

HUG MAGAZINE



September 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



ITEMS FOR SALE ON OUR STALL AT THE GWH

Email: hugswindon@btinternet.com

**** Website address: www.hugswindon.org.uk

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 3rd quarter of 2014 are the 2nd Mondays of months

13th October 2014

10th November 2014 and

8th December 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. However, the only remaining date for 2014 is Thursday 18th September, between 9am and 4.30 pm.**

INTERESTING HEALTH-RELATED NEWS

Rituximab by injection

A form of rituximab which can be injected in the layer of fat beneath the skin has become available to some people with Non-Hodkin lymphoma in Scotland. It can be administered subcutaneously in around 5 minutes, much faster than the intravenous infusion. It has been approved north of the border for

- Previously untreated patients with stage III-IV follicular lymphoma in combination with chemotherapy
- Maintenance therapy as indicated for the treatment of follicular lymphoma patients responding to induction therapy
- Treatment of patients with CD20-positive diffuse large B cell lymphoma in combination with CHOP chemotherapy

The access situation in the rest of the UK should become clear soon.

Lymphoma Matters, Issue 98, Summer 2014

The 100,000 Genome Project

Genomics England, with the consent of participants and the support of the public, is creating a lasting legacy for patients, the NHS and the UK economy through the sequencing of 100,000 genomes.

Genomics England was set up by the Department of Health to deliver the 100,000 Genomes Project. Initially the focus will be on rare disease, cancer and infectious disease. The project is currently in its pilot phase and will be completed by the end of 2017.

There are four main aims:

- to bring benefit to patients
- to create an ethical and transparent programme based on consent
- to enable new scientific discovery and medical insights
- to kickstart the development of a UK genomics industry

For more information refer to www.genomicsengland.co.uk/about-genomics-england/.

Anal Cancer statistics

The rate of incidences of anal cancer has risen by 300 per cent since the mid-1970s. The disease is now five times more common in women – and three times more common in men – than it was 40 years ago. And death rates have quadrupled over the same time period.

Cancer Research recently sent out a press release to journalists at all the national newspapers and broadcast outlets. They thought that an increase of this magnitude in any disease would warrant an explanation, or at least create some discussion. But they consider that the lack of any coverage suggests the national media is **too squeamish** to report on cancer of the anus. To find out more, refer to: <http://www.cancerresearchuk.org/about-us/cancer-news/press-release/anal-cancer-rates-quadrupled-since-mid-70s>

Food, Hospital Food

The Campaign for Better Hospital Food has recently said that NHS Trusts in England routinely rated their own food highly and are hiding patient dissatisfaction with the food they serve. In the past, NHS staff in England have carried out annual assessments of the quality of hospital food. In 2011 they rated nearly 98% of meals as "good" or "excellent". This does not tally with reported patient experiences. A Care Quality Commission survey of more than 600,000 patients, carried out earlier this year, found that just 55% of patients said the food they had been served was "good".

The campaigners would like mandatory standards introduced for hospital food, like those which already exist for prisons and schools. So far, no legislation has been forthcoming, but the inspection system is changing.

The NHS Choices website does give some guidance on what patients should expect from the hospital catering services, as follows.

“You should expect:

- nutritious, tasty, appetising food and drink – this is an essential part of your personal package of care
- to have a choice from a varied menu that includes meals that are suitable for your religious, cultural or dietary needs
- to have access to fresh water at all times – unless this contradicts medical advice
- to get any help you need to eat and enjoy your meals “

You can now see how some hospitals perform against key food indicators on the NHS Choices website. These indicators are as follows:

- Quality of food
- Choice of food
- Choice of breakfast
- Fresh fruit available
- Food available between meals
- Menu approved by dietician
- Cost of food services

This does not fully reflect the guidance to patients on what they should expect, with no mention of either fresh water availability or help with eating when required. The inclusions of fruit availability and dietician approval of meals are good additions, however.

To date, some Gloucestershire and Wiltshire sites have been inspected against the new indicators, but the GWH is not included as yet.

Keep a look out for an assessment of the quality locally at the GWH and other Wiltshire hospital and clinic catering at www.nhs.uk/hospitalfood/search/

Prospect Hospice News

In July the Prospect Hospice opened two brand new lodges in the grounds, to welcome families and carers of people staying at the in-patient unit. These have been funded by a grant from the Department of Health.

Previously there was just one single room available for family members to use. This new building will be much easier for family members to remain close to their loved ones when it matters most.

The grant also allowed the former relative's room to be kitted out to house a 16th bed, the refitting of an unused patient bathroom and revitalising of the patient catering facilities.

