questionnaire was unvalidated and the sample was small. However, for the first time, patient satisfaction was directly measured at our hospital. Another qualitative study will be conducted after correction of the critical points that emerged during this initial study, in a larger sample of patients.

\*\*\*

## Adherence to oral cancer therapies: nursing interventions.

Winkeljohn D.

[Clin J Oncol Nurs](#). 2010 Aug;14(4):461-6.

This article reviews nursing interventions to increase adherence to oral cancer therapies, such as patient and care-partner education, side-effect and medication management, and safety issues. Data sources included peer-reviewed nursing and medical literature, healthcare Web sites, and published monographs. Oncology nurses are

uniquely positioned to promote patient adherence to oral cancer therapies by ensuring that patients understand the goals of treatment, promoting safe prescriptive practices, proactively managing treatment side effects, and identifying and resolving underlying barriers to adherence. When adherence is optimized, clinical outcomes are greatly improved. Primary responsibility for adherence to an oral cancer therapy regimen remains with the patient. Oncology nurses, as part of a healthcare team, can have a significant influence on patient adherence by providing thorough and timely patient and family education and by monitoring and managing side effects of treatment. Monitoring adherence to oral cancer therapies is not a recent phenomenon nor limited to oral cancer treatments but presents an increasing challenge as additional oral therapies enter the marketplace. Oncology nurses should develop and enhance strategies and materials for patient education on oral cancer therapies, improve side-effect management, assist with patient access to medications, and develop practice guidelines to ensure adherence and promote safety.

\*\*\*

## Effectiveness of the implementation of an evidence-based nursing model using participatory action research in oncohematology: research protocol.

Abad-Corpa E, Meseguer-Liza C, Martínez-Corbalán JT, Zárate-Riscal L, Caravaca-Hernández A, Paredes-Sidrach de Cardona A, Carrillo-Alcaraz A, Delgado-Hito P, Cabrero-García J.

[J Adv Nurs](#). 2010 Aug;66(8):1845-51.

AIM: To generate changes in nursing practice introducing an evidence-based clinical practice (EBCP) model through a participatory process. To evaluate the effectiveness of the changes in terms of nurse-sensitive outcome (NSO).

BACKGROUND: For international nursing science, it is necessary to explore the reasons for supporting EBCP and evaluate the real repercussions and effectiveness.

METHODS: A mixed methods study with a sequential transformative design will be conducted in the bone marrow transplant unit of a tertiary-level Spanish hospital, in two time periods >12 months (date of approval of the protocol: 2006). To evaluate the effectiveness of the intervention, we will

# Research News – continued

use a prospective quasi-experimental design with two non-equivalent and non-concurrent groups. NSO and patient health data will be collected: (a) impact of psycho-social adjustment; (b) patient satisfaction; (c) symptom control; (d) adverse effects. All patients admitted during the period of time will be included, and all staff working on the unit during a participatory action research (PAR). The PAR design will be adopted from a constructivist paradigm perspective, following Checkland's "Soft Systems" theoretical model. Qualitative techniques will be used: 2-hour group meetings with nursing professionals, to be recorded and transcribed. Field diaries (participants and researchers) will be drawn up and



data analysis will be carried out by content analysis.

DISCUSSION: PAR is a rigorous research method for introducing changes into practice to improve NSO.

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## Optimal timing of G-CSF administration for effective autologous stem cell collection.

Kim JE, Yoo C, Kim S, Lee DH, Kim SW, Lee JS, Suh C.

Bone Marrow Transplant. 2010 Aug 9.

