

# HUG MAGAZINE



**April 2010**

(issued on the day of the get-together in alternate months)

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



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## 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:

<b>13 May 2010</b>	<b>–</b>	<b>Seminar Room 4</b>
<b>10 June 2010</b>	<b>–</b>	<b>Seminar Room 4</b>
<b>15 July 2010</b>	<b>–</b>	<b>Seminar Room 5</b>

### 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

## **Is breast cancer screening worthwhile?**

Following controversial debates in recent months over the risks and harms of breast screening, researchers – part funded by Cancer Research UK – set out to uncover how effective the programme is at saving lives. It has now been reported that for every woman over-diagnosed by breast screening, two deaths will be prevented.

31 March 2010 Cancer Research UK Press Release

## **Breakthrough in understanding the spread of cancer**

British scientists have announced a major breakthrough in understanding the spread of cancer, which could lead to dramatic improvements in survival rates. Researchers from the Beatson Institute in Glasgow have discovered that a protein which suppresses cancer in healthy people "flips" in some sufferers, allowing cancerous cells to break away and survive elsewhere in the body. The protein, P53, is mutated or flipped in 50 per cent of all tumours. The breakthrough could eventually stop the disease from spreading in thousands of patients a year. While recent advances in treatments for single-site tumours have saved thousands of lives, nine out of 10 cancer deaths are the result of secondary tumours or metastases. Experts agree that the biggest challenge in cancer treatment is to stop it from spreading to other parts of the body. This is very difficult to replicate in a test tube, which means that advances in this area have been slow.

Reported in peer reviewed Cell 20 Dec 2009

## **Seaweed Extract and Non-Hodgkin's Lymphoma Treatment**

Mohammad Irhimeh, Ph.D., assistant professor of haematology and stem cells from the Hashemite University in Jordan, and colleagues at the University of California, Berkeley, and Royal Hobart Hospital in Australia has been treating lymphoma with a commercially available seaweed extract. Seaweeds containing fucoidan, a sulphated polysaccharide similar to heparin in chemical structure, have been reported to have anti-tumour activity in mice and some cell lines.

They found that the extract had an inhibitory effect on the growth of lymphoma cell lines, while leaving the control healthy cells intact. Irhimeh said they would continue to study the mechanism of action for these biological effects and had a goal of conducting phase II or III clinical trials.

*ScienceDaily: 12 March 2010*

## **Medicinal properties of Rhubarb crumble?**

Scientists, as well as Delia Smith, are advocating baked rhubarb. It is high in polyphenols which can help prevent the growth of cancer cells. It is hoped that rhubarb extract could help to develop new drug treatments for cancers such as leukaemia. The research has been undertaken by scientists at Hallam University, Sheffield, who found that baking the rhubarb for 20 minutes increased the level of polyphenols.

Daily Mail 15 Feb 2010

## *Seasonal Food suggestions*

### **Spring greens:**

High in iron content, but may be a bit too strong a flavour for some of us, so why not try the following. After steaming or lightly boiling, dress with some vinaigrette or some toasted nut oil and pine kernels. Alternatively use the thick leaves for wrapping parcels of cooked rice and vegetables or mince.

### **Rhubarb:**

Back in fashion, thanks to Delia and reports of the health benefits! Here is an idea for a sauce which goes very well with oily fish – and you could also try baking the rhubarb instead of simmering.

1 star anise,  
1 small onion, chopped,  
2 large sticks of rhubarb,  
2 tablespoons water,  
2 tablespoons fromage frais,  
1-2 teaspoons caster sugar,  
1 teaspoon chopped tarragon

Melt the oil and add onions and star anise to soften. Add the rhubarb and cook for 5 minutes. Add the water and allow to cook for a few minutes. Remove the star anise. Stir in the fromage frais, sugar, tarragon and seasonings to taste. Do not reboil.

### **Spring vegetable mix:**

750g /1 lb 10oz of green vegetables  
2oz butter  
10g /0.25 oz fresh mint leaves  
15g/0.5 oz chopped chives

Cook vegetables until tender. Drain and keep to one side.

Add butter to the hot saucepan and melt then throw in the herbs and bubble for a minute to cook them slightly.

Return the vegetables to the pan to warm through, coating with the herbs and butter mixture. Season and serve.

## Spring makes you feel more cheerful, but if not .....

### **Clock Change Sleepiness**

Twice a year, we change the clocks for daylight-savings time. And twice a year, a normally punctual assistant arrives late to work the Monday after we do so. The boss finally had to find out why.

"Do you have a problem remembering to spring forward or fall back?" he asked. "Oh, no," she said, pouring herself a cup of coffee. "What gets to me is staying up until 2 a.m. to change my clock."