The Wiltshire Bobby Van

We have recently heard about the above Trust which works with Wiltshire Police and Wiltshire Fire & Rescue Service from one of our members.

Its aims are to:

- Reduce the incidence of crime amongst older, vulnerable and disadvantages people in Swindon and across Wiltshire.
- Reduce the fear of crime and make people feel safer in their homes.
- Reduce the incidence of repeat crimes
- Reduce the incidence of fires

So how do they do that?

They visit clients' homes by appointment only and give expert advice on safety and security. They install appropriate equipment from their mobile workshop to improve the security and safety of homes, following a risk assessment. What is even better, is that the service is completely FREE, although donations are welcomed for some services.

Bobby operators are skilled carpenters/lock fitters, trained crime reduction officers and trained fire safety advisers. They wear uniforms similar to those worn by Police Officers for reassurance and always carry formal identification.

The Bobby operators also distribute Message-in-a-Bottle, to provide vital health information to emergency services, supply carbon monoxide detectors and fit key safes with access codes stored on the Wiltshire Police database. Potential clients are either 60+ or vulnerable due to a disability.

Ring 01225794652 if you are in either of these categories and would like the Bobby Van to visit you.

GP Surgery Hours

Healthwatch Swindon has reported patient concerns over changes to the opening hours at Freshbrook surgery in West Swindon. Patients have been advised that it will only be open on Monday and Wednesday mornings and Fridays. This will make it even more difficult for patients to obtain appointments.

One patient contacted NHS England and was told that they had agreed with the practice that there will be a temporary reduction in their branch surgery hours from 1st August 2014, for four months. This reflected the concerns the practice have raised about GP capacity. The situation was to be reviewed again two months later.

Patients can still be seen for an urgent appointment at Ridge Green on Tuesday and Thursday. Help is available for patients going to Ridge Green, if they are unable to travel by public transport.

According to reports from HUG members, other GP surgeries in the area appear to be overstretched too. We have heard of non-urgent appointments having to be made a month in advance. This may be fine for a chronic long term condition, but not for many other health matters about which you wish to consult. There are also general difficulties in contacting surgeries by telephone to make any appointments.

Should you wish to report difficulties at your surgery, contact NHS England Area Team for Swindon & Wiltshire at

1st Floor,
Bewley House,
Marshfield Road,
Chippenham,
Wiltshire.
SN15 1JW

Just enough room for a couple of Doctor jokes

You know you're at an underperforming surgery when you recognize your doctor as the boy who was mopping the lobby when you checked in.

Brian, one of the world's greatest hypochondriacs, bumped into his doctor one day at the supermarket. "Doctor!" Brian exclaimed, "I've been meaning to tell you, remember those voices I kept on hearing in my head? I haven't heard them in over a week!" "Wow! What wonderful news Brian! I'm so happy for you!" his Dr. exclaimed.

"Wonderful?" asked a dismal looking Brian. "There's nothing wonderful about it. I'm afraid my hearing is starting to go now!"

Fridge magnets

If I lack the courage to start, I have already finished.



Remember that age and treachery will always triumph over youth and ability.

I've decided to sell my Hoover... well, it was just collecting dust!



Tax inspectors live off the VAT of the land.



Hope is the parent of faith. –



Cyrus A. Bartol



Hypochondria is the only disease I haven't got.

H.U.G. News – read all about it

- Get-togethers currently take place away from Great Western Hospital, as regular coffee mornings and lunches.
- Occasional group craft sessions are arranged as required.
- We are still making items at home to sell.

1. Get-Togethers

We are meeting 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. We did have to miss the September date because of unavailability of drivers and hope that no one new turned up.

Further additional dates and locations are often arranged on a month by month basis depending on members' availability. Contact us to find out what has been arranged.

2. Income and Expenditure

Sales at both the hospital and elsewhere have done well since our last issue. Our June to August GWH sales raised £234 and we also made £135 at the Dragon Boat Race stall at Coate Water. This event just started in 2013, but we made our first visit this year and will certainly go there again.

We continue to receive generous donations of knitwear to sell from friends. Another friend has also been making some jewellery for us to sell. Any surplus wool or broken necklaces would be most welcome for recycling.

We are once again hosting a Macmillan Coffee Morning at the Memorial Hall in Lambourn on Friday 26th September from 10.00 until 12.00. There will be a raffle, tombola and produce stalls, as well as HUG sales.

We are also booked into the Christ Church Christmas Fair on Saturday November 22nd and hope to have stalls at other Christmas events locally.

