

# HUG MAGAZINE



**June 2012**

(issued on 2<sup>nd</sup> or 3<sup>rd</sup> Thursday of alternate months on meeting days)

For HAEMATOLOGY and ONCOLOGY patients, being treated in the Day Therapy Centre and Dove Ward or under review



Our t-shirt logo – rainbow on a blue background

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## H.U.G. Swindon Get-Togethers at the GWH

We usually meet in the Academy on the second Thursday of the month.

Turn up there or at the alternative venue at any time between  
10:00 am and 12:30 pm unless otherwise stated

<b>12 July 2012</b>	-	<b>Seminar Room 5</b>
<b>16 August 2012</b>	-	<b>Cherwell, Brunel Centre (11:00 – 13:00)</b>
<b>13 September 2012</b>	-	<b>Cherwell, Brunel Centre (11:00 – 12:00)</b>

(The Academy is reached from the front of the Hospital through the double doors at the back of the atrium, going right and following the signs, which first appear at the end of the corridor. If you are eligible, you can use the disabled car parking spaces at the back of the hospital, cross the road and head back towards the entry road. The Academy entrance is about half way along, in the main building. The small parking area just outside the Academy is for staff.)

### What do we do?

HUG offers tea, sympathy, sharing of ideas and information and much more, to patients and their families or carers, including:

- **Organising monthly get-togethers at the Hospital, Coffee Mornings (contact us for details of the next one, usually around the end of each month) and Craft Sessions (on the 2<sup>nd</sup> Monday of the month) away from the Hospital**
- **Suggesting how and where to access professional help, where appropriate**
- **Attending Cancer Services User Involvement Meetings on behalf of patients and carers and discussing or raising and following up on issues of importance to them**
  - ✓ **Items currently under discussion include Complementary Therapies, End of Treatment Care and Radiotherapy for Swindon**
- **Fund-raising to provide practical help with purchases including thermometers, travel bands, mugs, slippers, gel bags and heat pads, when suggested by clinical staff, patients or carers**
- **Maintaining a website and making leaflets available to promote the group and advertise our activities**
- **Producing the HUG Magazine bi-monthly and leaving copies in Cancer Services areas, providing direct to members and posting on the website**

Items for sale at any time: chemo hats made of a silk/wool mix in a choice of colours and styles and our personalised mugs and teddy bears. Contact us for more details.

# INTERESTING HEALTH-RELATED NEWS

## **New breast cancer test**

A new test can predict whether a breast cancer tumour is likely to return after it has been surgically removed. It is suspected by scientists at the Royal Marsden Hospital that many patients undergoing chemotherapy to reduce the chances of a relapse do not actually need this treatment.

To date the size and characteristics of a tumour are the basis for deciding whether follow up treatment is necessary, but the new test, known as ICH4, enables many more patients to be classified as low risk. Following a clinical trial involving more than 100 women, they estimate that the test could identify between 4,000 and 5,000 women every year who would not need chemotherapy by measuring the levels of a number of proteins in the tumour after removal.

The NHS drugs approval body is expected to make a decision in October this year on whether the test should be made available on the NHS. It could save money as well as reducing the number of patients requiring chemotherapy in these circumstances.

Details were published in the British Journal of Cancer and reported in the Daily Mail and on the Daily News & Analysis website on 23<sup>rd</sup> May, 2012. Refer to [http://www.dnaindia.com/health/report\\_new-breast-cancer-test-to-predict-return-of-tumour-post-surgery\\_1692600](http://www.dnaindia.com/health/report_new-breast-cancer-test-to-predict-return-of-tumour-post-surgery_1692600).

## **Blood tests that indicate success of cancer treatment**

A new blood test, currently undergoing clinical trial, uses DNA sequencing to read genetic code. It is hoped that it will revolutionise the diagnosis and treatment of cancer and make it possible to predict whether a treatment is working, without the need for extensive imaging. It could also indicate how treatment could be personalised for individual patients. Dr Nitzan Rosenfeld led the recent study at the Cancer Research UK Cambridge Research Institute.

Details were published in the journal Science Translational Medicine on 31<sup>st</sup> May 2012.

## **Lymphoma Association awarded quality mark**

The Association has recently been accredited with The Information Standard quality mark, which is supported by the Department of Health. It is aimed at helping the public to recognise safe, reliable and evidence-based health and social care information. Association leaflets are available at the Cancer Services Information Point.

It is estimated that around 50,000 organisations provide health and social care information and according to a Department of Health survey in 2007, 75% of patients found it hard to decide whether information was trustworthy or not.

## **Gamma surgery**

Five units in the UK are now offering gamma knife surgery using beams of gamma radiation to treat brain, head and neck tumours. Although it's called Gamma Knife, there is no blade or blood involved. It is a radiosurgical treatment that delivers a dose of gamma radiation to the target with great precision without affecting surrounding healthy tissue.

