

HUG MAGAZINE



June 2010

(issued on 2nd Thursday of alternate months)

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



Remember sun safety

Email: hugswindon@btinternet.com

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H.U.G. Swindon Get-Togethers

We meet in the Academy (at the back of the Hospital), unless otherwise stated, on the second Thursday of the month.

Turn up at any time between
10:00 am and 12:30 pm.

15th July 2010 – Seminar Room 5
12th August 2010 – Seminar Room 4
16th September 2010 – Seminar Room 4

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, in an informal atmosphere over refreshments.

Producing the HUG Magazine, a light-hearted and informative bi-monthly publication, which is available in Dove Unit, the Day Therapy Centre, the Osprey Waiting Area and Wren Ward or provided direct to members.

Pointing patients in the direction of specialist help, 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. We have provided mugs, bookshelves, redecoration materials, purchased Christmas gifts, magnifying glasses, slippers and thermometers for patients and donated to Dove Ward Charitable Funds. Ideas are welcome for future projects.

Maintaining a website and distributing leaflets to promote the group.

Get-Togethers away from the Hospital

In addition to the get-togethers at the Hospital, as advertised above, we meet for coffee and a spot of lunch, for anyone who wants it, at least once a month. Contact us for the next location, date and time, if you would prefer to meet us, away from the GWH. We are a small friendly group, who would be delighted to see you.

INTERESTING HEALTH-RELATED NEWS

NICE guidance rejects advanced liver cancer drug sorafenib

It has been announced that Sorafenib (brand name Nexavar) will not be made available on the NHS for people with advanced hepatocellular carcinoma (HCC), the most common form of primary liver cancer. Final guidance published by the National Institute for Health and Clinical Excellence (NICE) says that the high cost of the treatment cannot be justified by its "marginal" benefit. Evidence reviewed by the institute's independent advisory committee suggests that the drug typically increases survival by an extra 2.8 months for people with HCC - for which life expectancy is usually less than 24 months.

The only treatment that may provide a cure is surgery, but most patients are not suitable candidates. However, at a cost of £27,000 per patient, the institute said that it could not recommend sorafenib as a cost-effective use of NHS resources.

Cancer Research, Thursday 27 May 2010

Prostate cancer vaccine approved in the U.S.A.

The US Food and Drug Administration (FDA) has approved a new 'cancer vaccine' for treating men with advanced prostate cancer. Provenge (sipuleucel-T) has been approved for patients with few or no symptoms whose disease has spread to other parts of the body and who are not responding to hormone treatment. It is a new type of immunotherapy treatment which stimulates the patient's own immune system to fight the cancer.

Immune cells are extracted from the patient's blood by a process called leukapheresis. The cells are then exposed to a protein found on prostate cancer cells to enhance their response against the cancer. They are then returned to the patient via a drip, with three doses given at two-week intervals.

A trial involving 512 patients with advanced prostate cancer found that those who received Provenge typically survived for around four months longer than those who were not treated with the vaccine. Side-effects such as chills, fatigue, fever, back pain and nausea were common, but tended to be mild.

Dr Chris Parker, a Cancer Research UK-funded prostate cancer expert at The Institute of Cancer Research, commented: "This is exciting news for the field of immunotherapy. It's the first time that any immunotherapy has been shown to increase survival for prostate cancer. Hopefully, this approval will open new avenues of research into using a patient's own immune system to treat cancer. The process for approving drugs in the UK is different from the US, so this treatment is not yet available here," he added.

Cancer Research 05 May 2010

Allergies may significantly reduce the risk of cancer

Allergies sufferers are far less likely to contact cancer according to the report of a study carried out at Texas Tech University, led by epidemiologist Dr Zuber Mulla. The study found that asthmatics were 30% less likely to get ovarian cancer than other women. Another study carried out at Minnesota University showed that children with airborne allergies were 40% less likely to develop leukaemia than other youngsters. This is thought to be because allergies are a general activation of the immune system, which could lead to another method of encouraging the body to fight harder.

