

HUG MAGAZINE



December 2009

(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



Relaxation Day – would you believe that some of us didn't even dress for lunch?

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), Room Number as shown on the second Thursday of the month.

Turn up at any time between
10:00 am and 12:30 pm unless otherwise stated:

January 2010 – Boardroom 1-2
February 2010 – Seminar Room 4
March 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 HUG 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, room redecoration materials, purchased Christmas gifts, magnifying glasses, slippers and gel bags for patients and donated to Dove Ward Charitable Funds. Ideas are welcomed 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 make you very welcome.

INTERESTING HEALTH-RELATED NEWS

Check out Cancer Symptoms

A recent survey by Cancer Research UK showed that one in seven of us can't identify a single symptom of cancer. They have now set up a new website,

www.spotcancerearly.com

The website features four films showing us how to monitor our bodies for signs of breast, bowel, lung or mouth cancer in the early stages. As we know, the earlier a problem is detected, the greater the chances of treatment being effective.

NICE decision on drugs

As you may have read, NICE has decided not to recommend sorafenib, also known as Nexavar, to the NHS for the treatment of advanced liver cancer. There will be no further consultation, but the decision is open to appeal for just fifteen days based on any new factors, until the final guidance is formally published in December. Later new evidence could also result in a re-examination of the situation. The drug is expensive, but is known to be effective and can extend life by an average of 4 months.

Around the same time, it has been reported that bowel cancer sufferers are to be denied a life-prolonging drug on the NHS which is available to patients in many other countries. Trials show that Avastin can extend life by almost two years, but NICE does not regard it as cost effective. It is already approved for breast cancer.

Various press reports – mid November 2009

New skin cancer cure

A disc the size of a fingernail that destroys the most dangerous form of skin cancer has been developed by scientists. The disc, which measures 8.5mm across, uses proteins usually found on skin tumours as 'bait' to trigger a powerful immune response. Fitted under the skin, the tiny device wiped out melanoma in up to half of the cases it was tested on. It paves the way for a treatment with improved prognosis and fewer side-effects than traditional anti-cancer drugs.

Read more: <http://www.dailymail.co.uk/health/article-1231028/Tiny-hidden-disc-wipe-skin-cancer.html#ixzz0Y9e9cvQd>

Breast cancer gene found

Scientists, led by Dr Paul Edwards of the pathology department at the University of Cambridge, have discovered a faulty gene, known as NRGI, which is involved in half of all cases of breast cancer and is also implicated in 50% of bowel and prostate cancers, as well as some ovarian and bladder cancers. It is hoped that this find will advance the understanding of the genetics of cancer and could open up a host of new strategies to improve diagnosis and treatment. Research was funded by the Breast Cancer Campaign and Cancer Research UK.

Breast Cancer Campaign, 5th October 2009

Becoming a registered charity

HUG is considering becoming a registered charity. Although the group's income is currently much less than £10,000 per year and registration is therefore not a requirement, there would be advantages for the group. Fund-raising at locations like shopping centres is only open to registered charities, grants become available and there is the possibility of tax relief on donations given. In addition public support is more likely, because the organisation is regarded as more legitimate.

For HUG to proceed, we need at 4 charity trustees, who might otherwise be regarded as committee members. These charity trustees are the people who serve on the governing body of a charity. They are responsible for the general control and management of the administration of a charity. As for the majority of charities, the trustees would serve as volunteers, and receive no payment for their work. The responsibilities of a trustee should be rewarding and enjoyable, and an opportunity to serve the community while potentially learning new skills.

Responsibilities of a trustee

Charity trustees come from all walks of life, and are united by their wish to create positive change in society. Most people are eligible to serve as trustees, with a few exceptions, based for example on a minimum age of at least 18, having been disqualified as a company director or having a criminal record.

Key responsibilities as listed on the Charity Commission website are as follows:

- (1) Trustees have and must accept ultimate responsibility for directing the affairs of a charity, and ensuring that it is solvent, well-run, and delivering the charitable outcomes for the benefit of the public for which it has been set up.
- (2) Ensure that the charity complies with charity law, and with the requirements of the Charity Commission as regulator; in particular ensure that the charity prepares reports on what it has achieved and Annual Returns and accounts as required by law.
- (3) Ensure that the charity does not breach any of the requirements or rules set out in its governing document (a Constitution) and that it remains true to the charitable purpose and objects set out there.
- (4) Comply with the requirements of other legislation and other regulators (if any) which govern the activities of the charity.
- (5) Act with integrity, and avoid any personal conflicts of interest or misuse of charity funds or assets.
- (6) Ensure that the charity is and will remain solvent.
- (7) Use charitable funds and assets reasonably, and only in furtherance of the

charity's objects.