Through the use of three-dimensional, computer-aided planning and the high degree of immobilization of the patient, the treatment can minimize the amount of radiation to surrounding healthy brain tissue. Because Gamma Knife radiosurgery is so accurate, the full dose of radiation can be delivered during a single session, compared with multiple visits for linear accelerator (linac) treatments, which use lower doses delivered in fractions (fractionated treatment). Only minor discomfort is experienced by the patient. NHS patients can be referred to one of the specialist centres, the nearest of which is in London.

See <http://www.bupacromwellhospital.com/services-and-specialties/gamma-knife-centre/> for more information.

# Future possibilities for Breast Cancer Treatment

## Classification of types

A major study carried out by Cancer Research UK scientists could revolutionise the way women with breast cancer will be diagnosed and treated in the future, by reclassifying the disease into 10 completely new categories based on the genetic fingerprint of a tumour.

Doctors should one day be able to predict survival more accurately in women with breast cancer based on these new subtypes, and better tailor treatment to the individual patient.

The scientists:

- Classified breast cancer into at least 10 subtypes grouped by common genetic features that are linked to survival. This new classification could change the way drugs are tailored to treat individual patients with breast cancer.
- Discovered several completely new breast cancer genes that drive the disease. They are all potential targets for the development of new types of drugs. This information will be available to scientists worldwide to boost drug discovery and development.
- Revealed the relationship between these genes and known cell signalling pathways - networks that control cell growth and division. This could pinpoint how these gene faults cause cancer, by disrupting important cell processes.
- Obtained new insights into how some women seem to be protected by their immune systems.
- Identified a 'good outlook' group for whom it may be possible to give less-intensive treatment (such as avoiding chemotherapy after surgery).

This landmark study, done in collaboration with the BC Cancer Agency in Vancouver, Canada, will completely change the way we look at breast cancer. It's the result of decades of research by scientists to identify the causes and drivers of the disease.

*Cancer Research Breaking News, 20th April 2012*

## Use of magnetism to potentially destroy breast tumours

Tiny magnetic particles that stick to breast cancer cells could soon help doctors to identify and destroy tumours. Researchers at the University of New Mexico have created microscopic iron particles that are fused to human anti-bodies which are responsible for killing pathogens in the body. They are injected in and bind to the outside of cancer cells. A patient could then be put into a magnetic field causing the iron particles to heat up, killing the cells to which they are attached, but not the surrounding healthy tissue. So far testing has only been carried out on animals.

## A Patient's Tale

C has had CLL (Chronic Lymphoblastic Leukaemia) for ten years. She went to a Practice Nurse and then her Doctor after discovering a lump under her arm. She was asked lots of questions and was then offered the option of having it investigated quickly privately (through her medical insurance) or more slowly via the NHS. She opted for the private consultation and saw an Oncologist in Bath who found nodes under both her arms, although her blood counts were normal.

Diagnosis followed a biopsy, but no explanation of the condition was given. The only part of the name of the condition that made sense to her was the "Leukaemia" word, and she was simply told that with chemotherapy people with CLL were known to be doing ok in 5 years.

On thinking about it, she decided to obtain a copy of the letter sent to her Doctor concerning her diagnosis. She had never heard of CLL before and with the help of a Pharmacist friend, she was able to get some medical literature and find out more about the condition.

It appeared that she was not going to die immediately

Following the diagnosis and some research, C decided to consult a CLL expert and spoke to her GP to find out how this could be achieved. C thinks that it is a national characteristic of Mexicans like herself to want to obtain a second opinion from an expert on whatever the condition is.

From the list of UK experts her GP felt that a London one would be easier for her to travel, so a referral letter was sent and an appointment made to see a CLL Expert through private insurance.

The CLL Expert's opinion confirmed that due to the proliferation of nodes that she had C would definitely need treatment in the future. When C asked the CLL expert what he thought about her going away to Brazil for three months, his reply was, go for it, and enjoy the break.

She then decided to close down her business and go on an extended 3 month holiday, doing volunteer work in Brazil and Guatemala. On her return she felt a bit empty and decided to go travelling again. However this time on her return her blood counts were all going in the wrong direction and the consultant felt it was time to start treatment.

From the time of diagnosis, C kept a spread sheet with all her blood count records to be able to monitor the pattern.

Although Rituximab is now approved by NICE for use in conjunction with other chemotherapy drugs, it was not available on the NHS at that time. Private treatment meant that she had to find her way through something of a maze, but her GP was a wonderful help. She felt that she had regained control over her own health during her treatments. Unfortunately she did not respond to treatment and had only partial, very short remissions.

When she came to the GWH after her private treatments, she was surprised when her GWH Haematologist suggested a stem cell transplant by donor in 2008. This would not have been possible for someone of her age (over 60), even 5 years before, but it was pointed out that her overall health was good and she should be able to withstand the treatment. A stem cell transplant is something that has to be considered very careful and it is not the answer for everyone or every condition.