Daily Mail 24 May 2010

CT: one year on from stem cell transplant

I thought I share some more news with you all. Recently I had a phone call from The Royal Free to say the test of my chimerism was back and things are good. She also added that she did not want to put it in an email but best to explain things to me over the phone. Well that is really nice but I am not sure I am good enough to relate the conversation we had in scientific terms to you, so I will try my best to pass on the news.

All my B cells were fine. the T cells they were 98% male cells, and 2% female, she gave me an explanation I really can not quite recall about how the 2% female cells were not mine, but that old cells from male get converted into female. Well to be honest I got lost on this part so I am not sure if that is actually what she said, but she seemed happy about the results, that I just have to accept they were good and wait for the next step. She also said she was going to talk to Prof. McKinnon and she was sure his opinion would be that I am 100% chimerims.

You might remember that in January this year I had to have Donor Lymphocyte Infusion as my T cells were 74% male (donor gentleman from Germany) and 26% female (mine). It was quite exciting at the time, although it only took 5 minutes for the infusion. I knew the cells were coming by plane from Germany the day before and I had instructions to get to the hospital next day at certain time, which I did.

I had some minor GVHD (Graft Versus Host Disease) afterwards but no much to affect my life, a rash on my face and I still got problems with sleep patterns which I read on an internet lecture that was part of GVHD. I can't remember where I got the link from but the lecture was very interesting, all about Graft Versus Host Disease.

I think I am well and feel healthy and life goes on. I am now 65, quite an amazing achievement. I very well remember once when Prof. Terry Hamblin asked me during one of my treatments if I did not want to live to 70, at the time that seemed such a remote thought that I said I was not sure.

There are some minor hiccups in life that I still have to sort out, such things as accepting I am not longer 55 and I can no longer do heavy work without getting tired like I used to do, also from being very good sleeping at night, I now do not sleep much so I will have to work on that.

The other thing is that after so many years of no planning the future and just doing things as they came enjoying each day as it was, I think it hard to make any long term plans.

Last time I saw Prof. McKinnon he said that 62% of CLL patients with his protocol were alive 3 years after SCT. I have manage to make the first year, would be nice to make the 3 years and improve the statistics, though being so much older than many of my fellow CLL transplanted friends, I think I might not make the years I hope they will from their much younger age.

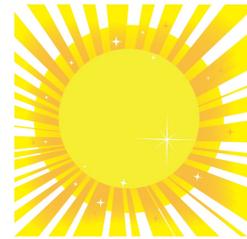
I hope my experience and the journey I have taken helps others starting on their journey and please I am here if anyone needs any help or likes to talk about any particular thing related to their SCT.

(C is a HUG Group member and also one of the founders of the national CLL Support Group. Anyone who wishes to contact her can do so via the usual HUG contact means. We shall pass any messages on to her.)



**It's a bit worrying that
Doctors call what they
do practice!**

HUG ★
fridge
magnet ★



Why does the sun
lighten our hair,
but darken our
skin?

A friend is a
present that
you give
yourself.

One thing I can't recycle is wasted time.



**Be an optimist!
Always try to see
the glass half full**



You know you're past it when a
bar of chocolate is preferable to
a night of passion.

Oxford Biomedical Research Centre

Two of us from HUG attended the Open Day at Oxford Biomedical Research Centre a few weeks ago. The Centre is a partnership between the Oxford Radcliffe Hospitals NHS Trust and the University of Oxford. OxBRC was founded in April 2007 through a competitively awarded grant of £57.5 million over 5 years from the National Institute for Health Research (NIHR). The goal of the health research strategy is to improve the health and wealth of the nation through research and establish the NHS as an internationally recognised centre of research excellence, by improving research, healthcare education and training. The aim of OxBRC is to undertake what is known as “translational research”.

Translational research is the application of basic scientific research to the development of new advances that directly benefit patients and improve healthcare. The concept is commonly known as “from Bench to Bedside”. OxBRC funds and supports research in several areas with the Oxford Radcliffe Hospitals NHS Trust and the University. There is ongoing research in the following areas:

Blood, brain, cancer, diabetes, heart, immunity, infection, vaccines, stroke, bioengineering and technology, cohorts and tissue banking, genetics and pathology and imaging.

