

HUG MAGAZINE



December 2007 to January 2008

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.



A Happy Christmas and a Healthy New Year to all our Readers

Contact
Email: hugswindon@btinternet.com

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

H.U.G. Swindon

Get-togethers take place
in the Osprey Unit Education Room.
Turn up at any time between
10:00 am and 12:30 pm
on the Thursdays shown:

10 January 2008
07 February 2008
13 March 2008

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 Appointments 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.**

Some Christmas crackers

**What happens if you eat
Christmas decorations?**

You get tinsel-itis

**Why did the little girl change her mind
about buying her grandmother a packet
of handkerchiefs for Christmas?**

She could not work out the size of her nose!

What do snowmen eat for breakfast?

Snowflakes

What do elves learn at school?

The elf-abet

Why does Santa have 3 gardens?

So that he can ho-ho-ho

**What is a parent’s favourite Christmas
carol?**

Silent Night

NEWS THAT MAY BE OF INTEREST

Cancer Reform Strategy

The Cancer Reform Strategy, launched on 3 December 2007, sets a clear direction for the development of cancer services in England over the next five years.

It aims to improve cancer prevention, speed up the diagnosis and treatment of cancer, reduce inequalities, improve the experience of people living with and beyond cancer, ensure care is delivered in the most appropriate settings and ensure patients can access effective new treatments quickly.

Over 1000 stakeholders were involved in the development of the strategy, including representatives from cancer charities, cancer professionals, NHS managers, patients and social care professionals.

Department of Health website, where full details can be read

Combination Treatment for CLL

A national clinical trial funded by Leukaemia Research has found that it is more effective to treat patients with Chronic lymphocytic leukaemia (CLL) with a combination of two drugs called fludarabine and cyclophosphamide, than using either of the current treatments alone. The CLL4 trial lasted for 6 years, collecting data from patients who were starting treatment for the first time, and including elderly patients who are often excluded from clinical trials.

It is hoped that combination therapy will be adopted as a standard treatment for future CLL patients.

Leukaemia Research News Autumn 2007

Stems cells from umbilical cords

It has been known for around 20 years that stem cells from umbilical cords of newborn babies can be used to treat more than 85 rare diseases. However just 3 NHS hospitals in Britain are collecting umbilical cord blood, producing around 1,200 units for the whole of last year. The National Blood Service says that 95% of new mothers are happy to donate their babies' tissue for general use, but the practice of freezing and storing the cells is limited by the funding made available from the Department of Health.

A number of private companies do collect and store cord blood for families as an insurance policy against their child developing a disease which could be treated by stem cells, at a cost of around £1,500.

Daily Mail 9 October 2007

Choose and Book

CG, General Manager, Diagnostics & OP (Out-Patients), popped in to our October 2007 get-together and brought along DM, the newly appointed Out-Patient Manager.

She filled us in, with great enthusiasm, on the new Choose & Book system and target times for treatment – a maximum of 18 weeks from visiting your GP to receiving treatment - with 4 weeks to outpatients, 2 weeks for diagnostic tests and 11 weeks for treatment such as an operation. (It should be noted that for suspected cancer patients, the timeframe is shorter.)

The 18 week pathway is a national target which has required a philosophy change and more efficient working practices. For example, more use is being made of specialist nurses, with some patients possibly not needing to see a Consultant at all. Follow up appointments may not always be necessary as part of new treatment pathways.

Patients will have more choice of hospitals. It is proposed that you may have treatment anywhere in the country so that you may be treated closer to family who could support you in your recovery, with the cost met by your (the patient's) local Primary Care Trust. Although this sounds like an administrative nightmare if more and more patients are treated away from their local hospitals, computer systems have improved and shouldn't be a problem.

The result will be that good hospitals will protect their services and expand. Hospitals that may not be providing a good service may struggle to attract patients. There will be more independent treatment centres for orthopaedics, audiology and other specialties which are felt appropriate to treat in these centres. This will create possibilities for replacing some services within Hospitals which are not provided at the moment.