- (8) Avoid undertaking activities that might place the charity's endowment, funds, assets or reputation at undue risk.
- (9) Take special care when investing the funds of the charity, or borrowing funds for the charity to use.
- (10) Use reasonable care and skill in their work as trustees, using their personal skills and experience as needed to ensure that the charity is well-run and efficient.
- (11) Consider getting external professional advice on all matters where there may be material risk to the charity, or where the trustees may be in breach of their duties.

If things go wrong

The Charity Commission offers information and advice to charities on both legal requirements and best practice to help them operate as effectively as possible and to prevent problems arising. In the few cases where serious problems have occurred they have wide powers to look into them and put things right. Trustees may also be personally liable for any debts or losses that the charity faces as a result. This will depend on the circumstances and the type of governing document for the charity. However, personal liability of this kind is rare, and trustees who have followed the requirements listed will generally be protected.

For HUG the responsibilities could include:

- Provide support to patients and their families (although trustees would not necessarily have to be involved in this)
- Assist with the production of the bi-monthly magazine
- Keep the HUG accounts up to date
- Become involved in fund-raising ventures
- Represent HUG at meeting, such as the Cancer Services User Group
- Follow up on patient comments and obtain information for them
- Discuss and action ways to use funds to help patients.


Ideally we hope to be able to enlist sufficient trustees from among existing HUG members or their families. If anyone else would be interested in becoming a trustee, please contact us.



One thing I can give and still keep...is my word.

HUG ★
 fridge magnet
 ★ fun

Growing old is inevitable; growing up is optional.





Think big thoughts, but relish small pleasures

A sharp tongue can cut my own throat.



It's hard to be nostalgic when you can't remember anything.



If it's cracker time, it must be Christmas!

by Boris

Why don't reindeer like penguins? Because they find it hard to get the silver paper off.

The secret of perpetual youth for a lady is make-up:- make up any age and stick to it!

How do you know that Father Christmas is a keen gardener? Because he goes Hoe, Hoe, Hoe.

Rudolph and Blitzer were chatting and Rudolph said "Why do we always have carrots while the old man has sherry or port? Let's get there first next time and have a drink." So at the next stop Rudolph and Blitzer dashed off down the chimney while Santa was unpacking and had sherry and mince pies. The same thing happened at the next four stops and the reindeer were quite merry. On the way home a police car drew up alongside the sleigh. "What are you doing up here?" Santa asked. "We are a new unit called the Flying Squad," said the sergeant, "and we hear that you have been drinking and driving, so I must breathalyse you." So Santa blew into a green balloon, and was of course quite clear. "All right," said the policeman, "on your way". Santa sped off as quickly as he could, and when they were clear of the police car, the Elf, who was sitting next to Santa, turned to him and said "It was a good job that they didn't test the reindeer, or we would all be out of a job for the next two years!"

A young lad was walking down the High Street with his Gran when they saw a large store advertising Santa in his Grotto. The lad did not need much persuading to go in (Gran was paying), so he met Santa in his cave. "Ho, Ho, Ho", said Santa, "and what would you like for Christmas, young man?"

"Well," said the lad, "I want a DVD Recorder, a new mobile phone, an IPOD, a Wii and a trip to Disneyland."

"OK," said Santa, "I'll see what I can do."

The lad and his Gran went on down the High Street and came upon another store with Santa and his Grotto and again the lad went in.

"Ho, Ho, Ho," said Santa, "and what would you like for Christmas, young man?"

"Blimey", said the lad, "I only told you five minutes ago. You've got a worse memory than my Grandad."

And now it's time for Christmas dinner.

Little boy: Mum, can I have a dog for Christmas?

Mother: No, you'll have turkey like everyone else.

Who is never hungry at the Christmas Dinner? The turkey, as he is already stuffed.

What's the most common wine at Christmas dinner? Do I have to eat the Brussels sprouts?

H.U.G. News – read all about it

Get-togethers were held at the Great Western on 8th October and 12th November 2009 in the Academy at the GWH, with social events at the Blunsdon Arms at the end of October and November.

1. Recent Get-Togethers

Both GWH get-togethers were used to discuss health matters, fund-raising and social activities. Arrangements were made for Christmas Lunch at the Toby Inn, which has been a popular venue in the previous two years, at a very reasonable price. This time we are going to include a Secret Santa present for everyone.