Perhaps the most interesting for us was the T cell receptor exhibit. We learned that T-cells are the white blood cells that circulate in the blood looking for cells that have been infected by a virus or that have become tumour cells. The cells are like knights riding around the body looking for invaders to kill. There is a constant battle going on between T-cells and viruses, with the body trying to produce enough T-cells to keep infections under control. Our bodies contain many different T-cells, “trained” to recognise a particular virus, tumour or other invader.

In order to study how the immune system reacts to a particular virus or tumour, scientists in Oxford found a way to pick out the relevant T-cells from other T-cells using “HLA tetrameric complexes”. The approach is now being used all over the world. The method is being used to study individual T-cell responses to viruses such as HIV, hepatitis, chicken pox, and also T-cells which recognise allergens and proteins that may be important in arthritis and kidney disease.

H.U.G. News – read all about it

Get-togethers were held at the Great Western Hospital on 15th April and 13th May 20109 in the Academy at the GWH, with social events at the Blunsdon Arms at the end of April and May.

1. Recent Get-Togethers

We were joined in April by D, whose brother, DL was a founder member of the group. It was lovely to see her again after about four years. D was particularly interested in hearing about proposed group projects for spending.

May was a quieter month, with several members absent because of treatment on the day or prior engagements. LH from Cancer Services joined us for part of the morning and gave an update on our complimentary therapy suggestions (see below), what is happening in the Pharmacy and parking (both on page 10).

2. Spending

We found a really good price of less than £1 per pair of seabands, said to reduce nausea, whether from pregnancy, travel sickness or chemotherapy. Because of the size of the order, delivery has been delayed, but we hope to make the first of these available to new patients in Osprey very soon.

It appears that complimentary therapies cannot be made available to patients via HUG for the foreseeable future. Guidelines for who could provide therapies and how they would be approved still need to be agreed for the whole of the Thames Valley Cancer Network. The rules will certainly include a requirement for practitioners to have an approved qualification in their specialities. However, they will also need to be trained to know the effects of the therapy on particular cancer patients, as well as the interpersonal skills needed for working with the seriously ill. Once all these requirements have been documented, Cancer Services might be prepared to signpost approved service providers. Our dream of subsidising such services for patients will not be fulfilled until then.

In the meantime, a new idea has been proposed for our consideration. It is a sky ceiling, which gives the effect of seeing an outside view through a skylight. A digital photographic reproduction on a ceiling is backlit by daylight balanced lighting, giving the effect of a real sky, complete with tree branches and clouds. This is said to be relaxing and soothing and could possibly be used above the Osprey waiting area, but would also be suitable for the scanning department, wards and operating theatres. We are currently awaiting details of the cost.

Clinical Trials at the Great Western NHS Trust

It is some time since HW of the Clinical Trials Unit joined us at a HUG meeting to explain something about the work the Unit is undertaking. It was therefore very interesting to read a progress report in their recently issued Newsletter, for the year to March 2010. For those who may not have read the previous report, Clinical Trials are research studies in which people have all or part of their treatment as part of a trial. None of the trials being run at the GWH involve previously untested drugs and safety is of paramount importance throughout. The trials may involve additional or new drugs being added to existing treatments, new treatment pathways and a better understanding of the genetics behind cancer. Quality of life also a major concern and many trials require patients to complete questionnaires about their health and quality of life both on and off treatment. People who take part in trials are volunteers, usually patients, but sometimes healthy volunteers.

The target to recruit 10% of cancer patients into trials was easily met, with 19.3% actually achieved. Recruitment to Genetic studies was also very successful, including Genetic studies in Hodgkin's Lymphoma and Ovarian Cancer, and a new Melanoma study. Randomised Control Trials are regarded as an area for development, with a target of an increase in recruitment of 7.5% for 2010-2011. Trials are currently running for Breast, Colorectal, Upper Gastro-Intestinal, Gynaecology, Urology, Skin, Lung and Haematology.