### **If April showers bring May flowers, what do May flowers bring?**

*Pilgrims.*

### **When do monkeys fall from the sky?**

*During Ape-ril showers!*

### **Caught out!**

Four senior school boys afflicted with spring fever skipped morning classes. After lunch they reported to the teacher that they had had a flat tyre.

Much to their relief she smiled and said, "Well, you missed a test today so take seats apart from one another and take out a piece of paper."

Still smiling, she waited for them to sit down. Then she said: "First Question: Which tyre was flat?"

### **A Week in the life of a Gardener's Spouse**

She dug the plot on Monday, the soil was rich and fine  
But she forgot to put the dinner on, so out we went to dine.

She planted roses Tuesday, she says they are a must.  
They really were quite lovely, but she forgot to dust.

On Wednesday it was daisies they opened with the sun,  
All pinks and whites and yellows, but the laundry wasn't done.

The poppies came on Thursday all bright and cherry red,  
I guess she really was engrossed, she never made the bed.

It was violets here on Friday in colours she adores;  
It never bothered her at all, the dirt upon our floors.

On Saturday I hired a maid, I'd not admit defeat,  
She can garden all she wants now and the house will still be neat.

It's nearly lunchtime Sunday I cannot find the maid,  
Oh I don't believe it. She's out there with my wife and her own spade!

### **And for the gardeners**

Spring does not arrive until the ice is out of the compost heap.

**The best way to garden is to put on a wide-brimmed straw hat and some old clothes. And with a hoe in one hand and a cold drink in the other, tell somebody else where to dig.**

A weed is a plant that has mastered every survival skill except for learning how to grow in rows.

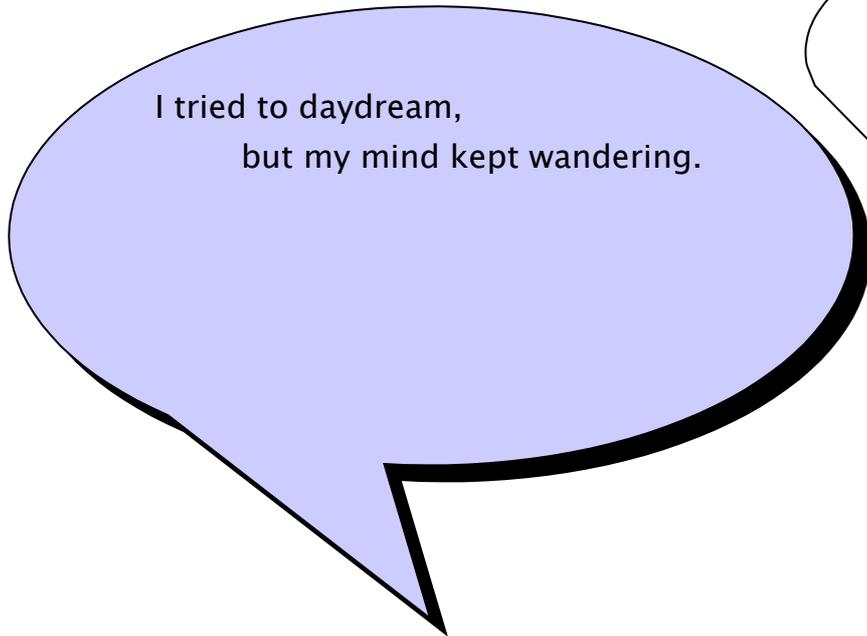
**Hard work doesn't harm anyone, but I don't want to take any chances.**

My wife said that if I buy any more plants he would leave me. I'm going to miss that woman.

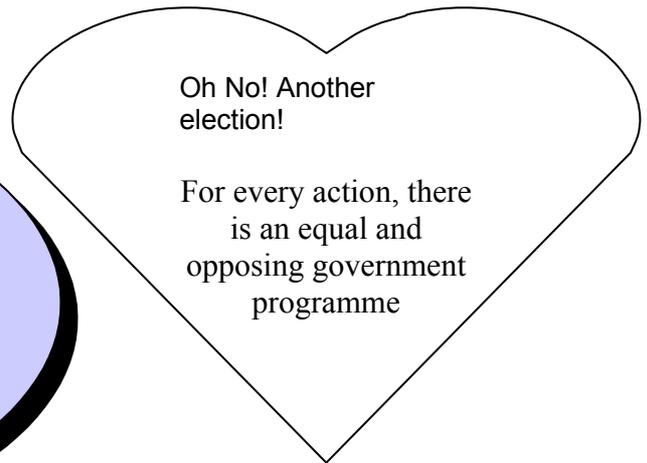


Women who live for the next miracle cream do not realise that beauty comes from a secret happiness and equilibrium within themselves.