In the lead up to the stem cell transplant she did some more research to find out as much as possible about the procedure and what steps she could take to help herself through it. Treatment to get her ready for a transplant involved drugs that were very immunosuppressive and on week 9 of treatment she was hospitalised for 4 weeks with 3 infections simultaneously. Thanks to the amazing dedication and care of the staff at GWH she recovered and got herself back onto her feet.

She made changes to her diet, including cutting out acidic foods, as due to the drugs, the stomach is more sensitive and gets easily affected by acid foods. She also continued to keep records of her blood counts.

She regarded the transplant as an exciting adventure and worked as a team with the Clinicians to prepare for it. Nurses played an important part in supporting her through the long preparation period. She felt so touched by their care and dedication that became part of her life during all those months.

The preparation for the transplant was still difficult in practice, as the patient's immune system has to be killed off. One of the scientific papers she read suggested that mouth ulcers arising during intensive chemotherapy with Melphalan can be prevented by sucking ice chips during the chemo sessions. (Although not mentioned on the day, we know that her family brought her ice lollies, which were a little more palatable than ice cubes.) This worked for C while she was in the Royal Free in London for the transplant and she did not suffer from mouth ulcers, a condition called Mucositis.

It is now three years since she had her stem cell transplant by donor and she was told that she was in the top 5% of patients in recovery terms. 10 months after her Stem Cell Transplant she had a Donor Lymphocyte Infusion of the donors cells.

This is a fairly new procedure being offered at a small number of hospitals, including the Royal Free, the only medications that she needs to take now are Penicillin for 5 years after the Stem Cell Transplant and she is also taking Acyclovier a drug to prevent Shingles, although the Acyclovier is not essential, the Transplant consultant said that for some reason 30% of transplanted patients get shingles and they do not know the reason, so if she was happy to continue taking the medication they were happy to prescribe it, the thought of getting shingles is something it does not appeal to her.

C will remain a patient, with regular check ups, for life. Travelling will still be possible for her. However it is always advisable to have a contact link with a transplant unit wherever one travels in case of any unexpected problem. Those specialists can then get in contact with the consultants in the UK and deal with the situation as a team. Blood test are easily understood in most languages as the names come from

Latin and Greek so they are all basically very similar and medical terms are the same throughout the world!

She found it much easier to talk to Doctors and exchange ideas with other patients, as she gained more knowledge. Indeed she helped to set up the national CLL Support Association, since there was no association specifically for this cancer. It is now a registered charity of considerable stature offering support and information to CLL patients. Refer to the CLL website at [www.clisupport.org.uk](http://www.clisupport.org.uk) for more information.

We wish C continuing good health for many years to come.

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And on a less cheerful note

Unfortunately, we have also recently lost one of our members, who died on 30<sup>th</sup> May. R had been involved with HUG since its inception and had been fighting myeloma for 11 years. She was amazingly cheerful despite the ups and downs of her condition, including numerous crisis points. Indeed she was not expected to survive at the time of her initial diagnosis and treatment.

R regarded every additional month and year as a bonus and never indulged in self-pity. Whenever she and her husband P managed to join us at meetings or outings, she was always more interested in how everyone else was faring, than in discussing her own state of health. Whenever possible the couple went off to their second home in Spain to relax and recuperate or up to Newcastle-upon-Tyne to visit family and friends.

R and P have been an extremely close couple, who had worked together running their own business for around 22 years of their working lives, until their retirement, as well as doing virtually everything together. Although having said that, there is no doubt that their devotion to each other and interest in life around them helped R to keep going. P made it his mission to look after her, taking her to all hospital visits, recording copious notes, asking questions and making sure that she got the best care available when she had to be an in-patient.

Last year R bought tickets for P and a friend to go to a rugby competition (Sevens, we think) in Dubai, because she thought he needed a break, an indication of her thinking of others, at a time when she was really unwell herself. He had to be persuaded to go, in fact, but thoroughly enjoyed the experience.

For some years P and R have been fortunate to be close to some of their family, after moving into an annexe to one son's house. This meant they were able to see him, their daughter in law and grandchildren on a daily basis and to help with ferrying the grandchildren around. R had been hoping to be well enough to attend the wedding of their other son, who lives in Jersey. We know that they will all be thinking of her when the day comes.

Our commiserations and very best wishes to all members of their family.



# HUG ★ Fridge magnet ★ fun

Only those who dare to fail greatly can ever achieve greatly.



Hope is the poor man's bread.  
*Thales of Miletus*



Life is the flower for which love is the honey.



You only live once, but if you work it right, once is enough.




Heard about the two peanuts uptown? One was a salted!



One of life's mysteries is how a two-pound box of chocolates can make someone gain five pounds.

