

HUG MAGAZINE



December 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



Best wishes to all for a Happy Christmas and a healthy New Year

Email: hugswindon@btinternet.com

Website: www.hugswindon.co.uk

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.

13 January 2011 – Seminar Room 2
17 February 2011 – Seminar Room 6
10 March 2011 – Seminar Room 5

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. We are also starting a craft group in the New Year. Contact us for the next location, date and time, if you would prefer meet us in either of these ways. We are a small friendly group, who would be delighted to welcome you.

INTERESTING HEALTH-RELATED NEWS

Home test for skin cancer

A simple home test which allows suspect moles to be checked out is being tested by scientists. Experts from the Universities of Dublin and Moscow are using a computer program created by the company Moletest, which compares submitted pictures to more than 3,000 photographs of cancerous and non-cancerous moles stored on the system.

The test cannot be regarded as a substitute for a proper medical consultation but it enables a first check for those who are reluctant to consult their doctor. A red or amber result would indicate that a doctor's advice should be sought immediately. The test is already available from Moletest, at www.moletestuk.com.

Daily Mail, 23 September 2010

The use of aspirin to avoid some cancers – Maybe not yet!

Aspirin's ability to prevent cancer, especially cancers of the digestive system (oesophagus, stomach and bowel cancers) is well known. However, there are several important considerations which influence whether long-term low-dose aspirin use is beneficial overall.

Aspirin has several serious side effects. Most importantly, aspirin can increase the chances of developing stomach ulcers – which can cause bleeding. In people over 75, this can be fatal. Drugs called “proton pump inhibitors” can increase the likelihood of bleeding from stomach ulcers caused by aspirin by up to fifty per cent. In very rare cases, aspirin can also increase the chances of bleeding in the brain. About one in a hundred people taking aspirin have an allergic reaction. And about one in ten find it can make their asthma worse.

A reasonable estimate, based on the available research, is that about a quarter (25 per cent) of people will benefit. This ‘aspirin resistance’ seems to be widespread and large genetic studies would be needed to discover who will benefit. While the recent scientific paper has looked at 75mg of aspirin we don't know that 150 or even 300mg isn't better. We don't know how long a person has to take aspirin to get a protective effect. The current paper indicates an unusually rapid response for this: five years. This is unique and in many ways doesn't fit with how we understand cancer develops. In particular, in order to stop cancer developing we believe aspirin must be taken at a very early stage in cancer's development, before it becomes ‘full-blown’ cancer. This prevents the small groups of abnormal cells obtaining more genetic changes that will eventually become cancer. We believe this takes about 10 to 15 years.

Excerpt from Cancer Research Blog: Professor Janusz Jankowski on 7 December 2010

Genetic link to Hodgkin's Lymphoma

An international team of scientists led by the Institute of Cancer Research has found three new regions of DNA linked to the development of Hodgkin's lymphoma, one of the most common cancers in young adults. One quarter to half of all cases of Hodgkin's lymphoma are thought to be triggered by infection with Epstein-Barr virus but the disease can also develop in patients who have never been exposed to the virus. Scientists suspected inherited genes were involved in these cases, as having a family history of disease increases risk, but until now they have not been able to identify any specific genetic risk factors. In a paper published in Nature Genetics today, Professor Richard Houlston from the ICR and colleagues reveal three new variations in the letters of the DNA code that give an increased risk of developing Hodgkin's lymphoma. Two of these genetic variants are more common in people not exposed to the virus.

Leukaemia and Lymphoma Research Press Release 01 November 2010

Penny Brohn Cancer Care Centre

The Penny Brohn Cancer Care (PBCC) centre in Bristol recently held an Open Day, which was attended by a HUG representative, to collect some information about current services.

