

# HUG MAGAZINE



**February 2008**

(issued bi-monthly)

A magazine for HAEMATOLOGY and ONCOLOGY patients,  
being treated in the Day Therapy Centre and Dove Ward or  
under review following treatment

The Magazine is now self-supporting, having previously been sponsored by PALS. If you could receive future editions by email or would like to make a contribution to the printing cost, contact Irene by telephone or email.



We would love to hear from you with your comments,  
suggestions or articles.

Contact

Email: [hugswindon@btinternet.com](mailto:hugswindon@btinternet.com)

## H.U.G. Swindon

Get-togethers usually take place in the Osprey Unit Education Room but recently this has been needed for clinical purposes. Any alternative location will be added to posters when known and a notice will be put outside the Education Room on the day

Turn up at any time between  
10:00 am and 12:30 pm  
on the Thursdays shown:

**13 March 2008**

**10 April 2008**

**01 May 2008**

**NOTE: Not always the SECOND Thursday of the month in 2008**

### **AIMS!**

**HUG aims to improve the environment for ALL patients of the Day Therapy Centre and Dove Unit or under review following treatment in these areas at the Great Western Hospital, Swindon by:**

- ❖ **Holding regular “get-togethers” where Haematology and Oncology patients and their relatives can make friends, share their views and experiences and receive information about hospital and other relevant services, all in an informal atmosphere over refreshments.**
- ❖ **Producing the HUG Magazine, a light-hearted and informative bi-monthly publication and making it available in Dove Unit, the Day Therapy Centre and the Osprey Waiting Area.**
- ❖ **Pointing patients in the direction of specialist help available, as required.**
- ❖ **Following up on comments about Hospital Services and reporting back on progress made.**
- ❖ **Fund-raising to provide items for the benefit of patients, such as mugs, bookshelves and the redecoration of rooms. Ideas are welcomed at any time for future projects.**

# NEWS THAT MAY BE OF INTEREST

## **Nintendo for the NHS?**

Kanav Kahol and Marshall Smith of the Banner Good Samaritan Medical Center in Phoenix, Arizona, have found that surgical residents performed better during simulated surgery after playing on a Nintendo Wii console. They put it down to the console's novel "Wiimote" control system, which allows players to direct on-screen action using a wireless wand that detects acceleration in three dimensions.

Now they are designing Wii software that will accurately simulate surgical procedures. A training platform based on the console, which costs about \$250, might be more practical for trainee surgeons in the developing world than traditional training tools, which typically cost a great deal more.

New Scientist magazine, 19 January 2008

## **DNA vaccine for myeloma in development**

Leukaemia Research scientists in Southampton and Oxford have discovered that a protein called PASD1 may be a promising new target for a DNA vaccine against myeloma.

Dr Surinder Sahota in Southampton and Dr Karen Pulford and Dr Alison Banham in Oxford have shown that PASD1 on the surface of the myeloma cells can be targeted by antibodies. The hope is that a DNA vaccine against PASD1 will kill any myeloma cells remaining in patients who have already undergone chemotherapy or a bone marrow transplant.

Leukaemia Research, Autumn 2007

## **Macmillan and Cancerbackup merger**

Macmillan Cancer Support and Cancerbackup have agreed to merge. The merger is expected to further the aims of both charities to ensure that, across the UK, everyone affected by cancer will get faster and enhanced access to high-quality information at every stage of their cancer journey. The merger, which will be effected by a transfer of Cancerbackup to Macmillan Cancer Support, is expected to take place within approximately six weeks. On completion, two of Cancerbackup's existing trustees, will join the expanded Board of Macmillan Cancer Support.

Macmillan develops and provides a wide range of medical, practical, emotional and financial services, including the distribution of information. Cancerbackup is the specialist cancer information charity, recognised as the UK's leading source of high-quality information on every cancer.

