

# HUG MAGAZINE



**October 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

This Magazine is produced by the HUG Group and is self-supporting.  
Comments, suggestions and articles are welcomed.



Some members after a recent get-together

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**H.U.G. SWINDON**  
**HAEMATOLOGY/ONCOLOGY UNITED GROUP, G.W.H.**

# H.U.G. Swindon Get-Togethers

We meet in the Academy (at the back of the Hospital), Room Number as shown.

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

**2<sup>nd</sup> October 2008 – Seminar Room 5**  
**13 November 2008 - Seminar Room**  
**11 December 2008 – Seminar Room 1**

## AIMS

**HUG aims to improve the environment for 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, room redecoration, donation to Dove Ward Charitable funds, Christmas gifts and slippers for patients. Ideas are welcomed at any time for future projects.**
- ❖ **Maintaining a website to promote the group.**

# NEWS THAT MAY BE OF INTEREST

## **Opening of Umbilical Cord Blood Bank**

The Anthony Nolan Trust Cord Blood Bank and combined research institute was opened by Alan Johnson, Health Secretary, on 11<sup>th</sup> September 2008. It will store stem cells from the blood of new-born babies' umbilical cords, to help save lives, and pioneer medical breakthroughs.

The £1.4 million centre at Nottingham Trent University spearheads a multi-million pound project that will call on the generosity of individuals and the support of eminent institutions, and aims to bank 50,000 cord bloods to provide lifesaving transplant matches for almost every patient.

Initially, mums delivering at London's King's College Hospital can donate cord blood; the charity aims to have ten collection centres in the next few years.

Cord blood transplants have already been highly successful in renewing bone marrow and regenerating the immune systems of those with life-threatening illnesses including leukaemia, sickle-cell diseases, and immune deficiencies, but there are not enough bone marrow donors available to meet today's needs. Cord blood offers further potential to change and save lives. Collected, processed and stored at birth, it becomes part of a global lifesaving resource.

Anthony Nolan Trust

The Lymphoma Association and Leukaemia CARE put together a quiz to test people understanding of their lymph nodes to mark World Lymphoma Awareness Day (WLAD), an event held annually on September 15th which aims to inform the public about lymphoma; the sixth most common cancer in the UK. You can find it, together with sections on Everything You Need to Know and the Signs and Symptoms of Lymphoma at the following website:

<http://www.knowyournodes.org.uk/>

## **Macmillan campaign against prescription charges**

Macmillan believes in the following principles and urges those who agree to tell your MP and local paper:

- No one should have to pay for their prescriptions – it is a tax on illness.
- No one should be in the position where they can't afford their prescription.
- Some people are already exempt from prescription charges, but the current list of medical exemptions is over 40 years old so a review is long overdue.
- Most people under 60 with cancer have to pay for their prescriptions.
- The Government needs to think again on their position that they will not put any more money into a solution. The review must consider new ways to fund extra spending on the prescriptions budget in England – such as more effective use of non-branded medicines which could save hundreds of millions of pounds a year.

Join the prescription charge campaign at

<http://e-activist.com/ea-campaign/clientcampaign.do?ea.client.id=70&ea.campaign.id=674>

## Our Thoughts on Paying for Top-Up Treatment

Much has been reported in the press recently about the rules for paying for top up treatment. We have all read about cancer patients being refused new potentially life-saving or life-extending drugs on the NHS, but running into problems when they offered to pay for them themselves. Also what is available from one PCT may not be available from another, with accusations of a post code lottery. Patients have then found themselves having to pay for all treatment, including scans, x-rays etc. It is not surprising that the subject has been discussed at a recent get-together.

The requirements may change anyway, following the announcement at the Labour Party Conference that there would be a review of the current rules, but don't hold your breath! In the meantime our thoughts were as follows:

- *Patients should be allowed to pay for top-up treatment or private treatment if want to and have the means. Other patients should benefit from any saving for the NHS. The possibility of a trust fund was raised.*
- *No should lose out because they cannot afford to pay for the best treatment.*
- *What does not appear to NICE (The National Institute for Health and Clinical Excellence) to be financially viable could be considered worthwhile to patients. If you are given just weeks or months to live, then an extra year can seem like a real lifeline, raising the possibility of an even better treatment on the horizon, through medical advances.*
- *People should be encouraged to help themselves in other ways, such as losing weight or giving up smoking and rationing of treatment should be considered if they do not make the effort to cooperate.*
- *There is a genuine problem of funding, with not enough workers to support an aging population, so more needs to be done to get people back to or into work for the first time, so that more money is available to provide the best services.*
- *Donations from grateful patients to help with the cost of treatment should be possible.*
- *Pharmaceutical companies can sometimes make misleading claims about new drugs in the press, as a marketing exercise.*



Ever wonder why sheep don't shrink when it rains?

