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BRINGING WM PATIENTS AND DOCTORS CLOSER

info@wmuk.org.uk

www.wmuk.org.uk

47, Longfield Road Bristol BS7 9AG 0117 3735733

Newsletter No 3 - 2014

5th International WM Doctor/Patient Forum London 2014

This summer the whole world of Waldenström comes to London in August for IWWM8, the 8th international WM workshop for doctors and researchers. This is from 14th-17th at the Park Plaza Westminster Bridge Hotel and organised by Dana-Farber at Harvard. Details can be found at <http://www.wmworkshop.org>



The last day, Sunday the 17th is the Doctor/Patient Day, the **5th International Forum** which WMUK is jointly running and subsidising with the IWMF. Many of the leading doctors (UK and international) will be at the forum, and Steve Treon and his Dana-Farber team will deliver the **keynote session on new advances in genetics and treatment.**

Old favourites like 'ask the doctor' and one to one doctor/patient meetings also feature. All in all, a unique event and not likely to be repeated.

The subsidised cost is £35.00 per head (you can also pay in Euros and Dollars) and includes all refreshments, including lunch. You can book online at www.wmuk.org.uk where you can also download the programme and a booking form if you want to sign up by post. There is a strict limit of 220 and booking is already brisk. Please don't leave it to the last minute. This is a family friendly event!

Please don't forget we need your **Patient Tales** for the forum and website as well as volunteers to be **Helpful Patients** - willing to talk to others and share your experiences. In either case contact Roger at info@wmuk.org.uk

WMUK website update

Since the last newsletter a huge amount of work has gone into the new, more professional WMUK site which can respond to mobiles and pad devices and offer, among other things, a customised online forum with a number of topics suggested by users. It went live on the 20th January.

We would really like comments and suggestions for future enhancements and pages. At present we are working on making the online forum more attractive, and for the time being the existing Yahoo! group will continue - to join just send us an email.

Do we have your email? If you have changed or acquired a new email, please let us know so we can keep in touch and keep costs down.

Regional Meetings

As previously announced we aim to launch regional meetings. To do this we need local people to volunteer to meet and greet. We will provide the resources, book a venue (suggestions for Hospital venues are welcome) and organise doctor participation. One or two patients have volunteered so far, but we need many more, and a leading contender at the moment is Birmingham.

Welcome to the third WMUK community newsletter. We need your help developing regular features to make it lively, informative and understandable. We'd welcome short contributions, news and links to websites. Why not become a citizen reporter for WM?

Surveys are ready - x 2!

The WM Patient survey is ready for you to complete. A lot of thought by Phil and his team has gone into the questions for the first ever survey in the UK. It's thorough - please stick with it and it will give valuable results. It's available on paper at www.wmuk.org.uk but far easier online. Here is the link: www.surveymonkey.com/s/WMUKPtSurvey

WMUK doctors, supported by WMUK have launched their **doctor survey** to establish treatment patterns throughout the UK. This is being organised by Dr Shirley D'Sa at UCLH. If you are a doctor, and don't get one via the BSH, the link is below. The survey is based on a very successful one carried out by Dr Monique Minnema in the Netherlands, and many will remember her excellent presentation at the forum last March. It is at www.surveymonkey.com/s/WMUKDR This is only for **Doctors** who treat WM patients. At time of printing over 40 had taken part.

Easy Fundraising

WMUK has no employees and relies on donations to fund projects and provide support. One easy way to do it is via Easy Fundraising at www.easyfundraising.org.uk If you click via Easy Fundraising before purchasing the seller will donate a small percentage of each sale to us via Easy Fundraising. Most online sites including Amazon, hotels and holiday sites participate, and you can download tools for your browser that remind you to buy through them.

New Faces at WMUK

WMUK will announce in June that a well-known celebrity has agreed to be WMUK's first patron. In media tradition we are keeping this under wraps, when we hope to have an appeal launch for our **clinical data registry** (if we can find sponsors!), and unveiling of other new projects (probably at the House of Commons.) We expect much Twitter speculation! However we can reveal that Dr Guy Pratt of Heartlands Hospital, Birmingham has joined WMUK as a trustee. This is in line with our commitment to be a joint doctor/patient charity. Many will be familiar with him from his 'Ask the Doctor' appearances at forums. Welcome Guy!