The key achievements for the year were described as:

- A balanced portfolio offering wider patient choice
- Nurse Principal Investigator (PI) and nurse consent for all genetic studies
- Nurse led follow up and assessment clinics for Gastro-Intestinal patients, including patient assessment and non-medical prescribing
- A rolling programme of teaching sessions in Good Clinical Practice based on ICH GCP
- Adoption of commercial studies into the local portfolio
- Achievement of genetic patient recruitment target and overall patient recruitment target
- A stable and growing team with a dedicated nurse for each tumour site
- Multi-Disciplinary Team review of all Tumour Site Specific Group documentation

As well as recruitment targets, the Unit has three further objectives for 2010-2011 to help to monitor and improve performance.

- Achieve 95% or above compliance for Case Reporting Form returns, for all Randomised Control Trials
- Achieve 95% or above return of data queries within two weeks
- Conduct an evaluation of the Clinical Trials service within the next six months to identify patient satisfaction

Other aims for the coming year are:

- To provide an equitable service for all cancer patients

- To maintain quality through robust team working
- To extend nurse consent to simple treatment trials
- To increase nurse-led research with nurse PI to ALL newly adopted non-treatment studies
- Develop teaching sessions for a trust wide audience
- Increase patient access through development of nurse-led clinics for other specific tumour site areas
- To work with the AO Clinic Nurse Specialist team to support nurse-led research within each tumour site

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SOME OF THE REASONS WHY MEN NEVER NEED TO BE DEPRESSED

(and they also say a lot about women!)

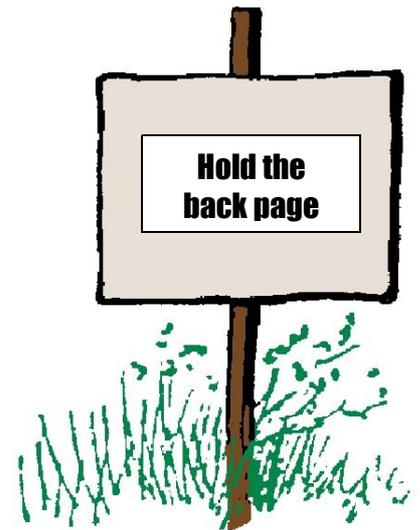
- ❖ Your last name stays put.
- ❖ The garage is all yours
- ❖ Wedding plans take care of themselves
- ❖ Chocolate is just another snack
- ❖ You don't have to stop and think of which way to turn a nut on a bolt
- ❖ Same work, more pay
- ❖ You know stuff about tanks and car engines
- ❖ You can open all your own jars
- ❖ You get extra credit for the slightest act of thoughtfulness
- ❖ If someone forgets to invite you, he or she can still be your friend
- ❖ Your underwear is cheaper
- ❖ Three pairs of shoes are more than enough.
- ❖ You almost never have strap problems in public
- ❖ You are unable to see wrinkles in your clothes
- ❖ You can play with toys all your life
- ❖ You can wear shorts no matter how your legs look
- ❖ You can "do" your nails with a pocket knife
- ❖ You have freedom of choice concerning growing a moustache
- ❖ You can complete your Christmas shopping for 25 relatives on December 24 in 25 minutes

New Development in the Pharmacy

Many patients have had to wait for a long time to obtain prescriptions in the Pharmacy, particularly TTAs (we think this stands for To Take Home after an inpatient stay on a ward).

To help reduce the time taken to pick the most frequently needed drugs, a robot has been obtained. Tests have shown that the robotic system can pick items some 70% faster than a Pharmacy assistant. When it goes live this month (June), further time savings are expected to be made.

No need to worry, though. You can rest assured that there will still be human checking of the prescription drugs collected by the robot before they are given to patients.



Parking

We, and others at Cancer Services User Group meetings, have been asking for clarification about parking rules and questioning whether additional spaces can be provided for both staff and patients. While we appreciate that public transport is more environmentally friendly, it is not always suitably timed or possible for those with a health problem. At busy times of day, it can be really difficult to find a space, and this affects part-time staff, visitors and patients.

It has been suggested that appointment letters could raise awareness of the issue. The trust acknowledges that car parking can be difficult at certain times and is actively consulting with a wide range of groups of users to find an equitable long-term solution. Data is being collected on the volume of parking at different times. Options are being discussed with Swindon Borough Council.

We also think that more needs to be done to encourage those who are well enough to use public transport whenever possible.

