

# HUG MAGAZINE



**March 2014**

(issued during the last month of each quarter)

For HAEMATOLOGY and ONCOLOGY patients, their families and friends being treated in Cancer Services areas or under review



**SOME OF US AFTER OUR SPECIAL POST-CHRISTMAS MEAL  
WHAT HAPPENED TO THE COFFEE???**

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### **HUG Get-togethers**

**We have suspended meetings at the hospital in favour of coffee mornings at other locations. We shall be meeting at the Blunsdon Arms pub, on Thamesdown Drive from 11am onwards on the second Monday of each month.**

**Further get-togethers and venues will be arranged on a month by month basis on dates to suit attendees.**

**Contact us for more details.**

**Known dates for 2nd quarter of 2014 are the 2<sup>nd</sup> Mondays of months**

**14<sup>th</sup> April 2014**

**12<sup>th</sup> May 2014      and**

**9<sup>th</sup> June 2014**

### **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 Coffee Mornings and Craft Sessions (as new stock for sale is required)**
- **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 a Patient Information DVD, Resuscitation, Radiotherapy for Swindon, home delivery of chemotherapy**
- **Fund-raising to provide practical help with purchases which have included thermometers, travel bands, mugs, slippers, gel bags and heat pads, when suggested by clinical staff, patients or carers.**
  - ✓ **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.**
- **Maintaining a website and making leaflets available to promote the group and advertise our activities**
- **Producing the HUG Magazine quarterly and leaving copies in Cancer Services areas, providing direct to members and posting on the website.**
- **We have a stall behind the atrium at the hospital, on a regular basis. Dates known for the remainder of 2014 are Thursday 22nd May, Monday 16th June, Tuesday 15th July, Tuesday 5th August, Thursday 18th September, between 9am and 4.30 pm.**

# INTERESTING HEALTH-RELATED NEWS

## **Aromatase Inhibitors to reduce risk of breast cancer in post menopausal women**

A recent clinical trial reported at the 2013 San Antonio Breast Cancer Symposium looked at whether giving anastrozole aromatase inhibitor to postmenopausal women at high risk of breast cancer could reduce the risk. The trial was supported by Cancer Research UK. An aromatase inhibitor can stop the body producing oestrogen, which can encourage breast cancer cells to grow.

The researchers found that taking anastrozole for 5 years reduced the number of breast cancers in post menopausal women who were at high risk of getting the disease. Almost 4,000 women, who had been through the menopause and were considered to be at high risk of getting breast cancer took either anastrozole or a placebo every day during the 5 year period.

It is intended to continue to monitor the women to see if the effect continues and to examine side effects. For more information it is possible to buy the Lancet report:

The Lancet, Early Online Publication, 12 December 2013 doi:10.1016/S0140-6736(13)62292-8

## **Lymphoma Association new information leaflets on rarer lymphomas**

The Lymphoma Association has just produced the following information sheets about rarer lymphomas:

- [Angioimmunoblastic T-cell lymphoma \(AITL\)](#)
- [Gastric MALT lymphoma](#)
- [Non-gastric MALT lymphoma](#)
- [Nodal marginal zone lymphoma](#)
- [Splenic marginal zone lymphoma](#)

Copies are available to download from the website or can be ordered by post. The Cancer Information point in Osprey can help you to order if you wish.

Download at [www.lymphomas.org.uk/about-lymphoma/download-or-order-information](http://www.lymphomas.org.uk/about-lymphoma/download-or-order-information)

Call on 0808 808 5555 or email [information@lymphomas.org.uk](mailto:information@lymphomas.org.uk).

## **Stem Cells to order?**

A new way of creating stem cells that is cheaper, faster and more efficient than before could transform the ability of scientists to develop "personalised medicine" where a patient's own healthy skin or blood cells can be used to repair damaged tissues. Japanese scientists announced that they had created stem cells – which are essential for bodily repair – by simply bathing blood cells in a weakly acidic solution for half an hour, triggering a remarkable reversion to the cells' original embryonic state.