There will be two ways to make new appointments, either via your GP, who will be able to do it direct or via NHS Direct, using a unique booking reference number provided by your doctor. There was a concern that it would be difficult for GPs and patients to make informed decisions about the best hospital for a particular treatment. C responded that GPs and patients can access a number of websites, including the NHS website, for information relating to hospitals. Word of mouth is also important. Patients tell others if they have had good or poor experiences.

As the patient is choosing the date for the appointment, it had been hoped that attendance levels would improve. Strangely enough, reported experience from another Trust shows that the number of patients not turning up has increased dramatically from 7% to 15%. Possible ways around this are being discussed, for example sending a text message, telephoning or emailing a few days before. In the week before the HUG get-together 45 patients didn't turn up at GWH for their appointments. There are reports that some try to ring in to change the appointments but can't get through, a difficulty which the Trust needs to address.

An area where HUG members have experienced delays with appointments is when they are referred from one department to another for some reason. This will continue to be handled via Consultant to Consultant referral, which will also have to meet the new targets.

One question posed after the meeting was related to the possibility of even more specialisation, meaning that patients have to travel further and further to be treated for some conditions. For example Osprey patients already travel to Oxford for Radiotherapy and some surgery, and to London for more specialist treatments. Chris explained that District General

Hospitals cannot offer specialist treatment for all conditions. Specialist centres are important to ensure that the expertise is available and that doctors maintain their skills by seeing high numbers of patients with the same condition. Patients are sent to these centres to ensure that they obtain the best treatment. Since hospitals and Primary Care Trusts have contracts to provide services, they cannot pick and choose which services they offer.

The Choose and Book process started in the summer of 2004 in England. The Swindon & Marlborough NHS Trust should have mostly completed the rollout programme by 1st December, before you read this article. There are some specialties with a complicated booking pathway, including Osprey, so these are being dealt with separately.

To find out more, a useful website is www.chooseandbook.nhs.uk/patients/whatiscab

-----000-----

Christmas Thank Yous

(ungrateful or what?)

1.

Dear Auntie
Oh, what a nice jumper
I've always adored powder blue
And fancy you thinking of
Orange and pink
For the stripes
How clever of you!

2.

Dear Gran
Many thanks for the hankies
Now I really can't wait for the flu
And the daisies embroidered
In red round the 'M'
For Michael
How
Thoughtful of you!

3.

Dear Sister
I quite understand your concern
It's a risk sending jam in the post
But I think I've pulled out
All the big bits
Of glass
So it won't taste too sharp
Spread on toast.

4.

Dear granddad
Don't fret
I'm delighted
So don't think your gift will
Offend
I'm not at all hurt
That you gave up this year
And just sent me
A fiver
To spend.

By Mick Gowar

from A Christmas Anthology by Alan Titchmarsh



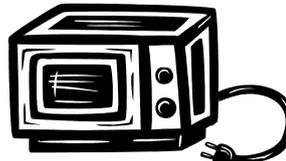
Champagne should be cold, dry and free.

H.U.G. ★
fridge magnet
★ fun

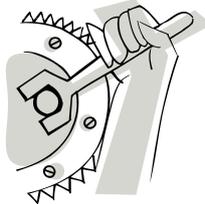
I would be unstoppable
if only I could get started.



YOU KNOW YOU'RE
LIVING IN THE 21ST
CENTURY WHEN....



YOU ACCIDENTALLY
ENTER YOUR
PASSWORD ON THE
MICROWAVE



If work was so good

the rich would have kept more of it
for themselves.



Behind every great man is a woman
rolling her eyes.

A MAN WHO WILL NOT LIE
TO A WOMAN HAS VERY
LITTLE CONSIDERATION
FOR HER FEELINGS.

Olin Miller, author



I have friends who swear they
dream in colour...



It's just a pigment
of their imagination.

Stem cell transplant – Pt 3

Another chapter in the account of the transplant of his stem cells by DH, a patient and HUG supporter, with Non-Hodgkin's Lymphoma.