**H.U.G.** ★  
fridge magnet  
★ fun

***The pursuit of happiness is the chase of a lifetime!***



Confession is good for the soul, but bad for the career.



**Whoever said you can't buy happiness forgot about puppies.**



***If I want my dreams to come true, I mustn't oversleep.***



**YOU KNOW IT'S TIME TO DIET WHEN...**  
Your driving licence says, "Picture continued overleaf."



## Puzzle over it

Time for a wordsearch again. This time the topic is possible symptoms of lymphomas and leukaemias AND IT'S QUITE DIFFICULT, with "ing's" and "ess's"

F	M	A	R	P	T	S	J	X	A	Q	U	V	Z	S	E	R	E	T	Y
D	T	A	B	E	C	S	D	E	S	S	E	L	H	T	A	E	R	B	F
C	E	U	T	R	V	E	W	S	N	W	M	R	G	J	R	I	U	G	H
U	N	E	V	S	U	N	I	A	Q	E	P	S	O	F	M	K	N	L	U
T	D	W	X	I	Y	I	U	C	C	A	M	N	I	R	P	H	D		N
W	E	F	S	S	T	H	S	H	B	T	N	O	D	E	I	N	O	Q	E
V	R	H	P	T	Z	C	Z	I	X	I	Y	A	D	J	T	L	W		X
X	N	G	R	E	A	T	A	N	N	N	T	M	E	B	G	K	N	O	P
G	E	I	O	N	B	I	C	G	D	G	E	C	F	M	A	H	M	K	E
N	S	L	N	T	M	A	N	P	I	O	R	T	H	Y	I	T	U	H	C
I	S	B	O	C	S	T	A	E	W	S	T	H	G	I	N	C	J	L	T
L	A	M	R	O	N	B	A	S	R	E	Z	O	O	R	N	T	F	B	E
L	A	N	D	U	K	C	E	N	N	I	L	F	A	T	I	G	U	E	D
E	B	S	M	G	R	O	I	N	S	O	V	A	W	X	A	Y	S	Z	E
W	E	I	G	H	T	L	O	S	S	U	P	T	P	R	F	Q	R	S	I
S	T	E	R	N	B	A	R	T	O	P	Z	Y	I	F	M	R	A	T	U

ABNORMAL BRUISING (Note : 2 POSITIONS IN GRID)  
 ACHING  
 ANAEMIC  
 BREATHLESS (UNEXPECTED)  
 FATIGUED  
 ITCHINESS  
 NIGHT SWEATS  
 PALE  
 PERSISTENT COUGH  
 RUN DOWN  
 SWEATING  
 SWELLING (IN NECK, ARMPIT, GROIN)  
 TENDERNESS (ABDOMEN)  
 WEIGHT LOSS

# **WANTED**



## **More volunteers**

In order to expand the HUG Swindon Group, we would like more help with any (or all!) of the following:

- ◆ Magazine production – individual articles, jokes and mottos – patients' experiences would be of particular interest
- ◆ Organisation of outings
- ◆ Committee membership
- ◆ Publicity
- ◆ Fund-raising

This is beginning to sound like a job advert, but the ideal candidates would have experience of cancer and cancer services at the Great Western, either as patients or carers.

If you think you could help, please contact Irene for more information.

# H.U.G. News – read all about it

Get-togethers were held on 7<sup>th</sup> August and 11<sup>th</sup> September 2008, with additional Coffee Mornings at the Blunsdon Arms

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## 1. Recent Get-Togethers

We have had some lively discussions recently, such as top-up treatment, as reported in this issue. Some more of our opinions to follow next time!

## 2. Fund-Raising

Our advertisement in the last issue for the teddies and mugs we have for sale has generated some interest and sales.

Some of us are busy sewing some Christmas items to sell on our stall behind the atrium on the ground floor, on 19<sup>th</sup> November and 5<sup>th</sup> December.

Don't be put off coming along to HUG, on the grounds that you might be asked to sew. It's not obligatory – honestly! It has kept Debbie busy while she's been confined to barracks with her broken hip, though. She has been our star producer for a few weeks, but we are pleased to report that she is now able to drive again.