The discovery was made by a young Japanese researcher called Haruko Obokata of the Riken Centre for Developmental Biology in Kobe. Neither she nor her colleagues could believe results at first.

It opens up the prospect of doctors taking small samples of skin or blood from a patient and using the tissue to create stem cells that could be injected back into the same patient as part of a "self-repair" kit to mend damaged organs without the risk of tissue rejection.

*The Independent 29 Jan 2014*

## Do you want to share your medical records?

Details of the NHS England scheme to transfer GP's patient medical records onto a national database should have been delivered recently to every household, with the transfer scheduled to start in March 2014. If you did not opt out, via your GP, records were to be copied. Names of patients were not to be included, but gender, date of birth, NHS number and post code would be included.

There have been concerns that some people have not been informed at all that this was about to happen. This could be because information leaflets were delivered along with other junk mail, may have been regarded as advertisements and binned unread. Some of us do that on a daily basis!

Others who did read the leaflet may have worried that it was not clear who would be able to access their test results, illness and medication records. The British Medical Association and the Royal College of GPs voiced concerns that the public had not been given enough information.

As a result, NHS England has now announced that the project start will be delayed until October. In the meantime, the awareness campaign will be extended.

The NHS Choices website states that the objectives were to set up a database to link individual patient records in a secure system, managed by the Health and Social Care Information Centre (HSCIC) to:

- find more effective ways of preventing, treating and managing illnesses
- make sure that any changes or improvements to services reflect the needs of the local patients
- understand who is most at risk of particular diseases and conditions, so those who plan care can provide preventative services
- improve your understanding of the outcomes of care, giving you greater confidence in health and social care services
- identify who could be at risk of a condition or would benefit from a particular treatment
- make sure that the NHS organisations receive the correct payments for the services they provide
- improve the public's understanding of the outcomes of care, giving them confidence in health and care services
- guide decisions about how to manage NHS resources so that they can best support the treatment and management of illness for all patients

For more details of the information originally made available, refer to:

[www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Documents/NHS\\_Door\\_drop\\_26-11-13.pdf](http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Documents/NHS_Door_drop_26-11-13.pdf)

As we go to the printers, it is reported that legislation will be announced to set the rules for which organisations can access the data and for what reasons. We suggest waiting for updates via new advertising and press reports before making the decision to do nothing and allow your records to be made available on the new database..... or to opt out.

## *Controversial cancer awareness campaign*

In February the Pancreatic Cancer Action charity published a very controversial group of advertisements. The one that had the greatest impact was of a woman called Kerry, in her mid- twenties, pictured looking very downcast, with complete hair loss and a number of swellings on her head, saying "I wish I had breast cancer". She was one of three patients to appear in the campaign and unfortunately she has now died, just weeks later.

The objective was to draw attention to the fact that the survival rate after 5 years for pancreatic cancer is just 3%, compared to around 85% for breast cancer and about 97% for testicular cancer. (These are the statistics quoted in the advertisement. advert.) It certainly generated a shock reaction and greatly upset many who have been affected by other cancer types, and particularly those used in the comparisons. It was most insensitive in the way it seemed to regard cancer as a competition.

Pancreatic Cancer Action reports that pancreatic cancer research receives only 1 per cent of overall cancer funding and that 50 per cent of diagnoses are made after an emergency admission; this is compared with a quarter for cancers overall. They do not apologise for trying to raise awareness of the figures, and no one could disagree that the campaign has brought a lot of publicity.

This is not the first shock cancer campaign. A recent television one with children regretting the lifestyle of their parents with lung cancer springs to mind.

You could take the view that we need to be shocked to pay any attention and that the campaign was justified. Alternatively you could consider that it is totally inappropriate to compare types of cancer in this way. We can understand both points of view, but realise that any shock campaign is bound to upset many people.

The amount of funding given for research into pancreatic cancer is probably related to the incidence of the disease. Between 8,000 and 8,500 people are diagnosed with pancreatic cancer each year, in the UK. The figure for breast cancer is 50,000 and for testicular cancer around 2,200. To put it another way 8 women per 100,000 in the UK were diagnosed with pancreatic cancer in 2011, compared with 125 per 100,000 diagnosed with breast cancer, i.e., over 15.5 times as many (2011 statistics published in January 2014 by Cancer Research UK\*).