The best time of G-CSF administration for PBPC collection remains to be defined. We aimed to identify optimal G-CSF administration timing for efficient autologous stem cell collection. A total of 262 lymphoma or multiple myeloma patients, who underwent PBPC collection from January 2000 to March 2008, were included. PBPCs were mobilized with chemotherapy followed by lenograstim at 10  $\mu\text{g}/\text{kg}/\text{day}$ . Patients received lenograstim at 2000 hours, about half a day before leukapheresis (PM group) before November 2004, and at 0600 hours, 3 h

before apheresis (AM group) subsequently. In the AM group, the median number of total collected CD34+ cells/kg was greater over a shorter duration of apheresis, and the median number of collected CD34+ cells/kg at first leukapheresis was larger. Stem cell collection efficacy (ratio of total collected CD34+ cells/kg per number of leukapheresis procedures) was higher, and proportion of patients who yielded an optimum harvest was larger. The statistically significant between-group difference was observed only in patients with high-dose CY chemotherapy for stem cell mobilization in subgroup analysis. The present study showed that G-CSF injection 3 h before apheresis improved the efficacy of autologous stem cell collection.

\*\*\*

## PBPC collections: Management, techniques and risks.

Gašová Z, Bhuiyan-Ludvíková Z, Böhmová M, Marinov I, Vacková B, Pohlreich D, Trněný M.

Transfus Apher Sci. 2010 Jul 31

We evaluated the efficiency, safety and risks of three techniques which were used for autologous PBPC collections: (a) large-volume leukapheresis (LVL), (b) standard collections, and (c) a new modified technique which was named as "Mixed" collections. In spite of the fact that the standard and LVL collection techniques are used routinely, there may occur special conditions in which the procedures cannot be recommended. Some patients may suffer from serious clinical complications and they cannot tolerate either standard procedures with administration of higher doses of ACD-A, or the high extent of procedure in the course of LVL. We tried to find the safe and efficient collection technique which could help this group of patients to overcome their problems. The "Mixed" collection technique could be such a choice. The numbers of 136 autologous PBPC collections were performed in 98 patients who suffered from hemato-oncological diseases. We evaluated the results of (a) 93 LVL (more than 3 TBV, total blood volumes of the patients were processed; anticoagulation: ACD-A and Heparin), (b) 16 Standard procedures (less than 3 TBV were processed; anticoagulation: ACD-A), and (c) 27 "Mixed" collections (less than 3 TBV of patients were processed; anti-

coagulation: ACD-A+ Heparin). Collections were performed by the use of separator Cobe Spectra, Caridian. In patients (a) with a good effect of mobilization (precollection CD 34+ cells in blood higher than  $20 \times 10^3/\text{mL}$ ) we prepared almost the same median dose of CD 34+ cells from the standard and "Mixed" collections, 3.8 and  $4 \times 10^6/\text{kg}$ , respectively. In LVL the median yield of CD 34+ cells was  $8.2 \times 10^6/\text{kg}$ . In patients (b) who were mobilized weakly (precollection CD 34+ cells in blood lower than  $20 \times 10^3/\text{mL}$ ), LVL enabled to prepare  $1.5 \times 10^6$  of CD 34+ cells from one collection, while the median yield of CD 34+ cells from the standard and "Mixed" collections was 0.9 and  $1.2 \times 10^6/\text{kg}$ . All the standard, LVL and "Mixed" procedures were tolerated well without any serious adverse reactions. We detected 22 adverse reactions, but only three reactions were associated directly with the procedure. Mild hypocalcemia (2) and hypotensive reaction (1) were transient and treated efficiently. Procedures could continue and were finished according to the planned programme. Other reactions were related either to the insufficient function of central venous catheter or to the poor clinical condition of the patients. LVL enabled to get a higher yield of CD 34+ cells than the Standard and "Mixed" collections in well mobilized patients as well as in weakly mobilized patients. We observed the similar efficiency in standard and "Mixed" collections in well mobilized and weakly mobilized patients. We can recommend LVL in all patients who can tolerate it due to a greater chance of collecting higher yields of progenitor cells. In the weakly mobilized patients LVL offers a greater chance of collecting at least a minimum amount of CD 34+ cells needed for transplantation. "Mixed" collections may be used as an alternative technique under the circumstances in which standard or LVL cannot be recommended - like in patients who do not tolerate a high amount of citrate or a high extent of the procedure, e.g. patients with cardiac arrhythmia, impaired liver or renal function or unstable vital signs.

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