PBCC is described on advertising handouts as the leading UK charity specialising in complementary, supportive care for people with cancer and their families. Until June of 2010, the full cost of services had to be met by patients. It was only then that services became free, although a donation towards the cost is encouraged. We thought that it would be useful to provide an update for patients who may not know about the change of status, as well as those who have not heard of PBCC previously

The "Bristol Approach" is a whole person approach to living well and a combination of support for the mind, body and spirit is offered, using a combination of complementary therapies, psychological support and self-help techniques. The aim is to work alongside medical treatment, to help patients to live as well as they possibly can with the impact of cancer diagnosis through:

- Information and advice on healthy eating and gentle exercise
- Helping with relaxation and stress reduction techniques
- Massage and other physical therapies
- Counselling, psychotherapy and group emotional support
- Advice on living with the diagnosis

Taster sessions, Day Courses and Residential Courses are offered. In addition an Open Programme made up of a range of relevant Day Courses can be arranged. Cancerpoint is a non-residential service offering a tailored range of complementary therapies, on a one to one basis or in group sessions. Complementary Therapies provided are:

- Nutritional advice, Counselling and Psychotherapy
- Relaxation, Meditation, Healing and Imagery
- Acupuncture, Shiatsu, Reflexology, Massage

These are supplemented by:

- Appointments with a Doctor and personalised homeopathic advice

There is a helpline on 0845 123 2310 from 9.30am-5.00pm on weekdays and a message can be left at other times, if you need someone to talk to or have an enquiry. Bookings can be made by telephoning 01275 370111 or making contact by e-mail to the appointment line at booking@pennybrohn.org.

The PBCC is not far from the M4 and M5, near Gordano Services and the Portishead exit from the M5. Travelling by train, it is approximately 6.5 miles by taxi from Bristol Temple Meads railway station. There is an hourly bus service from Bristol City Centre. For those using the Cancerpoint appointment service a volunteer driver scheme is offered on request.

We hope to arrange a group visit in the New Year.

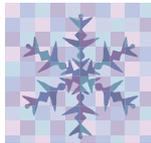


HUG ★
fridge magnet
★ fun

A Christmas shopper's complaint is one of long-standing



Throw open your doors and windows in the middle of winter to appreciate how lucky you are!
German saying




Happiness is not having what you want, but wanting what you have.
Rabbi H Schachtel

At Christmas, all roads lead home.

**Christmas is not a date.
It is a state of mind.**

The best Yuletide decoration is being wreathed in smiles.



Kilimanjaro climb benefits Day Therapy Centre and Dove Unit

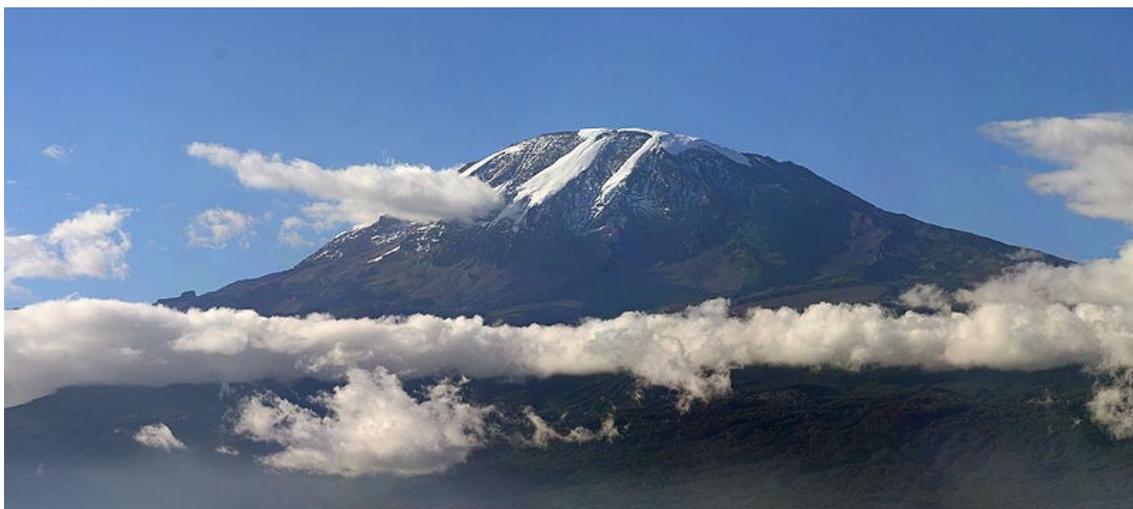
H.A., husband of a patient who has been treated in both of the above areas at the GWH, has recently raised the most amazing sum of more than £12,500 by climbing Mount Kilimanjaro in the north east of Tanzania. Friends, family and business colleagues helped to boost the total from sponsorship. The climb was organised by the Countryside Alliance, which has benefited to the tune of around £6,500, with another £6,000 coming to DTC and Dove, as a way of saying thank you for everything that has been done for his wife.