Sophia Loren (It's all right for her!)

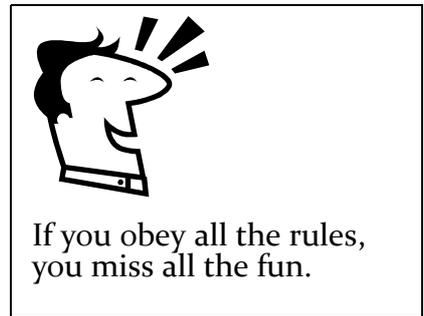


I tried to daydream,  
but my mind kept wandering.



Oh No! Another election!

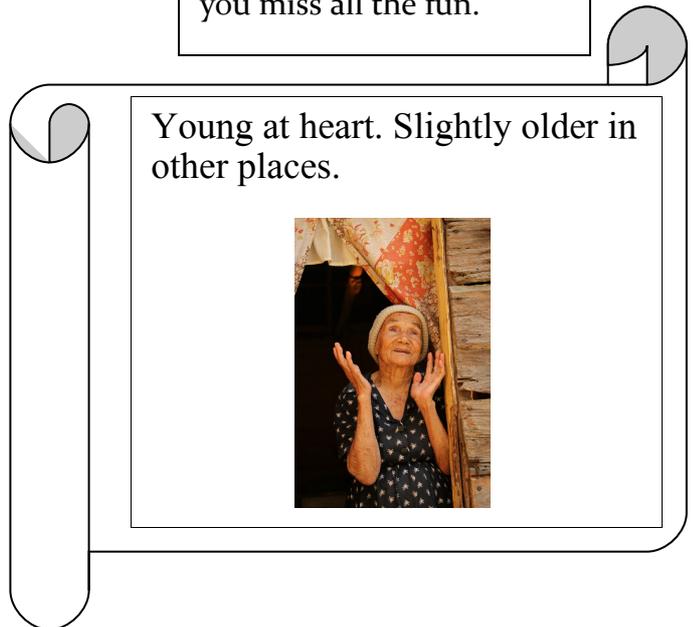
For every action, there is an equal and opposing government programme



If you obey all the rules,  
you miss all the fun.



You can't have everything.  
After all, where would you put it?



Young at heart. Slightly older in other places.



## Can you reduce the likelihood of a sore mouth during cancer treatment?

A sore mouth, or oral mucositis, is a common side effect of some chemotherapy and radiotherapy. Around 40% of chemotherapy patients and 75% of bone marrow transplant patients develop the condition. In extreme cases, the pain can be so severe that it is very hard to eat, drink and speak. Mucositis can provide a point of entry for a more serious infection, which can pass to the blood stream of patients whose immune system, is low.

### Signs of Mucositis

Signs and symptoms of mucositis include:

- Red, shiny, or swollen mouth and gums
- Blood in the mouth
- Sores in the mouth or on the gums or tongue
- Soreness or pain in the mouth or throat
- Difficulty swallowing or talking
- Feeling of dryness, mild burning, or pain when eating food
- Soft, whitish patches or pus in the mouth or on the tongue
- Increased mucus or thicker saliva in the mouth

Mucositis is more common in younger people than older people being treated for the same malignancy with the same regimen. This appears to be due to the more rapid rate of basal cell turnover noted in children.

Typically people don't start noticing symptoms until 5 to 8 days after starting treatment. The symptoms of oral mucositis can last between 7 to 14 days before healing begins. If you are warned by your Clinicians that you are likely to develop mucositis on your treatment regime, is there anything you can do to prepare for and reduce the likelihood of developing it?

### Preventive Steps

There are steps you can take before beginning radiation or chemotherapy treatment to help alleviate the side effects and symptoms of mucositis.

- Visit your dentist well before your treatment starts, if possible. If any work is needed (tooth extractions or refitting of dentures), it should be completed at least one month prior to starting therapy to make sure your mouth has completely healed and prevent damage to your existing teeth, gums or jaw bones.

