

## International Forum 17<sup>th</sup> March Update + your final call!

If you haven't registered there is still plenty of room. Join us!- book online or download a form and post at [www.wmuk.org.uk](http://www.wmuk.org.uk) This is likely to be your last chance to catch the Forum for two years.

### Latest News

•**The reception** on Saturday night at the Thistle, Euston at 7pm is being generously hosted by *The Binding Site*, followed by the 'Meet the Doctors' Dinner at 7-30 in the Cavendish Room with Dr Bob Kyle as Guest of Honour. Seats are available for the Dinner at £35 inc wine. To book a room at the Thistle on Saturday night at the guaranteed rate, remember it has to be done by the 17<sup>th</sup> February.

•**The very popular IWMF Publications** will be available for free at the WMUK/IWMF stall.

•**Could you be a 'friendly' patient** at the Forum?: we are looking for people who don't mind chatting, especially to the newly diagnosed, to break the ice. No need to be an expert, but those who have been 'around a while' would probably be best suited. You will have a badge and simply be accessible. Let Roger know if you fit the bill! (p.s. Phil Manning says we are all friendly, but you know what I mean!)

•**FAQ - are family members, friends or carers welcome?** Of course yes, and of any age!



Overseas speakers-  
Dr Bob Kyle,  
Dr Mathias  
Rummel and  
Dr Monique  
Minnema

### Help us gather data- another reason to be at the Forum

We'd like to build up a clearer picture of treatment patterns throughout the UK (and abroad) and of the complications of the disease—including the side effects of treatment—and its impact on families. We'll be inviting Forum attendees to help by completing a draft questionnaire, leading to a fuller survey online when the bugs have been ironed out!

Don't forget we still urgently need your new **Patient Tales** for the **Wall and general interest questions for the 'Ask the Doctors' session**. Examples can be seen under 'case studies' on our website. We help with formatting and editing to A3 size. You don't have to come to the Forum to contribute. Everyone has an interesting tale to tell, so don't hide your light under a bushel!

Welcome to the first WMUK newsletter. It is a work in progress, and we need your help to develop regular features to make it lively and informative. We'd welcome short contributions, links to interesting websites, particularly potential treatments and ideas for features. We have made a start here, but now it's over to you!

### Forum Preview - Dr Shirley D'Sa



This Forum will mount a three-pronged attack against WM by bringing together patients, physicians and organisations such as the Lymphoma Association, Rare Connect and the European WM Network. Focused on addressing the unmet needs of patients with WM across the UK by providing valuable and current information, as well as by encouraging participation, cooperation and dialogue, the Forum will get to the heart of what makes the disease tick and the means of combating it effectively. A distinguishing feature of WM is the IgM paraprotein—critical to the diagnosis, complications and monitoring of the disease—and the keynote address by the world's expert, Dr Robert Kyle from the Mayo Clinic (USA), will demystify this important element of the disease. A discussion of a promising new agent, Bendamustine, will be presented by the world leader in its use, Dr Mathias Rummel of Giessen (Germany), and we are truly fortunate to be having the input of this physician who is in hot demand all over the world at congresses and scientific meetings. Randomised trials in WM are as rare as the disease itself and, crucially, two new clinical trials that exclusively address WM—one for the newly diagnosed and one for those whose disease has relapsed—will be presented by the principal investigators: the R2W trial, following on from successful phase II trials, will offer upfront Bortezomib to patients with WM, while the OBOE trial will make Bendamustine and a brand-new monoclonal antibody, Ofatumumab, available at participating centres for patients with relapsed disease. All of this adds up to exciting times for patients and families affected by WM, so the Forum is not to be missed!

**“Owing to international clinical and research collaboration, the future for WM patients is brighter than ever”**  
Dr Shirley D'Sa UCLH

### WMUK website update

Due to the generous people who have made donations or rounded up their Forum registration we should be able to improve the website in the near future. Please have another look at the WMUK site and get back to us

with what you would like us to add to improve its usefulness. We have a dummy's guide to blood tests in preparation, but I'm sure there are other things that you would value, particularly for newly diagnosed patients.