The merger will enable Cancerbackup's existing services to be expanded and enhanced as they join with Macmillan's full range of services, to the benefit of people affected by cancer, their families and carers. Information services will be delivered under the sub-brand Macmillan Cancerbackup and will include:

- improved telephone helpline support through an enhanced direct cancer information service with access to cancer information nurses, nutritionists, financial and other experts
- enhanced information on the Macmillan Cancerbackup website and in booklet and new formats, based on need
- accessible, approachable information and support centres through the UK, not only providing high quality support, but also acting as central points for outreach services

Macmillan Cancer Support Website 11 January 2008

## Foundation Trust Membership

We were joined at the January 2008 Get-together by CG, Membership Officer for Swindon & Marlborough NHS Trust Foundation Trust Membership.

As most of us know, from the posters at the GWH, the article at the end of October in the Swindon Evening Advertiser and public meetings around the area, Swindon & Marlborough NHS Trust (S&MNHST, comprising the GWH, the Brunel Treatment Centre, Marlborough House, outpatient services at Savernake and Fairford and a number of GP practices) is in the process of gaining NHS Foundation Trust status.

Resources for S&MNHST currently come from the local Primary Care Trust (PCT), plus PCTs in Gloucestershire, West Berkshire and Oxfordshire, which also use its services. Any budget surplus at the end of an operating year goes back to the NHS. Becoming a Foundation Trust (FT) will give S&MNHST more say over its service provision and its resources and allow it to make use of any surplus in the budget, meaning that operating efficiency is rewarded. The FT would still have to meet NHS standards and range of care requirements, but no longer report to the Strategic Health Authority of the Department of Health. Instead the FT would be authorised and overseen by Monitor, the independent regulator for FTs. The Trust must prove that it financially viable for 5 years. The whole Board or individual Board members could be replaced by Monitor, if they were seen to be failing in their obligations.

FT status also gives the opportunity to strengthen links with the local community, listening to and taking into account their opinions and becoming more answerable to them. It is an FT requirement to recruit members equivalent to around 4.5% of the population for whom services are provided, which means that 15,000 members will eventually be needed. **Anyone aged 12 or over**, could have the opportunity to make a difference to how services provided by the Trust are developed, improved and run. It should be noted, however, that the members will need to be representative of the community they represent in terms of ethnic origins, disabilities, special needs etc.

All Hospital Trusts are expected by the Government to achieve FT status within the next three years. S&MNHST hopes to be authorised in 2008, by which time 3000 FT members need to have been recruited,

As an ordinary member you would receive a minimum of 4 newsletters per year, by email where possible to keep down the cost. You would be asked to vote on the acceptance of the annual accounts and the election of Governors, who must be over 18 years of age. From time to time you might also be asked to give your views on questions related to any special areas of interest in the work of the Trust, as indicated on your membership application form. You could also possibly be invited to join a focus group related to your interest.

At present S&MNHST is run by a Board of Directors. Following FT status, a Council of Governors of 15 people, of whom 10 must be public members, will be elected from the membership to work jointly with the Board at 4 meetings per year. Any member could apply to be considered for election to the Council of Governors, for the highest level of membership involvement. The election will be managed by the Electoral Reform Society and is expected to take place in May or June 2008. Of the 10 ordinary members of the Council, 5 must be from Swindon, 3 from Wiltshire and 2 from other areas using the Trust, with the remainder of the Governors from the PCT, the Academy, the Local Council, the Chamber of Commerce and Staff.

Clearly FT membership could allow you to exert influence on the health services provided and the running of the FT in years to come, with a level of involvement you would feel comfortable with.

In prison you get time off for good behaviour.



At work you get rewarded with more work!

# H.U.G. ★ fridge magnet ★ fun

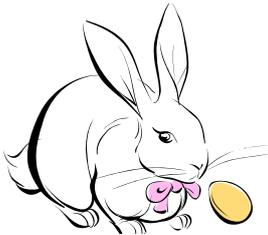
**You know you're living in the 21<sup>st</sup> century when....**

**you have a list of 15 phone**



**numbers to reach your family of 3.**

Depend on the rabbit's foot if you will, but remember it didn't work for the rabbit.



O

**I started out with nothing and I still have most of it.**



**Everyone smiles in the same language**

**All true wisdom is found on T-shirts.**



**One man in the house is**



**worth two in the street.**

## Stem cell transplant – Pt 4

This is the final chapter in the account of DH, a GWH patient and HUG supporter, with Non-Hodgkin's Lymphoma of his stem-cell transplant.