## 3. Events

Our next outing will be to Maggie's Centre in Oxford. We should be able to tell you all about it in the next issue.

We are already planning a Christmas lunch, to which we hope some old friends, now back at work, will be able to join us.

## 4. Spending

Having organised a stamp to add the web address to our advertising leaflets and a display stand for the magazines for Dove Ward, we now hope to purchase some wheat bags for day therapy and magnifying glasses for Dove Ward.



## Thoughts for the month on aging

Life is too short to wake up with regrets.  
So love the people who treat you right.  
Forget about the ones who don't.  
Believe everything happens for a reason.  
If you get a second chance, grab it with both hands.  
If it changes your life, let it.  
Nobody said life would be easy,  
they just promised it would be worth it.

**Old Age is a gift. I am now the person I have always wanted to be. Oh, not my body - I sometimes despair over my body with the wrinkles, the baggy eyes, and the sagging bottom. And often I am taken aback by that old person who lives in my mirror (and looks like my mother!), but I don't agonize over those things for long.**

**I would never trade my amazing friends, my wonderful life, and my loving family for less grey hair or a flatter tummy. As I've aged, I've become kinder to myself, and less critical of myself. I've become my own friend. I don't chide myself for eating that extra biscuit, or for not making my bed, or for buying that silly cement elf that I didn't need, but looks so avante garde on my patio. I am entitled to a treat, to be messy, to be extravagant.**

**Whose business is it if I choose to read or play on the computer until 4 AM and sleep until noon? I will walk the beach in a swim suit that is stretched over a bulging body, and will dive into the waves with abandon if I choose to, despite the pitying glances from the jet set.**

**I know I am sometimes forgetful. But there again, some of life is just as well forgotten. And I eventually remember the important things.**

**Sure, over the years my heart has been broken. How can your heart not break when you lose a loved one, or when a child suffers, or even when somebody's beloved pet gets hit by a car? But broken hearts are what give us strength and understanding and compassion. A heart never broken is pristine and sterile and will never know the joy of being imperfect.**

**I am so blessed to have lived long enough to have my hair turning grey, and to have my youthful laughs forever etched into deep grooves on my face. So many have never laughed, and so many have died before their hair could turn silver.**

**As you get older, it is easier to be positive. You care less about what other people think. I don't question myself anymore. I've even earned the right to be wrong.**

**So, I like being old. It has set me free. I like the person I have become. I am not going to live forever, but while I am still here, I will not waste time lamenting what could have been, or worrying about what will be. And I shall eat dessert every single day, (if I feel like it).**

## **Rough Guide**

*The Rough Guide to Accessible Britain*, jointly produced by Rough Guides and Motability has recently been obtained by one of the HUG members. It costs £6.99 or just £1.99 postage for those with blue badges for disabled parking. Debbie reports that it contains details of 100 accessible locations, but that there are very few local ones because it is a national guide. It might come in useful for holiday trips. It is available for ordering, while stocks last, at [https://www.accessibleguide.co.uk/buy\\_now](https://www.accessibleguide.co.uk/buy_now). You can probably also arrange at the Motability centres.



## **More about Motability**

Motability centres are now in most large towns. If have regular need of an electric buggy it is well worth registering to join the scheme. The cost (or not) varies from centre to centre. You may have to book at busy times.

If you just have occasional days when you need a bit of help to get around, it is worth remembering that Asda Stores and some other supermarkets have similar schemes that you can make use of.

## **Stop the bus, please. I want to get on**

Norma reports that for those who find it difficult to see bus numbers it is possible to obtain large laminated hailers can be used to let approaching bus drivers know which bus number you want. The driver of the correct bus number should then stop, if the sign is big enough for him to see. It seems to work for Norma. She tells us that the hailers are obtainable from the Royal National Institute for the Blind.

## **Get-Togethers away from the Hospital**

Ain addition to the get-togethers at the Hospital, as advertised on page 2, we meet for coffee and a spot of lunch for anyone who wants it at least once a month.

Contact Irene for the next location, date and time, if you would prefer to meet us, in a purely social setting. We are a small friendly group.

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Just enough room for a couple of our popular medical jokes

Doctor: We need to get these people to a hospital! Nurse: what is it? Doctor: It's a big building with a lot of doctors, but that's not important now!

Sam: I get so nervous and frightened during driving tests! Doctor: Never mind, you'll pass eventually. Sam: But I'm the examiner!