Mount Kilimanjaro is the highest mountain in Africa at 5,895m or 19,341 feet above sea level and the highest free-standing mountain in the world. H. was very fit from earning a living from a really physical job and running in marathons, before he even thought about taking on this climb. Even so, he spent a whole year preparing, with gym sessions and special altitude fitness training. Despite all this, he found it to be the most physically and mentally challenging experience of his life.

The trip took 10 days, of which 8 days were spent climbing and descending the mountain, walking 6-8 hours a day. There were 38 starters and just one failed to make it all the way. The youngest in the group was 17 and surprisingly the eldest was in his mid-60s. They slept in tents, in groups of five. The last vertical mile actually required a walk of 9 miles! The view of the glaciers at the top was terrific. Unfortunately his camera batteries did not survive to the end of the climb.

This particular mountain was particularly appropriate for him, since he had spent some of his childhood in Africa. He explained that 95% of the country's water comes from the mountain. Tourism is helping to improve the economy, but people are still very poor, to an extent we could not even imagine. He feels that it is good to step outside the box once in a while.

The funds donated to Dove and Day Therapy will be used to train more staff to administer chemotherapy. What a magnificent effort!



Kibo Summit of Mount Kilimanjaro – picture from Wikimedia

Christmas Crackers

Nearing Christmas, one turkey said to the other, "It's best to say goodbye now - I don't think I'll be around after necks-tweak."

What did one Angel say to the other ?

Halo there !

After Christmas, it's mother's job to separate the men from the toys.

How do sheep greet each other at Christmas?

A merry Christmas to ewe.....of course!

'Father Christmas has two reindeer. He calls one Edward and the other one Edward! I bet you can't tell me why he does that!'

'Oh, yes I can.'

'Because two 'Eds are better than one, of course!'

How does Rudolph know when Christmas is coming?

He looks at his calen-"deer"!

What's beautiful, grey and wears glass slippers?

Cinderellephant

What do snowmen eat for lunch ?

Icebergers !

What bird can write under the Arctic Ocean?

A ball-point pen-guin.

What do you call a letter sent up the chimney on Christmas Eve?

Black mail !

What does Father Christmas suffer from if he gets stuck in a chimney?

Santa Claustrophobia !

What do snowmen eat for breakfast?

Snowflakes.

What do you get when you cross a snowman with a vampire?

Frostbite.



H.U.G. News – read all about it

Get-togethers were held at the Great Western Hospital on 14th October and 18th November 2010 in the Academy at the GWH, with a coffee morning at the Blunsdon Arms at the end of October and the beginning of December.

1. Recent Get-Togethers

In October we discussed how we could move forward with our plans to offer complementary therapies to patients who are in need. The final version of the Thames Valley Cancer Network guidelines based on national guidance had not been received by then, however, which made it difficult to come to any decisions.

In November, we finalised the arrangements for the Christmas Fair at Christ Church in Old Town and discussed our Christmas activities. It was eventually decided that we would not have our “Christmas” lunch until January, when more of us are likely to be available.

It was decided to have nibbles and soft drinks at our December get-together, as usual and to advertise this as a “Drop-In”, although patients and their families are always welcome to come along in any month.

2. Spending

The next batch of travel bands was delivered, to be given away to patients receiving chemotherapy.

We also hope to obtain electric heat pads for use in Dove Ward soon. We were unable to source the one for which a specification was provided, but an alternative supplier has been suggested. We are awaiting confirmation that it is fine to go ahead.

Planning for our art and craft days has progressed and we hope to finalise dates and locations to start in mid-January.

3. Fund-raising

The Christ Church Christmas Market proved very successful, with a total of £138.40 profit on our stall. A big thank you to our helpers on the day and to the members who made items for sale.

4. Activities

We intend to visit the Penny Brohn centre early in the New Year as well as hold the late Christmas lunch at the end of January.

