



## WMUK Patient – Doctor Summit July 2019, King's Fund, London

**Over 150 delegates attended the annual WMUK Patient – Doctor Summit at the King's Fund, London on Saturday 6 July 2019 – our largest Summit so far. WM patients, their supporters, expert doctors, and representatives from other blood cancer charities came together to hear presentations and panel discussions; to ask questions of the experts; and take part in small group sessions to share experiences.**

Highlights of the day included an early-bird session on Understanding WM by Dr Shirley D'Sa from University College London Hospital which hosts the largest WM clinic in the UK. Delegates then enjoyed a session focused on the psychological aspects of living with WM. There were entertaining, inspiring and upbeat presentations from Oxford-based psychiatrist Dr Iain Jordan and WM patient Bob Perry who talked about how setting up a WM support group helped him cope with his diagnosis. The morning session concluded with a panel discussion about the WMUK Rory Morrison Registry and the work it is doing to support the collection of data about WM patients' experiences of treatment, including Ibrutinib.

A new format in the afternoon gave patients and their supporters the opportunity to meet others in small group sessions, as well as book into an individual 5 minutes session with one of the WM expert doctors who were present throughout the day.

A parallel session focused on What's New in WM, with speakers including Dr Roger Owen from Leeds giving informative presentations about new treatments and clinical trials.

*continued overleaf*

*Bob Perry*



WMUK is the only charity in the UK focused solely on Waldenström's Macroglobulinemia (WM).

We work to improve the quality of life of people with WM by providing support, and ultimately finding a cure.

[www.wmuk.org.uk](http://www.wmuk.org.uk)

We were delighted to welcome a significant number of new people who were more recently diagnosed and attending the Summit for the first time, as well as meeting old friends and Summit 'regulars'.

Thank you to everyone who attended, spoke and helped us to put on this event. For future events, we will look at making presentations available via the website. We are also looking at how we can support more regional groups and meetings for people who want to get together in between national Summits (see Support Group news on page 5).

Cat Colebrook was attending her second WMUK Summit since her diagnosis. Cat said, "The Summits have been big milestones for both me and Matt, my husband. We attended in 2018 for the

first time which was just 8 months after being diagnosed. We jumped in feet first, it was scary but it felt like the right time to connect with people with WM. We didn't know what to expect but we knew we wanted to make links and learn more. This year, it was more to support WMUK and to catch up with those people we'd met the year before. Now it's about living as long and as well as possible without a focus on the cancer label. This year, it was so lovely to catch up and have a laugh with the people we'd met last year who had provided guidance and an understanding ear. The Summit provides a wealth of useful and important information but also for us it gives us the opportunity to have that annual connection with others which means so much."

Read about Cat's fundraising efforts on page 4

Eric Low



Lindsey Bennister



Colin Rainford

Dr Shirley D'Sa



Bob Perry



# Research

## The Rory Morrison Registry update

The WMUK Rory Morrison Registry is the charity's flagship research project. It collects anonymised clinical data about WM patients at key hospitals around the country, providing us with an in-depth understanding of, and insights into, the way WM behaves and how treatments impact on patients. The Registry is hosted at University College London Hospital, and is run by a small team of clinical fellows led by Dr Shirley D'Sa. The work of the Registry is guided by a Registry Committee that is made up of WM experts – patients and clinicians who are closely involved in WMUK's work.

The Rory Morrison Registry's PROMs project (Patient Reported Outcome Measures) is continuing to enrol patients and we are pleased to announce that we now have more than 120 participants. Questionnaires are sent out every three months via email or text, designed to assess the impact of WM on daily life and overall wellbeing. This project will provide

us with valuable new insights into WM and how it affects patients. We are very grateful to everyone participating in this. For more information about this project or to sign up, please email [registry@wmuk.org](mailto:registry@wmuk.org).

A current priority for the Registry is the collection of data relating to Ibrutinib. This treatment is available for WM patients in England and Wales via the Cancer Drugs Fund whilst more data is collected. NICE (the body that appraises new treatments in England) will carry out an assessment of the effectiveness of Ibrutinib for WM (within the next 18-24 months) and will make a recommendation about whether funding via the NHS will be continued. WMUK and the Registry are playing an important part in the collection of these data and the presentation of patient experiences to NICE to support the continued funding of this important treatment. We will keep you informed about developments.

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## BIObank project

Many WM patients have taken part in our biobank project, providing saliva samples at our national Patient-Doctor Summits. We have been storing donated serum and saliva samples in the biobank which is hosted by University College London.

We are now using these samples as part of an exciting project together with the National Institute for Health in the United States, who will be analysing over 100 of our samples in order to look for previously undiscovered genetic causes of WM.

This analysis focuses in particular on familial cases of WM. This is a fantastic example of what can be achieved when patients and clinicians work together, and from international research collaborations.

Thank you to all the patients who have donated samples!

## Clinical trials update

The 'PembroWM' trial will investigate the use of the Pembrolizumab/Rituximab combination in patients with relapsed WM who have already received at least one other treatment line. Pembrolizumab has previously been used for several other conditions and has shown early promise in WM; this trial will explore its effectiveness for WM. This trial will soon be available for patient participation in eight centres across the UK.

The 'RAINBOW' trial aims to assess 'chemotherapy free' first line treatment for WM. Currently, Ibrutinib is only being used as single-agent for patients who have already had chemotherapy. This trial will compare the existing combination chemotherapy option of Dexamethasone, Rituximab and Cyclophosphamide (DRC) with the non-chemotherapy combination of Rituximab and Ibrutinib (RI) for patients who have not previously had any treatment. It focuses on assessing safety and effectiveness and offers patients a chance to receive this novel combination. This trial will open in several centres in the near future.