Ideas for more ways to spend for the benefit of patients would be welcomed.

3. Activities

Three of us got together recently to try making a new idea for Christmas sales, which involves recycling milk bottle tops. Having got the general idea, we are working on sections at home and will then reconvene to put them together into a Christmas tree wall hanging.

The venue for our "summer" outing (more like autumn, since so many members were going away in September!) will be Littlecote House near Hungerford.

The idea is to have a spot of lunch and a walk around the gardens. We shall also have a look at the Roman mosaic in the grounds.

We hope to be able to include some old friends of the group, who can't always join us at regular get-togethers.

Cancer Research thoughts on Aspirin for cancer

Cancer Research has recently commented on research indicating that aspirin may help to prevent cancer and may also lower the risk of cancer spreading. They do not advocate general use for this purpose.

It is well known that aspirin can cause serious side effects, such as internal bleeding, for some people. Cancer patients may have a higher than normal risk of bleeding anyway, because of either their cancer type or the treatment for it. Also some cancer drugs can also cause bad side effects when taken with aspirin.

Aspirin can also cause serious complications in people with other medical conditions such as asthma, stomach ulcers, or the blood clotting disorder haemophilia. In addition anti-inflammatories and steroids taken by many people for an assortment of health conditions also irritate the stomach.

In trials, the amounts of aspirin taken each day varied from 75 to 300 mg. That's between a junior aspirin (75mg) and one regular aspirin (300mg). At the moment, it is not at all clear how much could be appropriate to reduce the likelihood of cancer spreading.

In August 2014 an analysis of previous aspirin studies was reported in the Annals of Oncology. The study confirmed that aspirin can lower the risk of developing bowel, stomach and oesophageal cancers. It can also lower the risk of lung, prostate and breast cancers but not to the same extent as for the other cancer types.

Because aspirin can cause serious side effects for some people, it isn't certain that the benefits of taking it always outweigh the risks. Everyone really must talk to their doctors to discuss their personal level of possible risks and benefits, before making a decision to take aspirin.

Leukaemia & Lymphoma Research join a cancer charities pressure group

Leukaemia & Lymphoma Research has recently joined leading UK cancer charities under an umbrella campaign to call for political parties to make cancer a priority in the 2015 General Election and beyond.

There are currently two million people living with, or having survived, cancer in the UK. This means that there are two million reasons for the next Government to make cancer a priority. This figure is likely to increase in the future.

There are 38,000 newly diagnosed blood cancer patients each year. In the 53 years since this blood cancer charity began, they have made some world leading discoveries. Today, they continue to develop new ways of working to beat blood cancer, such as the innovative Trials Acceleration Programme that helps more patients get on clinical trials and access the newest medicines. But more progress is needed to give patients the best possible outcomes, in line with the best in Europe.

Through the "Cancer: 2 million reasons" campaign they are calling on all political parties to commit to improving research, prevention, diagnosis, treatment and care for people affected by cancer today and in the future.

Over the months until the next general election they will be sharing data and stories on what they do to improve patient outcomes and make cancer a priority on the political agenda.

Death of a friend of the HUG Group

We are really sad to report the death at the beginning of August of one of our longest serving HUG members, YR, who joined the group in late 2004.

Y was a devoted wife, mother and grandmother, who was extremely proud of all her family. She was also something of a mother hen to other HUG members, keeping up to date with the happenings in all our families.

At HUG group activities, she was well known for her happy, smiling face. She really loved to help with fund-raising events, and was “queen” of the tombola whenever we included a stall at our sales.

She continued to be cheerful and uncomplaining, even when she became seriously ill.

We shall miss her greatly.



Symptoms of Sepsis

The Summer issue of the Foundation Trust Horizon Magazine includes an article on the symptoms of sepsis and who is at risk. In addition it specifies the action to take if you think you have been affected. Patients receiving chemotherapy are of course at high risk. Even if you don't have access to the Magazine for Foundation Trust members, you can have a look at the symptoms to watch out for at

<http://www.gwh.nhs.uk/about-us/news/gwh-celebrates-success-in-tackling-sepsis/>

Look Good, Feel Better

As reported last time, the Look Good, Feel Better pampering sessions for cancer patients are currently undersubscribed. Sessions consist of cleansing and make up to suit your condition and skin type. If the free charity service is not used by enough patients, we may lose it.

Dates for the remainder of the year are 14th October and 18th November. For more information speak to a member of your health care team or contact Cancer Services between 1pm and 4pm, Monday to Friday, on either 01793 646152 or 01793 605859.