BBC Cake Bake for Rory Morrison Raises £3,000 for WMUK: Pictured John Whaite, Corrie Corfield, Susan Rae

Chemo Corner

Novel treatments and trials

New agents at the American Society of Haematology Meeting in December, New Orleans: We hope to have a fuller report on our website soon, but there were no less than 35 presentations relating to WM. It's clearly an exciting time with a range of novel agents showing real effectiveness in WM and related B cell malignancies. Now trials are progressing on combination therapies - for example some very good results have been obtained with **Ibrutinib** and **Rituximab** in CLL. Also coming up is **Idealisib** a so called **PI3K-delta** inhibitor which has shown good results, again with Rituximab in CLL. It remains to be seen how soon we shall be seeing the benefits in the UK in view of the lack of trials, NICE and NHS finances.

UK Ibrutinib Trialist Update

We reported on the first UK Ibrutinib trialist who was flying to Dana-Farber in the USA monthly for his oral trial of Ibrutinib (now known as Imbruvica). Our friend reports that from April to November his IgM went down by 90% from 50 to 5.1 Here is his update:

"I feel like I did a few years before I was diagnosed with WM. I was warned before my initial treatment in the States not to build my hopes up too high and I haven't, but I never expected to feel this good ever again. I have more energy, not so tired in the afternoons and am doing activities that I never thought I would feel like doing again. No real side effects that you can point at Ibrutinib, most are from Waldenström's or after effects from my 2010 transplant. I understand as with all medicines there might come a time when the tablets stop working but at the moment life is good again. The American IgM results are 5.1, down from 6.5 in September. I asked about approval dates for Ibrutinib for Waldenström's and they were of the opinion it would not be until the 2nd quarter of 2014."

63 people were on the trial and the results were reported in detail at the American Society of Haematology meeting-here is a useful summary:

<http://www.onclive.com/conference-coverage/ash-2013/Ibrutinib-Induces-Rapid-Durable-Responses-in-Waldenströms-Macroglobulinemia>

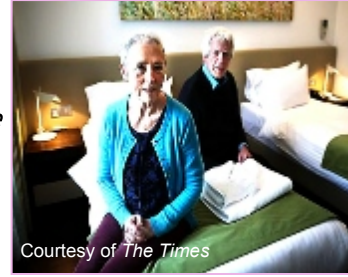
Finally, our trialist is very keen to get support for **Louise Millard** who is running in the London Marathon at Easter for Dana-Farber: her fund raising page is:

<http://www.rundanafarber.org/2014/louisemillardvml>

Last year Roger Tudor ran for WMUK in the Great Manchester Run raising over £1,250 to honour his father, who has WM and we are happy to support anyone who wants to enter a sponsored event with materials. We have our own BT Mydonate and Just Giving pages so sponsors can make donations online and tax can automatically be reclaimed.

Ambulatory Care - the future for high dose chemotherapy and transplants?

A personal tale : Gillian Bennett and Philip Aris



Courtesy of The Times

When asked the meaning of *Ambulatory Care* most are likely to say it means receiving medical treatment in a hospital, in a single day, for example for chemotherapy infusions. Today, some hospitals are attempting complex and challenging procedures in an ambulatory care setting. This can involve treatment over a number of consecutive days or weeks with nights spent in a hotel close to the hospital where there are special arrangements. This has big advantages for the NHS, as hotel stays are far cheaper than hospital beds. Patients too may prefer the extra freedom and control that out-patient treatment can bring.

WM patients undergoing stem cell transplant procedures may be given some of their treatment this way. Additionally if, as can happen (though very rare) WM transforms into a more aggressive lymphoma, such as a brain tumour, it is again possible that most of the treatment (high-dose chemotherapy) will be carried out in Ambulatory Care.