Perhaps the campaign should have concentrated on the early symptoms, which are admittedly quite vague and vary according to the area of the pancreas affected.

The symptoms could also apply to other health problems and may initially come and go sporadically. They also vary depending on where the cancer is in your pancreas - in the head, body or tail. Early symptoms can include:

- Weight loss , nausea and loss of appetite
- Pain the stomach area or back with possible tenderness to the touch
- Jaundice, fever and shivering

\* [http://publications.cancerresearchuk.org/publicationformat/data\\_tables/dtincmortrates.html](http://publications.cancerresearchuk.org/publicationformat/data_tables/dtincmortrates.html)

*A new recipe!  
(It's been a while)*

## French Olive Cake

I tasted this cut up into small squares as an appetiser before a meal. That is the traditional Provençal way to serve it. It could just as easily be a vegetarian starter for 6-8 people or a main course for 3-4..... And it definitely qualifies as suitable for a Mediterranean diet! I have also seen a version of the recipe which included chopped cooked ham, as well as cheese and olives.

### Ingredients

- 4 tablespoons of plain flour
- 2 teaspoons of baking powder
- 1/2 teaspoon salt
- 4 large eggs, lightly beaten
- 270 mls whole milk
- 85 g freshly grated cheese (the recipe said Gruyere, but I used cheddar)
- 115g pitted olives, halved lengthwise (can be a combination of your black and green ones)
- 1 tablespoonful of extra-virgin olive oil

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1. Grease a 2lb (1 kilo) loaf tin or line with baking paper.
2. Preheat oven to 220°C)/Gas Mark 7 (220°C in a fan assisted oven).
3. Combine the flour, baking powder and salt in a large bowl and stir to blend.
4. Slowly whisk in the eggs.
5. Whisk in the milk, cheese, olives and oil.
6. Set aside for 2 hours in the fridge.
7. Stir the batter to blend and pour into the prepared loaf pan.
8. Place in the middle of the oven and bake for 30 minutes or until firm and golden.
9. Allow to cool to room temperature before slicing.

All I've put by for a rainy day is a newly washed car!



# Fridge magnets



If walls could talk, they might have mortar say.

I learned that courage was not the absence of fear, but the triumph over it. The brave man is not he who does not feel afraid, but he who conquers that fear.

Nelson Mandela



To succeed in life, you need two things: ignorance and confidence.

Mark Twain

I'd like to understand shale gas exploration, but I don't know the drill and I'm no good at fracktions!



The first time I see a jogger smiling, I'll consider it!



When your only tool is a hammer, all problems start looking like nails.

# H.U.G. News – read all about it

- Coffee mornings and lunches have continued at locations away from the hospital, with the Blunsdon Arms being the most regularly visited.
- Group craft sessions have not re-started, but we intend to try out some new ideas soon. We are still making items at home to sell in the meantime.

## 1. Get-Togethers

We shall meet on the second Monday of each month at the Blunsdon Arms pub, on Thamesdown Drive, for coffee or tea from 11am onwards, throughout 2014. A lunch afterwards is optional. The dates for the next quarter are given on page 2.

Further additional dates and locations will be arranged on a month by month basis according to availability of members.

We enjoyed a post-Christmas special in January at the Blunsdon House Hotel, where we made full use of the wide selection of food at the carvery.

Contact us for details of additional venues and times arranged.

## 2. Income and Expenditure

We decided not to proceed with the January hospital sale, with the proposed date a little too close to the Christmas period. Our February sale raised £68.

We have reached a quieter spell, with no more sales in the Hospital Atrium until May. This gives us plenty of time to produce some different craft items, either at home or as a group..

We have also booked a slot at the Dragon Boat Race at Coate Water on 29<sup>th</sup> June.

Although we don't have so many sales dates scheduled at the hospital this year, we shall continue to raise funds for the benefit of cancer patients at the GWH.

Consideration is being given to whether we should organise another Coffee Morning in the Spring or early Summer. A decision will be made when details of fund-raising campaigns for the two radiotherapy projects are known (see page 10).