As with the first two articles the mechanics of the preparation and transplant are covered by the 2 reference sources which are available in booklet form 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 follows to a pdf file.)

Both Cancerbackup and the Leukaemia Research Fund are registered charities that offer advice and support services in addition to your own medical teams.

I was admitted to the Dove Unit at the Great Western Hospital at the end of March 2007 a little apprehensive about the treatment to come but also excited that after many delays things were now moving on. After being monitored on the unit overnight I began the BEAM chemotherapy which is a varying cocktail of drugs to kill off my own bone marrow before the harvested stem cells are transplanted. On the first day the cocktail has a very potent drug and for the first time I was sick after treatment, very sick. This was a shock to me, not because I was not told about this possibility but because I hadn't previous been sick with the other chemotherapy regimes and the speed of sickness developing in spite of the anti sickness drugs taken.

The 5 days that followed were not as bad and I started hydration on the 5th day of treatment. There were 6 days of chemotherapy in total. The 7th day was a rest day from drugs though I was still being hydrated and was also now feeling very tired and diarrhoea was becoming more problematic for personal hygiene. Thank goodness for wet wipes! After my day of rest the stem cells were delivered from the Oxford Blood Transfusion Service and the gentleman from the NBS stayed to supervise the thawing and infusion of the stem cells, along with my consultant and 2 of the ward nursing team. During the transplant my obs (blood pressure, pulse and temperature) were taken very frequently, as the preservative which is added to the stem cells for storage can cause some patients to suffer an adverse reaction. In my case no such reaction presented and so after about 40 minutes the transplant was completed. Then the door to my room was closed and I began the period of protective isolation.

At this point the preservative, which is based on a sweet corn extract, has to go somewhere and the body will excrete a distinct aroma of sweet corn, not that I could smell it, and this was noticed by my family when visiting for the next 2 days and also by the nursing team. Peter, one of the nursing team, is vegetarian and did comment to me that at times he felt quite hungry as sweet corn is a favourite of his.

My tiredness was getting difficult to endure now and along with a sore mouth and throat, I developed persistent hic-coughs when I tried to eat or drink anything other than milk based foods.

In the following days I was given platelets because my blood counts were low, antibiotics to combat infections my body couldn't, and hydration due to the difficulty in eating and drinking. I also found my eyes becoming increasingly light sensitive and took to keeping the blinds drawn for comfort, though by now I was sleeping for nearly 16 hours a day. I'm sorry to say that some of my visitors found me asleep with a "do not disturb" sign on the door. I also found myself having nosebleeds and breathlessness after very little exertion in spite of the platelet transfusions which also tested my resolve. Potassium was also given with hydration fluids. 2 weeks after the transplant my blood count had risen to a point where I could be released from isolation and I went for a walk outside in the spring sunshine with my wife - lovely!

Unfortunately this progress was short lived as the day after release from isolation my temperature rose quickly and I had to return to isolation and restart antibiotics. My appetite had started to improve even though I was on a "clean diet" with most of the those I craved restricted foods and hic-coughs still making eating challenging. The days that followed were not very interesting as fatigue, lethargy and concentration limited to very short periods restricted just about all of the activities I had imagined doing (reading, crossword and Sudoku puzzles, television and DVD films.

I was eventually allowed home at the end of April, 30 days after being admitted, and continued my recuperation there with the support team of family, hospital and Day Hospice at the Prospect at Wroughton all playing their part. During my stay in GWH I lost nearly 2 stones in weight and was glad that I had taken the advice of my doctors beforehand to build up and try to get as fit as possible to help with the toleration of the treatment and recovery afterwards. The ongoing recuperation will be the subject of the final part of this series of articles.



Seasonal Puzzle

Louis, Sarah, Andrew, and Chelsea each have their own Christmas tree. Each Christmas tree has a different number of crackers (17, 13, 15, and 18) and a different number of baubles (23, 40, 39, and 32). How many crackers and baubles are on each person's Christmas tree?