This happened to me. I was diagnosed with WM in 2009. In January 2011 it transformed into Diffuse Large B cell Lymphoma. There were tumours in many parts of my body. After six rounds of R-CHOP and two booster rounds of Rituximab, mostly as an outpatient at UCLH, I went into full remission. Then, in June 2012, there was a sudden relapse and a scan revealed a brain tumour

Surgery would not work. High-dose chemotherapy involving the toxic drug Methotrexate, could penetrate the blood-brain barrier and attack the tumour, if given with chemotherapy drugs and Rituximab. My husband Philip and I were amazed when doctors said it was possible to carry out this either as an inpatient or via Ambulatory Care at the UCLH Macmillan Cancer Centre. There was no pressure. We were given a choice: treatment as an in-patient over several months or daily infusions at the Cancer Centre with many nights spent at the Cotton Rooms, a hotel, owned by UCLH's charity, where infusions would continue with the aid of computerised pumps. Philip stayed with me and we both shared responsibility for monitoring the treatment. To some people this may sound daunting but throughout I felt very safe and Philip benefited enormously from being involved in the care.

This treatment was completed in November 2012. I am in full remission and feeling remarkably well. My blood readings including paraprotein levels are virtually normal and the tumour remains absent. We are both determined advocates of Ambulatory Care of the kind carried out by our magnificent NHS hospital. We had the opportunity of meeting Health Secretary Jeremy Hunt and telling him how keen we are to see this model adopted. While we were at the Cotton Rooms, we met patients from as far away as Yorkshire, receiving complex treatment. High dose chemo, with stem cell rescue, is having very encouraging results for some WM patients. I believe my current remission is the result of the wonderful care I received in Ambulatory Care.

Ed Note: This has been hailed as the way forward by NHS England. A UCLH video of Gillian and Philip is at <http://www.youtube.com/watch?v=wiKCM-z18fA>

Very Sad News

Sadly we announce the death of two stalwarts of the WM community, **Raphael Altman** and **Mike Dewhirst**. Both fought long battles with the disease, but in doing so shared their wisdom and compassion with many. Raphael of course ran the UK online forum for 7 years and patients far and wide sent tributes to him to be read at his moving funeral at Witney. WMUK was very flattered that his family made a substantial donation in his name towards research at WMUK as was his wish, and several other donations were received directly in his name. It is no exaggeration that he changed many, many lives for the better with his timely advice. Mike Dewhirst was the Sussex regional co-ordinator for the UK Support Group, but moreover was an active researcher in WM, supplying his information to doctors and particularly the IWMF. His family asked for donations to his beloved hospital the Pevensy Ward at Eastbourne DGH, and has a page at <http://www.justgiving.com/mdewhirst>

Editor: Roger Brown - info@wmuk.org.uk

Medical Advisory Board: Shirley D'Sa Consultant Haematologist and Honorary Senior Lecturer in Haematology University College Hospital, London **Rebecca Auer**- Senior Lecturer in Haematology, Barts and the London. **Roger Owen**, Consultant Haematologist, Haematological Malignancy Diagnostic Service (HMDS) Laboratory, Department of Haematology, St James' Institute of Oncology, Leeds. **Guy Pratt**- Senior Lecturer in Haematology, School of Cancer Sciences, Honorary Consultant Haematologist, Heart of England NHS Foundation Trust, Birmingham. **Chara Kyriakou**- Consultant Haematologist, North West London Hospitals NHS Trust, London **Saad Rassam**- Consultant Haematologist, Maidstone and Tunbridge Wells NHS Trust, Maidstone, Kent **Helen McCarthy** Consultant Haematologist, The Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust, Bournemouth, **Feargal McNicholl**, Consultant Haematologist at the Western Health and Social Care Trust, Northern Ireland **Michael Lunn** - Consultant Neurologist, Clinical Lead in Neuroimmunology and Honorary Senior Lecturer at the National Hospital for Neurology and Neurosurgery, UCLH NHS Foundation Trust, London **Rita Flatley**- Sister, Clinical Assessment Unit (Acute Oncology), Royal Marsden NHS Foundation Trust, London **Patients:** Roger Brown, Phil Manning, Jain Purchase