

WMUK

UK Point of Contact for
Waldenström's
Macroglobulinemia

Registered Charity Number 1149692

BRINGING WM PATIENTS AND DOCTORS CLOSER

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Newsletter No 5 - Summer 2015

Laugh4Rory 10th October- 7-30 pm - book now!



The late newsreader Rory Morrison was a founder member of WMUK and after his death in 2013, friends and colleagues at the BBC have very much kept his memory alive with numerous internal fundraising events for us such as Bake4Rory. Now they have come together under the direction of Lyndsay Fenner (producer of the BBC R4 *News Quiz*) to provide a really good evening of family comedy, with many well known R4 comedians and special guest appearances at the Bloomsbury Theatre, 15 Gordon Street, London, WC1H 0AH. Tickets are selling well on the Bloomsbury website <https://www.thebloomsbury.com> We have a very good arrangement with the theatre, commercially run, but owned by UCL which means that if we fill it we will raise up to £10,000 to support our projects. **If you can sponsor the show or take space in the programme, let us know at info@wmuk.org.uk**

We are also including a special small £25 goodwill programme message space where you can place a 20 word message of support - this will be via the WMUK site www.wmuk.org.uk The evening will provide a really good opportunity for groups and families to book seats - there are only 550 and there is a decent bar to meet up and have a chat beforehand. A great evening of entertainment, our largest event ever and time for a big group hug!

Travel Insurance - any thoughts?

This is a thorny problem for many of the WM community, who are a pretty adventurous bunch. Many of the automated medical screening sections of online sites are pretty unhelpful and lump us in with NHL generally, and take no notice of the treatments which have greatly improved outcomes, so people are rejected or given very high premiums. The indolence of WM for most patients means that any hospitalisation is usually planned, and few have any day to day complications which might lead to a claim. **We want to hear from you** about any firm you have used which seems to have a reasonable attitude - to info@wmuk.org.uk and then we will attempt to work with one or two closely (possibly in conjunction with the Lymphoma Association) to produce a recommendation.

STOP PRESS- Ibrutinib approved for relapsed WM by EU!
See P3

Birmingham Regional Meeting

This was our first regional meeting, held at the iconic Library of Birmingham, and was a full house with about 65 patients, carers and doctors bringing us up to date on treatments and diagnosis. The more intimate meeting lent itself to experimenting over and above the formal talks and Q & A, with four patient volunteers showing us in a moving way how WM had affected their lives, and then answering questions. There were the usual displays and the event was kindly sponsored by the Binding Site, who are a Birmingham based assay firm. Many took the opportunity to explore the library and viewing platform. We hope to put on more regional meetings where there is demand from doctors and patients.



Our Doctors!

WM patients in the UK are amazingly lucky in the number of expert doctors signed up to the WMUK Doctor forum. Many have international reputations and all work very co-operatively together. In May, Drs. Shirley D'Sa and Roger Owen were honoured to be the only non-USA doctors invited to New York for a special international meeting (including Steve Treon) to map a pathway ahead for treatment. The outcome of the meeting is reported in the current IWMF *Torch*. www.iwmf.com/sites/default/files/docs/Torch_16.3_July2015.pdf At their last meeting our doctors also agreed in principle to developing WM centres of expertise in the UK, which is the way to go for rarer diseases, especially WM, which presents in so many ways and needs back-up services such as scanning, neurologists and amyloid specialists to integrate care.

Cancer Drugs Fund Rejects Velcade

Thanks to all who helped in our the campaign to reinstate Velcade® (Bortezomib) as a treatment for relapsed WM by contacting your MP and using social media. This was supported by the Lymphoma Association. The technical data was presented to the committee very ably by Dr Shirley D'Sa. The level of discussion was poor, ignored the peer reviewed national guidelines and the committee seemed to focus more on cost reduction. The application was rejected. At previous meetings, Ibrutinib had been approved for Mantle Cell lymphoma and CLL which would have been encouraging for a future application for WM (now that it has been approved at EU level.) However we understand that there is pressure to have these reviewed and possibly delisted soon. Potentially very disappointing indeed.