Local patient makes the national news

It was brought to our attention by Clinical Nurse Specialist J.H. that there had been an article in the Daily Express about a Great Western Hospital patient meeting his stem cell transplant donor. You can read the article, published on Tuesday 12th October, by using the web address below.

<http://www.express.co.uk/features/view/204815/Leukaemia-I-met-the-stranger-whose-bone-marrow-saved-my-life>

It should be noted that there were some inaccuracies to the report. D.P. has tried to correct them in the following brief resume.

D. had 5 rounds of intensive Chemotherapy at the GWH under the AML 15 Trial regime following diagnosis with leukaemia in February 2005. D. was the Dove Unit's first customer. After the treatment and a short holiday with his family, David returned to full time work. He was in remission for just over a year, relapsing in May 2006. It was immediately decided that the best chance of survival was a Bone Marrow Transplant (BMT). Initially D. did not go in to remission. However, during this time a donor was identified via the Anthony Nolan Trust. (www.anthonynolan.org). After a further 3 rounds of chemotherapy he was well enough to have the BMT, and was transferred to the Royal Free Hospital, Hampstead to undergo further Chemotherapy, Total Body Radiation and then the Bone Marrow Transplant. The transplant took place on September 15th 2006; D's 16th Wedding anniversary. He was allowed home 4 weeks later and was able to restart work in April 2007.

The Anthony Nolan Trust only allows anonymous contact with donors for the first two years after transplant. During this time cards and letters were exchanged unsigned. In August 2010 D. and his donor, of the same name, made contact, initially to promote the need for more donors on the Anthony Nolan Register. This gave D. the opportunity to meet his donor and to thank him for his life-giving gift. Both D's met along with their respective partners, the press, and representation from the Anthony Nolan Trust in a pub in West London, in September of this year. Radio broadcasts, as well as articles in various publications followed, in the hope of getting more donors onto the Anthony Nolan Register.

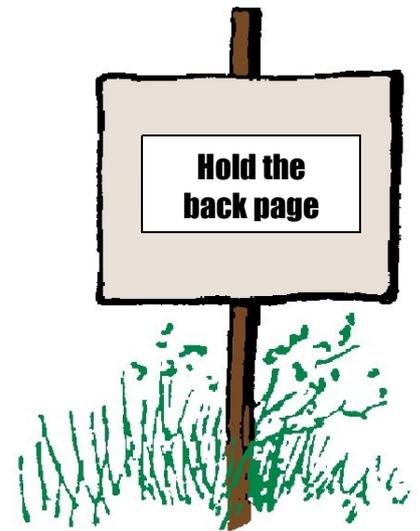
Although D. did not come to the HUG get-togethers, his wife J. did. It is marvellous to hear how well D. has progressed, after his life-saving treatment.

If you have friends or relatives who are interested in becoming a donor please do look at the Anthony Nolan web site to check whether you are eligible. It's easy to register and you could save someone's life.

Macmillan Support line

For free cancer support at home over the phone, the Macmillan Support Line – 0808 808 00 00 – is a vital service and the organisation is concerned that not enough people know about it.

With dedicated nurses on hand to answer medical questions, and welfare rights advisers ready to identify benefits and grants, Cancer Research reports that one phone call can provide a whole host of support and urges us to pass the message on. Job done!



Look Good, Feel Better

The application put together by Clinical Nurse Specialist C.C. for the Look Good, Feel Better charity to come to the Great Western has not been successful. Carole was informed that the current emphasis is on providing centres in parts of the country which are not covered at all. We do have the possibility of booking sessions at Maggie's Centre in Oxford, not ideal if you are really poorly.

Cancer Services User Involvement Group News

In January 2011 a Workshop will be held in Oxford by the Thames Valley Cancer Network, to which the local Cancer Services group is affiliated. It is aimed at discussions about an End of Treatment Care Plan. This is because it has been identified that some patients could benefit from more support at this stage of their cancer journey. If you have any ideas about what you would like to be in place after treatment ends, based on your own or a family member's experiences, do let us know. We shall make sure that they are passed on and can be taken into account during discussions.

Positive Experiences

It is encouraging to be able to report in this Christmas issue two uplifting stories, one about a patient's recovery and the other about the fund-raising by a patient's husband. We would love to include more of these articles next year. Do let us know if you would like to tell your story.