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Apologies that this issue is on rather serious subjects! A joke is included to compensate.

A man walks into a doctor's office. He has a cucumber up his nose, a carrot in his left ear and a banana in his right ear.

"What's the matter with me?" he asks the doctor.

The doctor replies, "You're not eating properly."

## Cancer Survival Rates in England

The National Awareness and Early Diagnosis Initiative was launched in 2008 and Improving Outcomes: A Strategy for Cancer was published in January 2011.

The full document can be found at:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213785/dh\\_123394.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf)

A summary of the document is at:

<http://www.nhs.uk/NHSEngland/NSF/Pages/Cancer.aspx>

The aim was to save an additional 5000 lives per year by 2014/2015 because England is lagging behind in terms of survival rates compared to the best outcomes in Europe.

The third annual report was published in December 2013, but noted that although survival rates had improved, it was too early to confirm that the target for saving lives would be met.

The Be Clear on Cancer initiatives this year include the new national breast cancer campaign targeted at women over 70, which launched on February 3.

National and regional campaigns will be launched throughout 2014, including a regional campaign for ovarian cancer in the North West TV region, for oesophageal cancer in the North East and Borders TV regions, and a campaign for melanoma skin cancer. There will also be more support for GPs to aid early diagnosis.

So far, all Be Clear on Cancer campaigns have focused on cancers with the largest number of avoidable deaths compared with countries with the best survival rates. While all existing campaigns are reviewed regularly, the Department of Health, Public Health England and NHS England will also work with relevant experts to see what might be done to tackle other cancers.

However, we service users must also be prepared to take preventative actions. NHS England reports that half of cancers could be prevented by:

- **Stopping smoking:** the major preventable risk factor for cancer
- **Avoiding obesity:** obesity is now the most important preventable risk factor for cancer in non-smokers
- **Eating a healthy diet**
- **Undertaking a moderate level of physical activity**
- **Avoiding too much alcohol**
- **Avoiding excessive exposure to sunlight.**

## Radiotherapy for the GWH is a step closer

Since our last edition, progress has been made towards radiotherapy for Swindon. Two HUG members were among the group of “users” who met with the architects, reviewed draft plans for the new building and offered some comments. The Swindon Advertiser has highlighted the need for local fund-raising to meet the cost of some of the equipment, estimated at £3m.

However, the first radiotherapy at the GWH should be on offer to some breast cancer patients later this year. GWH is aiming to be one of the first hospitals in the UK to offer “Intrabeam” treatment on the NHS. So far this method of delivering radiotherapy has produced equivalent survival rates to traditional radiotherapy, at a private London hospital, but in a single treatment, under general anaesthetic, at the same time as surgery. Experiences have shown that there is less skin sensitivity after its use. Patients currently have to make daily weekday trips to Oxford for a number of weeks as a follow on from surgery. The saving in time, energy and stress levels for patients would be enormous.

The equipment will cost £500,000 and it is understood that a fund-raising campaign is underway for the Intrabeam. We do not yet have details of how you can donate, to make sure that your donation reaches the correct fund. We should be able to tell you in the next edition.

## Health Talks at the GWH

The following talks are scheduled for this year

- Wednesday 7 May - Thinking of having a baby? - What you need to know, by Dr Fazal
- Wednesday 2 July - A short history of tics, twitches and tremors, by Graham Lennox
- Wednesday 3 September - How to survive your menopause, by David Griffiths and Kevin Jones
- Wednesday 5 November - Prostates, Bladders and Willies, by Rupert Beck.

All health talks take place from 6.30pm - 7.30pm in Lecture Hall 1, The Academy, Great Western Hospital, Swindon. Foundation Trust members and staff are welcome and there is no need to book in advance.

For further information click

[www.gwh.nhs.uk/members/meetings-and-events/](http://www.gwh.nhs.uk/members/meetings-and-events/)

If you have any questions you can email [foundation.trust@gwh.nhs.uk](mailto:foundation.trust@gwh.nhs.uk) or phone 01793 604185.

