

3rd International WM Forum - New Year Newsletter

Bringing Doctors & Patients closer in London 2012



Hello!

This is an update on the Third WM International Patient Forum in London on 11th March, following on from the successful Stockholm and Venice meetings. The event is being hosted by WMUK and generously sponsored by the **IWMF** and the **EWM network**. The latest details are attached which now contains timings for the day, which is shaping up to be something very special and a meeting place for the WM community. This is being sent to all, including those already registered.

'Meet the Doctor Lite' - A significant new addition is 'Meet the Doctor Lite', giving individual patients and carers (subject to time constraints) the chance to talk one to one with leading WM specialists, in line with the WMUK aim of bringing doctors and patients closer. This is in addition to the more general *Ask the Doctors* session. For this we are asking for really interesting general questions, which you can send to us info@wmuk.org.uk

New Genetic Research - Our keynote speaker is Dr Steven Treon from Dana-Farber at Harvard, who will discuss his latest research, including new information about the genetic background to WM which he recently spoke about at the American Society of Haematology. Here is the summary from the IWMF Site- www.iwmf.com Some of our other speakers also attended the ASH conference. There is a Dana-Farber press release on both IWMF and our WMUK sites. Dana Farber information is at <http://www.dana-farber.org/Newsroom/News-Releases/researchers-identify-genetic-mutation-responsible-for-most-cases-of-waldenstroms-macroglobulinemia.aspx>

A single gene mutation in 90% of Waldenstrom patients whose DNA was sequenced. This mutation will help to distinguish WM from other types of lymphoma, multiple myeloma, and MGUS. This mutation produces an abnormal protein which activates the NF-kB pathway, essential for the growth and survival of WM cells. When researchers shut down this pathway with drugs that blocked the abnormal protein, the tumor cells died. Healthy cells did not. This suggests that new, effective treatments that target WM tumor cells directly are on the horizon

Patient Tales - can you help? We are having a 'wall' of Patient Tales at the Forum, and a selection will be put later on the WMUK website. These are brief summaries of your 'journey' since WM diagnosis, giving basic details of when and where treated, your personal response to the disease and any other comments you would like to make. A photo would be good. You do not have to attend the Forum to submit to WMUK. Ideally it should fit on one sheet of A4 and be easily readable, in Word or PDF format. Email me if you have any questions. Our website has a specimen. This will be a valuable exercise if enough people respond and thank you to those who have already indicated. At the forum there will also be displays from other organisations including: **Rare Disease UK, The Lymphoma Association, Macmillan, National Cancer Research Network, European WM Network, the IWMF and The Binding Site.**

Please don't leave registering until the last minute! - Thank you very much if you have registered, but if not, can I encourage you to come to this very special international event and PLEASE don't leave registration to the last minute. We are already 60% subscribed two months from the event, with delegates from Australia, France, Belgium, Ireland, Netherlands, USA, Sweden, Finland, Norway, Denmark, Germany, Greece and of course the UK. It would be good if you could forward this message to anyone else who may be interested *or to your clinic or specialist*. You can book online at www.wmuk.org.uk. There is also more information on our website and you can download information about hotels. Any problems registering, just e-mail us! **Early registration (ideally by end of January) is vital to help up plan the day and the Saturday events.**

New Online European Community Launched - Whilst we are thinking internationally, can I direct your attention to a new online WM community WMUK and EWM Network are promoting at - <http://www.rareiseasecommunities.org/en/community/waldenstrm-macroglobulinemia> One of the key features is the ability to post in German, English, Spanish, French and Italian with automatic translation. Join in and make it lively! The moderator is our Phil Manning, of auto transplant blog fame. I cannot emphasise the importance of talking - I recently spoke to a lady diagnosed 7 years ago, and was the first WM patient she had spoken to. Many patients are convinced that WM is so rare that they feel totally isolated, so groups like this do a vital job, so why not join in?

Can I point you to the European WM Network, who are holding a meeting in London on Saturday 10th March for their country Associates. Their website is <http://www.ewmnetwork.eu> The network is an association of European WM support groups and is keen to encourage support groups in ALL European countries - many countries surprisingly, do not have such groups- could you help and get involved? if so contact Marlies Oom at EWM. (Belgium, Denmark, Finland, France, Germany, Greece, Ireland, the Netherlands, Sweden, Switzerland and UK currently have support groups)

On a personal note, It's been an 'interesting' year for me following a successful (to date!) auto transplant at University College Hospital in London and the establishment of WMUK, working with of some of the UK's leading WM specialists. I look forward to meeting many of you who have recently contacted me at the Forum in March and I wish you a healthy and prosperous New Year.

Roger Brown, on behalf of WMUK and 3rd Forum.