- Adopt a good oral care regime to help prevent the development of infection through open mouth sores
  - Clean teeth thoroughly with a soft bristle toothbrush and mild toothpaste after eating 3 to 4 times each day. Avoid toothpastes with whitening agents and products that irritate the mouth and gums.
  - Use mouth wash. Salt water is one of the best and most cost effective mouth rinses available.
  - Gently floss your teeth once daily, unless your platelet count is low.
    - Avoid alcohol and irritating foods, such as those that are spicy, hot, acidic or coarse.
    - Avoid smoking and drinking alcohol.
    - Keep lips moist with moisturisers, but avoid oil based products such as Vaseline.
    - Increase your fluid intake, aiming for 3 litres a day.
    - Try to include foods high in protein in your diet.
    - Remove dentures whenever possible to expose gums to air and do not wear them at all if mouth sores are severe.
    - Suck on ice chips during and for your mouth for 30 minutes after each chemotherapy or radiation session. The scientific rationale for this approach is that cryotherapy leads to vasoconstriction and decreased blood flow to the oral cavity, which reduces the exposure of the buccal mucosa to chemotherapy. One of our members swears by this!
    - Check your temperature regularly and report immediately if it reaches a level which indicates infection.
    - Eat either cold or warm foods as hot foods may make symptoms worse.
    - Try cold milk products to help soothe the painful areas.
    - Eat cold sour cream before meals to coat your mouth and throat and ease discomfort.
    - If you think your mouth and throat sores have been made worse by an oral yeast infection, talk to your doctor about anti-yeast medications.

# H.U.G. News – read all about it

Get-togethers were held in the Academy at the GWH on 11<sup>th</sup> February and 11<sup>th</sup> March 2010, with social events at the Blunsdon Arms at the end of February and the beginning of April.

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## 1. Recent Get-Togethers

In February we worked in pairs to play a game called *Who Sees What?* This was a discussion game to learn more about the way in which patient records are changing. The kit was produced by The Democracy and Participation team at the New Economics Foundations and funded by the Wellcome Trust, as part of the Who Sees What project. Discussions were so lively that we didn't manage to reach the end of the game in the time suggested. Clearly this is a topic which members do worry about.

The topic for discussion at the March meeting was whether there is any value in positive thinking for cancer patients. Jenny Murray of BBC Woman's Hour had written a press article complaining about friends telling her to think positively when she was being treated for breast cancer. HUG members seemed to be agreed that positive thinking was helpful to them, although there was some disagreement over what it actually meant in practice. For example, some of us considered that getting our affairs in order was a positive thing to do, while others felt that this indicated negative vibes. The conclusion has to be that patients should do whatever they feel might help them and also deal with any worries that might hinder their recovery.

## 2. Events

We hope to hand out some edibles again soon in the Osprey waiting area and the Day Therapy Centre. These were popular with both staff and patients last time and allow us to make ourselves known to patients and their families

## 3. Fund-Raising/Donations

We have received a donation of £450 raised by the friends of a patient. The three patients who gave a talk to Oxford Brookes University students were offered expenses which they didn't want to accept. It was suggested by the tutor that perhaps they would like to donate to HUG instead, so thanks to all three, we have an additional £148.36 in the bank.

We have plenty of donated items to sell, but have been waiting for some warmer weather before venturing out to car boot sales.

## 4. Spending

An order of gel packs, which will reputedly not leak, has been purchased and provided to the Chemotherapy Clinical Nurse. These are heated in the microwave and used to warm up and raise veins so that a line can be inserted more easily. We are now agreeing on the supplier for sea bands, which are said to help to alleviate nausea during and after chemotherapy. These will be provided to Osprey patients when we have sewn labels on.

The possibility of the group paying for complimentary therapies for patients in Day Therapy and Dove will await agreement on the rules to be applied to such services by hospitals in the Thames Valley Cancer Network.

## **Lymphoma Association National Conference**

The Lymphoma Association national conference will be held at the University of Reading on Saturday 8<sup>th</sup> May. There will be presentations on

- High grade lymphomas in later life
- Welfare benefits
- The latest developments in lymphoma
- Look good....Feel better
- Targeted therapy of B-cell malignancies
- Ask the experts – open question session



If you are interesting in going you can register at

<http://www.lymphomas.org.uk/news/news.asp?newsid=106>

or alternatively book by ringing 01296 619400. There is no charge, although a £15 donation to cover lunch and other refreshments would be appreciated. Unfortunately our editor, Irene, will be unable to attend. If anyone would be prepared to report on the day for our next issue, that would be terrific. Contact Irene by telephone or the HUG email address.

The Association's latest newsletter, "Lymphoma matters" has interesting articles on Radiotherapy and "What Precautions should I take before I go abroad". This is also available to download from the website.

### **Medical Equipment**

**Did you know that the Hilditch Group regularly holds specialist auctions of medical equipment, including adjustable beds, mobility scooters etc, which could be used at home? They are based in Malmesbury, and an online search revealed patient hoists and electric beds, wheelchairs, bath lifts in their April sale. They can be contacted on 01666 822577.**

### **Mobility Aid Purchase**

According to a recent newspaper report complaints about sharp practice in the sale of mobility aids are on the increase. Make sure that you are buying from a member of the British Healthcare Trades Association, which is approved by the Office of Fair Trading.