**Your doctor will be able to give you more information about these trials, or contact us at [info@wmuk.org.uk](mailto:info@wmuk.org.uk)**

# Fundraising

## 2 Castles Run, June 2019

In 2018, WM-er Cat Colebrook took on the 2 Castles 10k run from Warwick Castle to Kenilworth Castle. She was joined by seven friends and family all dressed as Where's Wally, to raise funds for WMUK. In June this year, Cat decided to do it all again but this time with 2 buggies and 2 children, all dressed again in Where's Wally costumes.



Cat said "We did it! We even won "best fancy dress" medals. I'm so proud of the team and all that we achieved. It was tough, so tough but I did it in 00:58:53 so smashed my target of under an hour. We had the amazing Mike and Neil pushing kids in buggies for 10k up all the damn hills. Laura pushed so hard to get in just seconds over an hour. Jola and Jen kept us company and talked us round the course when we were struggling. Unfortunately, an injured Matt was unable to run but was still very much part of the team in cheering us on at the finish. It

really and truly was a team effort. Living with this rare cancer brings loneliness and immense uncertainty. WMUK have helped me understand more about my diagnosis and provide some hope that a cure may be found in my lifetime."



Cat also became a radio star for the day, being interviewed live on BBC Radio Coventry and Warwickshire. Cat and her

Where's Wally team raised an amazing £1000 for WMUK – thank you so much!



## Cycle ride in memory of Phil Manning, August 2019

Phil was one of the founders of WMUK and a much-loved member of the WM community. Over the August bank holiday weekend, Phil's family and friends took on an epic cycle ride from Amsterdam to Calais to raise funds for WMUK.

Phil's daughter Nicola said, "My lovely Dad, Phil Manning, sadly passed away from WM in October 2017 and since then I had wanted to set myself a challenge in order to raise money for WMUK. Luckily some of my amazing colleagues (including my husband) agreed to join me in cycling over 300km from Amsterdam to Calais. We completed the ride in three days and had a fantastic time doing it! It was definitely a huge challenge but a greatly enjoyable and rewarding one too. We were blessed with beautiful weather throughout and although the heat made it super tiring at times, whenever the

going got tough, I would remind myself of why I was doing it and that helped me to keep going! We managed to just beat our target of £1500 for WMUK too."



## London Marathon April 2019

Grant Huddleston ran a fantastic race in a WMUK vest, completing the London Marathon in 4.15, a personal best. Grant followed this up 5 weeks later with the ultra-marathon Race to the Tower, completing the 53 miles after 13 hours of running!

Grant raised £800 for WMUK in support of his father-in-law who has WM.

# Support group news

Surrey,  
Hampshire,  
Sussex,  
Dorset &  
Wiltshire

WM patient Bob Perry who runs the Bournemouth and District WM Support Group (BAD WMers) has decided to make his Support Group more accessible to other patients outside of Dorset. This is as a result of the interest expressed at the national Summit in London recently. He has booked a Community Centre at Badger Farm, near Winchester (close to the M3 motorway).

The Group will meet from about **1pm -4pm on Saturday 23th November** and will have a few speakers. He hopes to attract patients and partners who live in the Surrey, Hampshire, Sussex, Dorset and Wiltshire areas. Bob will put more details out nearer the time, but would appreciate an expression of interest so that he can consider numbers. Bob is away until 14th October but please let him know on bob5773@hotmail.co.uk

London  
&  
South East

You are invited to join other WMers for a social event at **2pm on Friday, 18th October 2019 at Maggie's Barts, London EC1A 7BE**. The afternoon starts with a health walk with an opportunity to meet fellow WMers while taking in some of the fascinating history of the city of London. This special walk will be led by a City Guide and volunteers from 'Walking for Health' and the Maggie's centre, and is being organised just for us. After the walk, one of the Maggie's staff will give a short welcome and introduction to the centre. Representatives from WMUK will also be there to talk about the work of the charity, and there will be time to mix and mingle.

We are limited to around 30 places for this event. Places will be allocated on a first-come basis. To register your interest, or for more information, please contact the WMUK office by email: info@wmuk.org.uk or phone: 020 3096 7858. The location details and directions to the centre can be found at [www.maggiescentres.org/our-centres/maggies-barts](http://www.maggiescentres.org/our-centres/maggies-barts)



## Roger Brown

WMUK founder, trustee and patient, Roger is a familiar, well-known, and much-respected presence in the WM community. He established WMUK, alongside Dr Shirley D'Sa, as a unique organisation focusing on support for patients, carers, doctors and nurses involved in the treatment of WM. Over the years, Roger has dedicated his life to others with WM, whilst also coping with his own health problems. He has provided a lifeline to so many people through his expert advice and support. Roger has been a determined crusader for access to new treatments for WM and successfully campaigned for Ibrutinib to be available through the Cancer Drugs Fund. His foresight led to the establishment of the Rory Morrison Registry which has given us a greater understanding of how WM affects patients.

In July 2018 at the annual Patient-Doctor Summit, Roger announced his wish to 'retire' from the day-to-day running of the charity and plans had been put in place to enable Roger to do this. This transition has now been achieved. With a new Chair of Trustees in place, and the charity's first Chief Executive appointed in April 2019, Roger is completing his retirement from WMUK, stepping down as a Trustee of the charity. He continues his work as chair of the European WM Network.

We would like to say a huge and heartfelt thank you to Roger, and his wife Alison, for their dedication to the WM community. We look forward to keeping in touch and seeing them at WMUK events in the future.



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**020 3096 7858**

24 hours - leave a message and we'll call you back

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### How you can help...

WMUK is a small charity that relies solely on donations from supporters. If you would like to support us in our work, please email [lindsey.bennister@wmuk.org.uk](mailto:lindsey.bennister@wmuk.org.uk) or call **020 3096 7858**