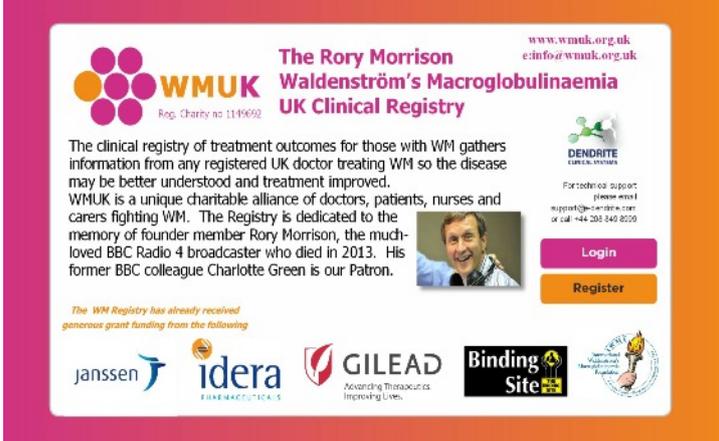
Do we have your up to date email? If you have changed or acquired a new email, please let us know so we can keep in touch and keep costs down.

A Summary of current projects

WMUK is committed to funding four ongoing complex projects, over and above providing support and information - with others on the horizon. It was tempting to say 'job done' after last summer's marathon effort, but there is a lot more to do to improve the lives of WM patients.

The Rory Morrison Clinical Registry - (Set Up £26,000, maintenance £10,000 a year)

Fund raising was through the appeal, via pharma companies, IWMF, family trusts and BBC colleagues of Rory. Set up costs were successfully raised, but to ensure we can guarantee its operation far into the future and encourage doctors to enter data we will need to establish an operating fund of £10,000 a year. This should also cover extending the Registry to include patient provided, remotely entered 'quality of life data' which is increasingly demanded by regulators to grant approval. This will be done via your mobiles, tablets or PCs. The data extraction tools provided as part of the Registry package will help researchers improve the knowledge and effectiveness of treatments. The technical side of this is being driven by Dr Helen McCarthy at the Royal Bournemouth Hospital, in conjunction with Dendrite, one of the largest providers of medical software, widely used in the NHS.



The Rory Morrison Waldenström's Macroglobulinaemia UK Clinical Registry

The clinical registry of treatment outcomes for those with WM gathers information from any registered UK doctor treating WM so the disease may be better understood and treatment improved. WMUK is a unique charitable alliance of doctors, patients, nurses and carers fighting WM. The Registry is dedicated to the memory of founder member Rory Morrison, the much-loved BBC Radio 4 broadcaster who died in 2013. His former BBC colleague Charlotte Green is our Patron.

The WM Registry has already received generous grant funding from the following:

janssen **idera** **GILEAD** **Binding Site**

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Initially we envisaged that the Registry, which is about to launch, would be filled by new data, but if **£12,000** additional funding can be found **now** we could also rapidly populate (using paid data entry) with historic data to speed up the process of study and research. UK Doctors have a really hard time getting support to enter high quality data, and we are looking at ways of helping them with this administrative support.

The UK Biobank (£20,000 a year for two years initially)

This joint project with the IWMF will store tissue and blood plasma samples at University College Hospital London for DNA analysis - increasingly the key to developing targeted personal medicine where treatments are matched to DNA defects. Matched funding is secured for an initial two years only and the project has started. We need to fund into the future and extend the capture of WM DNA to other sites. Dr Shirley D'Sa at UCLH is in charge of this project. This will be linked to the Registry.

WMUK/University of Leeds Fellowship: IgM production in WM (£10,000 a year for 4 years)

This new venture is a PhD Project at Leeds Teaching hospital under Dr Roger Owen, where existing WM tissue samples will be studied and DNA defects related to IgM production in patients, to establish production mechanisms. An appointment had been made as we went to press.

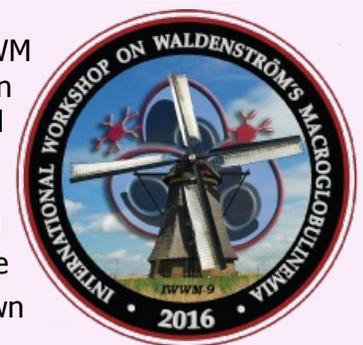
GECEP 100,000 genomes DNA Project - (See clinical article)

Here the costs involved are collecting DNA samples and sample containers - we are budgeting **£5,000**

So the cost of UK projects alone in the next four years is nearly £90,000 - so we need your help!

IWWM9 – Amsterdam 2016.

Every two years the WM great and good get together to discuss advances in WM treatment and new drugs. This is led and organised by Steve Treon and Chris Patterson at Dana-Farber in the USA. The very successful meeting in London last year attracted over 200 for both the technical sessions and the Sunday doctor - patient international meeting. The latter was jointly organised by the IWMF in the USA and WMUK, and we hope have similar format again for Amsterdam working with the host team, and maximise patient attendance. How about a coach party or a Eurostar group from the UK? The doctor-patient day should be on the 9th October 2016. IWWM9 has its own website: <http://www.wmworkshop.org/conferences/amsterdam-2016>



British Society of Haematology Meeting - Edinburgh

We ventured north of the border in April at the BSH where 1000 serious haematologists met and listened to the latest trials results.