We repeat the reference sources, which are available in booklet form (can be ordered at the Cancer Services Information Point) or online at:

<http://www.cancerbackup.org.uk/Treatments/Stemcellbonemarrowtransplants/Generalinformation>

or

<http://www.lrf.org.uk/en/1/infteetreste.html> (Follow the link to bone marrow transplants and this leads to a pdf file.)

I left hospital after the transplant at the end of April, very weak and with an outpatient appointment for 3 days later. The follow-up monitoring was to become a feature of the next 3 weeks with frequent trips to the clinic, blood tests, lung function tests and CT scan to confirm my recovery was continuing as expected. My psychological state improved quite dramatically on getting home and with my appetite improving so did my energy levels. A month after being discharged I had the Hickman Line removed in the day surgery clinic at Great Western Hospital, which was another lift to my spirits, as this signalled a return to swimming, an activity that was stopped due to the risk of infection and irritation.

I continued to regain my strength and stamina, which allowed me to do more without the aids that I had needed for mobility though the lessons from previous chemotherapy cycles undoubtedly played a part in my planning of activities and rest. In the 6 weeks that followed my discharge, as the time between clinic appointments was extended from the initial twice weekly to fortnightly, I started to feel ready to try more testing physical tasks and after some conversations with my consultant, GP and physiotherapist started a more vigorous regime including swimming at the hydrotherapy pool in Swindon.

The end of June came with an invitation to a family 50th wedding anniversary party and a chance to try dancing! Not the most competent performance but I doubt that there were many more satisfying. With a planned holiday approaching, I was ready to try a return to work as a lorry driver, but first had to convince my company doctor that I was not rushing and liable to put myself or the people around me in harm's way. The consultation went very well, with a recommendation to double up (with another driver) for a month to make sure that I could cope, and I went on holiday happy that I was getting closer to restoring another part of my life.

Finally, at the end of July 2007, I started back to work. The first time back behind the wheel of a lorry was tentative but also exciting and at the end of the first week I was certain that I could cope with the job. By the end of week 2 I was absolutely shattered as my strength returned to work levels. During week 4 I had appointments with both my GP who concluded that I was fit enough to have my vocational driving license renewed (with an annual

medical) and the company doctor who also gave me the clearance to work solo.

My return to work was some 4 months after my stem cell transplant was started. This is quite quick and the chance to prepare beforehand by getting as fit as possible undoubtedly had a bearing on this. I know that at least 2 other members of our HUG group have had stem cell transplants by donor and will have to face graft versus host disease possibilities that I never will with this procedure. At the time of writing I am taking only 6 antibiotic tablets a week and this is due for review.

Finally, the advice and care that my family and I received from the medical teams at Great Western and Royal Brompton Hospitals, the support of organisations like the Prospect Day Hospice, HUG, Macmillan Nurses and my employer and the opportunity to use facilities like the Hydrotherapy Pool must be acknowledged. To all of those who helped make my recovery happen a sincere and heartfelt thank you.

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### **Killer Biscuits Wanted for Attempted Murder (I don't believe it!)**

Lisa Burnett, 23, a resident of San Diego, was visiting her in-laws, and while there went to a nearby supermarket to pick up some groceries. Several people noticed her sitting in her car with the windows rolled up and with her eyes closed, with both hands behind the back of her head.

One customer who had been at the store for a while became concerned and walked over to the car. He noticed that Lisa's eyes were now open and she looked very strange. He asked her if she was okay, and Lisa replied that she'd been shot in the back of the head and had been holding her brains in for over an hour. The man called the paramedics, who broke into the car because the doors were locked and Lisa refused to remove her hands from her head. When they finally got in, they found that Lisa had a wad of bread dough on the back of her head. A Pillsbury biscuit canister had exploded in the heat, making a loud noise that sounded like a gunshot and the wad of dough had hit her in the back of the head. When she reached back to find out what it was, she felt the dough and thought it was her brains. She had initially passed out, but quickly recovered and had tried to hold her brains in for over an hour, until someone came to her aid.

## Sudoku again this time and some lateral thinking

Can you end up with the digits 1-9 in every row, each column and each 3x3 box?