1. The Christmas tree with thirty-two baubles is not the tree with fifteen crackers.
2. There are no more than thirty-nine baubles on Louis's Christmas tree.
3. Sarah's Christmas tree has the fewest number of baubles.
4. Chelsea's tree has twenty-two more baubles than crackers.
5. There are no more than thirty-nine baubles on Andrew's Christmas tree.
6. Sarah's Christmas tree has the fewest number of crackers.
7. Andrew's Christmas tree has fifteen more baubles than the number of crackers.

(Answer on Page 10)

H.U.G. News – read all about it

Get-togethers were held on the 2nd Thursdays of October and November in the Osprey Unit and Coffee Mornings at the Blunsdon Arms at the end of each month. Contact us for future dates of the Coffee Mornings.

1. Progress on proposed purchases for Dove and Day Therapy

Testing of stools for nurses to whiz between beds in Day Therapy is continuing, and why not when they are on approval! We expect a decision soon on the best design, so that the group can go ahead with purchases. Progress on other purchases is still slow.

2. Visitors to the Get-Togethers at the GWH

Patientline has still not managed to come and talk to us, but they have reduced call prices again. We have put some questions in writing and Angela from PALS will now ask them for written responses instead of a visit. In January 2008, CG will tell us what is involved in becoming a member of the Foundation Trust.

3. Fund-Raising

As planned, we set up a sales table in the Sales Room behind the atrium in November, selling our HUG china mugs and teddies, plus donated scarves, jewellery, books, cross-stitch and decoupage.

IB is keen to fit in another boot sale before Christmas, to make some space in her spare room!

We are going to use some of our funds to put together Christmas gifts for patients who have to spend Christmas in Dove Ward.

4. Increasing Awareness of the group

We are looking at ways to increase awareness of the group. Some ideas were obtained at a recent Macmillan event in Bristol, which 2 of us attended.

5. Christmas

Our members' Christmas lunch is on 17th December at the Toby Inn.

Our December get-together, on 13th December, is an Open House. Staff and visitors to Osprey are invited to join us for refreshments and a chat any time between 10:30 and 12:30 on that day.

New Clinical Nurse Specialists

SF and LM started in September 2007 to work with patients with rarer cancers, such as brain tumours, head and neck, sarcoma, melanoma and thyroid cancers. They will be funded by Macmillan for 3 years.

S previously worked for 12 years at the Prospect in Palliative Care and L in Clinical Research at the GWH, which means that they compliment each other well, in terms of experience. They are covering 4 days a week between them, with two days of overlap. The day without cover will change from week to week.

Their first few weeks have been spent receiving orientation training, collecting information, networking with clinical teams in both Swindon and Oxford and meeting patients.

S was interviewed for the HUG Magazine and regards the job as particularly challenging because they are covering a new large area. She considers that the appointment should be very good for patients, giving them additional support and helping to improve their experiences. She would also like to improve communications between the GWH and the JR in Oxford.

S and L can be contacted on their direct line, which is 01793 604339 between 9am and 5pm on weekdays. An answer phone message can be left if neither of them is available to answer.



HUG has received a donation of £100 from Mrs W, whose son D has been writing about his stem cell experiences. She writes:

Our friend Charlie

“Charlie W lost his battle with throat cancer in December 2006. He is missed by all his friends at the Southern Electric Retirement Association. He was an outgoing person who was great fun to be with, life and soul of any party, but had a very gentle side. He would help anybody who needed it, and always had time for people, and of course his family.

He loved organ music and good wine and food. He made people feel good about themselves and never felt sorry for himself. This donation is in his memory, to make things more pleasant for others.”

The money was the profit from a couple of raffles held by the Retirement Group. Thank you very much to Mrs Wootten and her friends at the Southern Electric

Retirement Association.

(Christmas Puzzle Answer: Louis has 15 crackers and 39 baubles, Sarah has 13 crackers and 23 baubles, Andrew has 17 crackers and 32 baubles and Chelsea has 18 crackers and 40 baubles.)