## Chemo Corner Novel Treatments

Mike Dewhirst and Raphael Altman have drawn our attention to this article and video relating to the recent American Society of Haematology meeting. Whilst it's technical, and refers to other lymphomas, it shows the way things are going, and is well worth a viewing. The question is, how soon will we see results in the UK? [www.medscape.com/viewarticle/778397](http://www.medscape.com/viewarticle/778397) you may have to sign up free to view it, depending on your browser.

For those not able to view, the conclusions of **Dr Bruce Cheson**, are - *"I came away from the ASH meeting feeling enthusiastic that the world is changing. Clearly, we now will be hearing a lot about targeted therapies. Hopefully, we will get to a point where we can combine these targeted therapies. If we can do this in a rational manner in the right patient population, I think some of these approaches may cure diseases that have been incurable to date. And if not cured, aggressive diseases -- indolent, incurable diseases -- may be transformed into chronic diseases for which a patient takes 1 or 2 pills a day and does just fine. These are very exciting times"*.

More down to earth, but no less useful is **Iain Purchase's guide for WMUK on 'How the NHS Accepts a New Medicine'**. It's at:

<http://www.wmuk.org.uk/documents/HowdoestheNHSacceptanewmedicineV2.pdf>

Of course it doesn't explain what's **actually** available on the NHS! The article (Courtesy of the Times) centre, shows the current concerns shared by cancer charities over the future of the Cancer Drugs Fund.

**Have you been treated for WM under the Fund? let us know of your experiences.**

### Are you alert?

Keen to keep up with the WM world? One way is to set up an online alert with Google. Anyone can use it. Go to [www.google.com/alerts](http://www.google.com/alerts) (there are instructions there,) put 'Waldenstrom' as your alert word and give your email, and you will get an email with a link every time WM appears, usually in connection with new drugs or treatments. You also get Kevin Waldenstrom, a finance CEO in the USA, from time to time, but no matter!

### Welcome to the Club

A patient suggested we should all be enrolled in one of the world's most exclusive clubs, '**Club WM**', but we don't really have much of an option to turn it down - unlike Groucho Marx who said *"I refuse to join any club that would have me as a member"*. Perhaps as exclusive clubs do, we need a joining ritual - a bone marrow biopsy? Discuss!

### Rory Morrison

Those of you at the Forum last year will remember the succinct and humorous links delivered in that familiar BBC accent by Rory when he acted as M/C. Sad to say, shortly after the Forum, he relapsed from his auto transplant, and was scheduled for an allo transplant from



One to ones with doctors in 'Meet the Doctor Lite' 2012

his brother. Unhappily before this could happen, his WM transformed into a Diffuse Large B cell Lymphoma, and he is being treated at UCLH to bring this under control before he has his allograft. He sends his good wishes.

### European News

WMUK also supports the coming together of European WM patients and doctors through its membership of EW-

Mn, who are having a European meeting on the Saturday afternoon before the Forum. Our Board Member Phil Manning is also the English moderator for the Rare-Connect website of rare disease communities in Europe. The site allows chatting and message posting to be translated between main European languages, and Rob Pleitcha will be at the Forum on Sunday and the European meeting Saturday to explain how it works. Have a look at :-

<http://www.rareconnect.org/en/community/waldenstrom-macroglobulinemia>

We also the support the development of an international Patient Registry for WM, to share experience of outcomes and to find more patients for clinical trials. Many rare diseases now have such registries.



The European WM network meeting at Forum 2012



Chris Smyth Health Correspondent

Thousands of cancer patients might miss treatment because a new drug funding system is not ready, MPs are to warn today.

A year before the Government brings in "value-based pricing", based on how useful drugs are, it is not clear how it will work, the Commons Health Committee believes. There is concern that this "nebulous concept" will not be ready to replace the £200 million-a-year Cancer Drugs Fund, the committee says in its report on the National Institute for Health and Clinical Excellence, the medicines watchdog. The Cancer Drugs Fund pays for drugs not yet approved by NICE.

Stephen Dorrell, the committee's chairman, said: "It's important that the patient has continuity of care at the discretion of the clinician beyond the end of the Cancer Drugs Fund."

Duleep Allirajah, head of policy at Macmillan Cancer Support, said the situation was extremely alarming. "Cancer patients could face a return to the days of being denied potentially life-saving treatment," he said.

The MPs also want it to be compulsory for the results of all drug trials to be published so that NICE has full evidence. About half of trials lead to publication, with a bias against negative results.

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