			1			2		
		5	4			3		
			8			5		4
1	9				6		7	5
	6	8					1	
	2							
				2			4	
8		7		3		1		
2						9		8

### A-Haunting we will go!

An ancient castle had been converted into a hotel. After a few months, many ghostly sightings had been reported. The manager was under pressure as many bookings were being lost, but he was getting some business from ghost hunters. The problem was that he could not guarantee to match the appearances with the right guests, until one day he noticed a pattern in the sightings and their timings. If he could predict where and when the ghost would appear, he would keep all of his guests happy.

He found that from January to March, room number 3 was haunted every other night. From April to June, room number 4 was haunted every third night. From July to September, room number 9 was visited by a ghost every fourth night. He then needed to plan which room would be visited in the last quarter of the year and the frequency. How did he work this out and what was his answer?

Answers on P10

# H.U.G. News – read all about it

Get-togethers were held on 2<sup>nd</sup> Thursdays of December and January in the Academy and Coffee Mornings at the Blunsdon Arms at the end of the January.

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## **1. Get-Togethers - General**

We are now well established with our coffee mornings between Hospital Get-Togethers. Contact us for forthcoming dates and times.

## **2. Progress on proposed purchases for Dove and Day Therapy**

There still isn't anything concrete to report on the existing wish list. We'll let you know as soon as we can.

We have been asked if we would consider contributing towards the cost of the PICC line medical equipment (refer to page 10). This is still under discussion as we go to print.

## **3. Recent Get-Togethers**

In December it was the usual pre-Christmas Open House with tasty snacks, drinks and a raffle. Unfortunately few visitors called in because we were 4 floors away from our normal Osprey location. Those of us who were there had an early lunch! In January we were joined by CG, Foundation Trust Membership Officer, and the report is in this issue.

## **4. Fund-Raising**

A second sales table was run behind the atrium in December. Car booting was put on hold in the wet weather, but should resume again soon. We are continuing to sell our collector's item mugs. Other fund-raising initiatives have still to be decided.

## **5. Other Christmas Events**

We were able to use some of the excess from the Zurich Challenge towards Christmas lunch at the Toby Inn and we still have enough over to contribute towards another event. The date hasn't been set yet, to enable those members who missed some of last year's festivities to join us.

We again gave Christmas gifts to patients who had to spend Christmas in Dove Ward. On Christmas morning J and his brother-in-law played carols on their classical guitars in the Dove corridor, which provided an excellent opportunity to deliver the gifts.

### PICC lines

Some nurses in the Haematology department have now been trained to insert a PICC line (Peripherally Inserted Central Catheter), which is a possible alternative to a Hickman line for some patients receiving frequent intravenous treatment. It does not require a surgical procedure.

Currently the equipment needed, a Sonasite, which seeks out suitable veins, is being shared with another GWH hospital department on a trial basis.

### Benefits Advisor

LB started work in January 2008 as the Citizens Advice Benefits Advisor for people affected by cancer in the Swindon area. She intends to liaise with cancer support groups about how she can link in with us and develop the service.

The Macmillan Cancer Support Campaigns team would like to hear from anyone who has made a claim against a critical illness policy during the period from June 2006 to December 2007, as part of their work looking at critical illness insurance cover and the difficulties people affected by cancer may have when making a claim. Anyone interested in finding out more or taking part in this project, can contact Jagtar Dhanda (User Support and Involvement Manager) on 020 7848 7847 or email [campaigns@macmillan.org.uk](mailto:campaigns@macmillan.org.uk).



### Sudoku Answer

4	8	9	1	5	3	2	6	7
6	7	5	4	9	2	3	8	1
3	1	2	8	6	7	5	9	4
1	9	3	2	4	6	8	7	5
5	6	8	3	7	9	4	1	2
7	2	4	5	8	1	6	3	9
9	5	1	6	2	8	7	4	3
8	4	7	9	3	5	1	2	6
2	3	6	7	1	4	9	5	8

### Haunting answer

The number of days between sightings increases by one for each quarter of the year and the room number of the next haunted room is related to the previous haunted room. Take the room number haunted in the current quarter multiplied by the number of days between the sightings and then subtract the number of days between sightings. This means that the next sighting will be  $(9 \times 4) - 4 = 32$ , i.e., Room 32 every fifth night.