It gave us the chance to increase the number in contact with us, develop our display materials and dispel the idea that WM is a very rare disease in academic backwater. Hopefully it will increase those who are prepared to give out our materials to the newly diagnosed. We also launched a modified doctor WM treatment survey, based on one in 2014 to better understand the patterns of treatment in the UK which is now online. The only specific WM talk was by Steve Treon of Dana-Farber who updated his talk to the 2014 London Forum. Next year in Glasgow there is to be a bigger WM programme, and we hope to be able to assist aspiring WM doctor specialists to attend, produce abstracts and poster sessions, funds permitting, as this year there was very little WM clinical material on display.



Doctor completing the online treatment survey

Monthly Giving - Thank You

Again, thanks to those who have joined the monthly giving programme by standing order. This has given us much more certainty and enabled Trustees to be confident when dealing with future projects that entail long term funding. You can also help us to reclaim 25% extra using Gift Aid if you fill in one of our forms. Just send an email to Roger at info@wmuk.org.uk and you will be sent our bank details. Even very modest monthly donations help a great deal. Don't forget we also have pages for BT MyDonate and JustGiving for sponsored events, and a toolbar for online shopping using Easyfundraising which has raised £300 so far.

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

Clinical News

Ibrutinib Approved by EU

We have featured Ibrutinib (Imbruvica) trialists in previous newsletters, and we are glad to be able to announce that it was granted marketing approval for relapsed WM by the European Medicines Agency on 10th July. This is the first European approval specifically for WM. WMUK were happy to comment positively in the Janssen UK press release. The firm now have the task of gaining approval for reimbursement in England through NICE or the Cancer Drugs fund as well as in the devolved administrations. We are having discussions to see if UK doctors can provide more data to demonstrate unmet treatment need to justify the substantial cost, using the Registry. In the USA the drug is becoming commonly used in insurance funded treatment, but research seems to be focusing on combinations of Ibrutinib plus one or two other existing treatments. Ibrutinib is the first BTK inhibitor to be widely used, and takes the form of daily oral tablets.

UK Trials Update

As part of the web update we are adding a clinical trials page to encourage uptake as finally there are several open or about to open. This is not a trivial task. They are well documented, but they tend to open at different times in different centres as they get local approval, and we want to be able to give both doctors and patients up to date information. At present the **R2W trial** (BCRvFCR) is open in many centres and recruiting ahead of target, and will be joined by **ECM1 (DRC+-Velcade)**. Also opening is **Innovate** (Ibrutinib+ Rituximab V placebo + Rituximab) and **Acerta ACE-WM001** (ACP 196 BTK Inhibitor) at 6 sites - also recruiting well according to Dr. Roger Owen at Leeds. Details can be found at <http://www.clinicaltrials.gov> This is an American site, but lists worldwide trials for WM, but is not always fully updated.

Education Seminar - early 2016

As a result of our recent Doctor Forum meeting at UCLH, we will hold our first professional training day for clinicians (doctors and specialist nurses) at the Royal Free Hospital Hampstead. We are currently seeking sponsorship and finalising the date and intend to invite the Lymphoma Association to participate. If you could encourage attendance by your doctor, that would be ideal.

Genomics UK - GECIP

WM has been accepted as a 'sub domain' in the myeloma domain in the UK '100,000 Genomes' Project. This initiative is by Professor Simon Wagner at Leicester University of our Doctor Forum. Overall this involves mapping the whole genome of 100,000 UK patients. This is very new, but it will allow our patients to join the scheme to have their DNA mapped for chromosome abnormalities, which is likely to affect success of new treatments. It's probable we shall have to raise funds for such attractive things as spit containers for samples! Congratulations to our doctors who have placed WM in a very advantageous position. The NHS is looking towards this 'personalised medicine' as a way of improving treatment whilst keeping costs under control. You can find out more at www.genomicsengland.co.uk/about-gecip/gecip-domains

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 Hematologist 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, Jamail Kothari, Churchill Hospital, Oxford. **Patients:** Roger Brown, Phil Manning, Iain Purchase, Colin Rainford

Registered Charity Number 1149692 Patron: Charlotte Green; Trustees: Dr Shirley D'Sa, Kenneth Dias, Roger Brown, Phil Manning, Dr Helen McCarthy, Dr Guy Pratt, Colin Rainford