## H.U.G. News – read all about it

- Get-togethers were held in the Academy at the Great Western Hospital in the middle of April and May.
  - Coffee mornings continued at the Blunsdon Arms at the end of April and May. Dates were arranged according to the availability of members.
  - We haven't managed to fit in a craft session since the last issue. Must do better next time!
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### 1. Get-Togethers

Attendances have remained low at hospital meetings. This makes it difficult to justify inviting speakers along, but does allow plenty of time to compare notes on treatments at the state of everyone's health..

### 2. Income and Expenditure

We have managed to sell a few donated items via Ebay. Although the chemo hats did not generate any interest, we shall continue to put some of our other new items out there.

We have recently purchased a gazebo, which we may well be able to make good use of in 2012, given recent weather! It has three sides to give plenty of shelter when needed.

We are planning to sell at a car boot sale or two over the summer months, using our stock of books, plants etc.

In addition we have a stall at the Old Town Festival on Saturday 16<sup>th</sup> June, between 10am and 5pm, when we shall be selling gift items, craft makes and running a tombola stall. Hopefully the new gazebo will stand up better than the one we borrowed from Margaret last year and had to replace, after it was damaged by wind. To be fair, it was a particularly awful day.

Our next hospital sales table behind the atrium is not till 10<sup>th</sup> September. We had to cancel the June date, because it turned out to be the date of the Monday Bank Holiday. Places do have to be booked a long way in advance.

We have received a donation of some very pretty hand-made cards to add to our stock, from a friend of one of our members.

We purchased what we hope will be enough postage stamps to keep us going for a year, in advance of the hefty price increase. We do try to distribute as many Magazines as we can by email and make them available on the internet, as well as making paper copies available at the Hospital. However, we are happy to post to those who do not have access to a computer, on request.

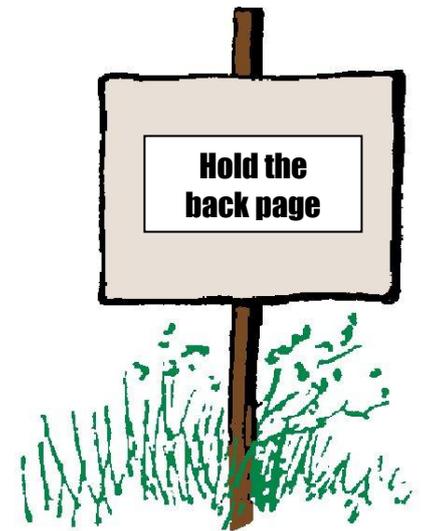
### 3. Other Activities

The Outing to Evesham Country Park, sponsored and organised by Day Therapy volunteer Jenny Yallop, had to be postponed because insufficient patients and carers were able to make the date. Such is the nature of the group. It has now been re-scheduled for Wednesday 25<sup>th</sup> July, with abc members also included.

We shall be organising our own summer outing, probably in September. Ideas are being discussed as we go to press. We have gone for boat trips twice in recent years, because they don't involve too much walking. Perhaps a train ride would be appropriate this year and also quite easy to do from Swindon.

## **Mobile Chemotherapy Unit in Wiltshire**

BBC News announced on 3rd May 2012 that a mobile chemotherapy unit (MCU) will soon start operating in Wiltshire. Funded by charity Hope For Tomorrow, the £250,000 unit will be based at Salisbury District Hospital but will travel to rural areas of the county. Hope for Tomorrow founder, Christine Mills said it had taken "lots of planning and fundraising to get it here".



The Unit aims to cut the travel time for those seeking treatment and could carry out more than 3,000 treatments a year. Because Wiltshire is a large, predominantly rural country, many patients have to travel a long distance for their care. It also gives patients the opportunity to receive their treatment in a calm, relaxed and intimate atmosphere.

It is the third unit the charity has built in the UK after other launches in Gloucestershire and Somerset. The charity owns and maintains the units and provides them to the NHS to operate. Staff from Salisbury District Hospital's specialist cancer treatment centre, the Pembroke Unit, will run the Wiltshire MCU. Sir Stirling Moss, the ex Formula One racing driver, is a patron of the charity.

It should be noted that mobile treatment may not be suitable for all chemotherapy patients, depending on the regime required.

## **Suburban Turban**

We have recently come across Suburban Turban which specialises in pretty headwear for women suffering hair loss. There are hats and scarves as well as turbans. Prices start at around £23 plus VAT, but if you are buying because of a recognised medical condition, no VAT is chargeable. Call on 0845 003 2 800 or visit [www.suburbanturban.co.uk](http://www.suburbanturban.co.uk).

For a much cheaper option, HUG has knitted a number of silk/wool mix beanie-style hats without seams, and ours cost just £8.50. Contact us via email or by telephone for more details of the styles and colours we currently have available.