Some of us will be dishing out Christmas food goodies in Day Therapy and Osprey on 8th and 10th December, as a way of advertising the group, just too late to report in this edition.

2. Events

The Zurich Challenge Relaxation and Treatment day was absolutely wonderful. We went to the Four Pillars Cotswold Water Park, which is a lovely venue. Twelve of us were able to choose any two from a selection of treatments on offer in advance, and on the day we had free use of the gym, swimming pool, sauna, steam and relaxation rooms. Lunch was provided, and soft drinks and snacks were available throughout the day in the members' lounge. The Zurich team who made it all happen had left a final treat for us, a present of wine and chocolates to take home. Some of us are now scheming to find a way to have another day there, perhaps as a Christmas present.

The scarf tying demonstration by a member at an October ABC Support Group meeting went well, and we have now drafted a leaflet on how to make turbans, which some patients may like for hair loss. The details should be available soon on the Cancer Information Point.

3. Fund-Raising

Our stall at the Christ Church Christmas Market was crammed with an array of Mexican pottery and jewellery, hand-made Christmas cards and tree decorations. Including some additional sales after the event, we raised a total of £76.50 for funds.

We have also recently sold a few more of our HUG mugs, raising a further £48.

4. Spending

A sample thermometer has now been obtained for approval. We hope to be able to provide these as personalised items to give away to patients at risk of neutropenia, now that stocks of similar items donated by a company have been exhausted. We may also provide stocks of sea bands which may help to alleviate nausea during and after chemotherapy. It is going to be rather more challenging to personalise these, to promote the HUG group, and it looks as if we may have to sew labels on.

We have also been looking at the possibility of providing complimentary therapies for patients in Day Therapy and Dove. As might be expected, there are NHS guidelines on this, which are examined at present.

Simple Sweets for Christmas – the children could make them!

Chocolate Truffles

125g plain chocolate
75g plain cake
75g icing sugar
75g ground almonds
30mls brandy
60mls double cream
Cocoa or icing sugar for dusting

Break the chocolate into pieces and melt in a bowl over a pan of simmering water, or warm slowly to melt in the microwave.

Combine the crumbs, icing sugar, almonds and brandy in a bowl. Gradually pour on the melted chocolate and mix well. Roll teaspoonfuls of the mixture into balls and roll in either sifted icing sugar or cocoa. Chill for 2 hours until set.

Keep for **up to 2 weeks** in the fridge between greaseproof paper layers in an airtight box.

Macaroon Snowballs

1 small boiled potato (unsalted, cooled and washed)
150-200g icing sugar
Melted chocolate
Desiccated coconut

Gradually add sifted icing sugar to the potato until the mixture is still. Roll into balls and chill. Coat in melted chocolate and roll in the coconut.

Tipsy Marzipan

100g marzipan
25g red and green cherries, chopped
25g mixed nuts, chopped
1 tablespoon chopped dried apricots
1 tablespoon chopped dates
Grated rind of half an orange
1 dessertspoon liqueur to taste
Icing sugar for dusting

Crumble marzipan in bowl. Work in all other ingredients. Use enough sugar to stop the mixture sticking to the hands. Shape mixture into a long thin log. Cool overnight in cling film. Dust with icing sugar and slice into sweet sized rounds.

Enhanced Recovery from Colorectal Surgery

An interesting presentation was given on the above at the November meeting of the Cancer Services User Group.

The Enhanced Recovery Programme (ERP) was pioneered by Professor Henrik Kelhet in Copenhagen. It has allowed changes to be made to the pathway for patients before, during and after operations.

The time patients need to be hospitalised has been reduced significantly. Changes before surgery have included a reduction in the fasting time and other preparations. Laparoscopic techniques are used for operations, and a reduced recovery time is achieved, assisted by changes to the method of pain relief and an earlier resumption of normal diet. The total length of stay in hospital has been reduced from 7-14 days to 3-5 days. A home visit by a stoma nurse is used to follow up on patient progress.

The programme to date has managed around 70 patients at the GWH and feedback has been positive. Patients are able to attain normal activities within a shorter time frame.

Survivorship programme

The GWH has been selected as a pilot site for a Survivorship programme, following an application to NHS Improvements and a presentation to the national team by the Lead Cancer Nurse. The pilot scheme will be operated for lung cancer and myeloma patients. She has promised to provide updates on this exciting project.

Twenty Four Hour Triage Line

The Lead Chemotherapy Nurse has reported that a 24 hour triage line is now being piloted for patients receiving chemotherapy, when they have temperature of 37.5° or higher. A coded "traffic light" system is being used to ensure that patients are treated appropriately and quickly.

