

**EUROPEAN
WM
PATIENT FORUM**
iWMF **Wmuk**

21 October 2023



European WM Patient Forum

Saturday 21 October

Birmingham & Amsterdam

WMUK is registered as a charity in England and Wales (1187121) and a company limited by guarantee in England and Wales (12358324)

The IWMPF is a not-for-profit organization under the IRS code, section 501(c)(3).

EIN: 54-1784426

Welcome to the 2023 European WM Patient Forum

Whether you're in Birmingham or Amsterdam, we're delighted that you can join us for a day of community, learning and sharing.

We'll be streaming sessions between our two venues, giving you unprecedented access to experts and patients from across Europe.

Find enclosed the programme, more information about your speakers and our organisations.

WMUK and the IWFM are charitable organisations, relying on you to fund events like this. If you've used our services, please consider donating so we can continue to bring expert information and personal support to the WM community.

Donate to WMUK



Donate to IWFM



What to expect from today

Live-streamed session

Some sessions are being streamed between both locations. These are highlighted. See the Birmingham schedule for speakers based in that location.

Amsterdam

8.15 Morning Walk (optional)

8.45 Registration and coffee

9.30 Speed-dating Bob Perry

10.15 Support worker and PhD posters

10.45 Welcome and introduction Newton Guerin

11.00 WM in the body – what is it, how does it develop and why do I feel this way? Dr Josephine Vos

11.30 Living with WM Dr Marie José Kersten

12.15 Current WM treatment landscape Prof Christian Buske

12.45 Lunch

1.15 Approaching clinical trials Prof Monique Minnema

1.45 What's new in WM? Dr Simon Ferrero

2.15 Coffee Break

2.30 Fatigue Stream from Birmingham

3.00 Mental Health and Active Monitoring Dr Sarah Dwinger

3.45 Ask the HCP – panel Facilitator – Carl Harrington

4.30 Close Newton Guerin

What to expect from today

Live-streamed session

Some sessions are being streamed between both locations. These are highlighted. See the Amsterdam schedule for speakers based in that location.

Birmingham

9.15	Registration and coffee	
9.45	Welcome and introductions	Jane Nicholson, WMUK CEO
10.00	WM in the body - what is it, how does it develop and why do I feel this way?	Dr Dima El-Sharkawi
10.30	Living with WM	Dr Shirley D'Sa
11.15	Coffee break	
11.30	What are my symptoms and how do I manage them? - Panel	Charlotte Bloodworth Will Franks Sandra Holstead
12.15	Approaching clinical trials	Harriet Scorer
12.45	Lunch	
1.30	Fatigue	Vern Middleton Isabella Jones
2.00	Mental Health and Active Monitoring	Dr Catherine Ogilvie
2.45	Ask the HCP - panel	Facilitated from Amsterdam
3.30	Getting involved in research - putting patients first	Joy Ellery Orlando Agrippa Jonathan Moshinsky
4.15	Close	Jane Nicholson
4.40	Clinician 1-2-1s	Please book at registration

Your speakers

Our speakers come from a range of backgrounds, from expert healthcare professionals through to patients at different stages of their WM journey. Some will be presenting in Amsterdam, others in Birmingham.

In Amsterdam



Dr Josephine Vos

is a staff haematologist at the Amsterdam UMC/University of Amsterdam. Together with Prof. MJ Kersten, she leads the WM expertise centre. Also, Dr. Vos is the chair of the Dutch WM guideline committee. She received her PhD on WM in 2019 at the University of Amsterdam, after having also spent 6 months for a fellowship with Prof Steven Treon at the Bing Center for WM at the Dana Farber Cancer Center in Boston, USA. In her clinic, she sees patients with WM as well as IgM related disorders such as IgM neuropathy, and Cold Agglutinin Disease. She (co-)supervises 4 PhD students working on those diseases. She has initiated 2 clinical trials in the field, and is an active member of the international WM community.



Dr Marie José Kersten

is a professor of haematology at Amsterdam University Medical Centers.

B-cell malignancies are the main focus of research in this department which forms the basis for the LYMMCARE

Institute (Lymphoma and Myeloma Center

Amsterdam). Dr Kersten is the principal investigator

investigator for several phase I/II clinical trials focusing on the biology and treatment of NHL, WM and Hodgkin lymphoma.

She is the chair of the European Hematology Association (EHA) Scientific Working Group Lymphoma. She is also an

active member of the international Lunenburg Lymphoma Biomarker Consortium (LLBC) and the European

Waldenstrom's Macroglobulinemia Consortium (EWMC).



Professor Christian Buske

is the Medical Director at the University Hospital Ulm, leads the Institute of

Experimental Cancer Research at the University of Ulm, Germany, and is an

attending physician and senior consultant

at the Medical Department or Internal

Medicine III, Hematology/Oncology, University

Hospital Ulm. He and his colleagues are coordinating the

European Consortium for Waldenstrom's macroglobulinemia

(ECWM). Prof. Buske is principal investigator of several national

and international trials in indolent lymphomas such as WM. In

addition he is heading up a large translational research group

focusing on the biology of haematological neoplasms.



Prof Monique Minnema

initiated and supervises the haematology clinical research team, which coordinates and supports all clinical studies at the Department of Haematology. Her main focus of clinical research is the

development of novel therapies (both cellular and drug) for plasma cell disorders and lymphoma.

She was a member of the organising committee of the 2016 International Waldenstrom's macroglobulinaemia workshop in Amsterdam. She is the co-author of many WM related national and international guidelines and the lead author on the first international guidelines for Bing Neel Syndrome. In addition, she is a member IWMF Scientific Advisory Sub-Committee on the Waldenstrom's macroglobulinemia Global Awareness Building Initiative.

Want to ask our speakers questions?

To submit your question and take part in polls:

1. Type www.sli.do into your web browser
2. Enter 'PatientForum2023' into the event code box
Select 'Join event'
3. When polls are activated, you will be prompted to take part and submit a response
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Dr Simone Ferrero

attended medical school and was trained in Hematology at the University of Torino, Italy. He completed further fellowship training at the University of Munich and at the University of Kiel (Germany). He has been Assistant Professor in Haematology at the University of Torino since 2016, where he attends both clinical duties, caring for lymphoma patients, and clinical research, as well as leading a translational research group in the haematology laboratory. He sits on the board for the Italian Lymphoma Foundation (FIL) and chairs its scientific committee for biological studies. He is also a board member of the European Mantle-cell Lymphoma Network and a member of the European Consortium for Waldenstrom's macroglobulinaemia. His main interest focuses on lymphoma research and application of molecular biotechnologies in clinics.



Dr Sarah Dwinger

is a psychotherapist and psycho-oncologist currently working at the Department of Medical Psychology, University Medical Center Hamburg, Eppendorf. She has conducted research in psycho-oncology, cancer survivorship and patient centered care/shared decision making. Her research topics include 'Health Coaching for Chronic Conditions.



Newton Guerin

is the President and CEO of the IWMF. He brings over 40 years of leadership experience with senior management positions in four of the USA's leading voluntary health agencies. His previous roles include: National Representative, American Cancer Society; Chief of Staff, National Multiple Sclerosis Society; Regional Director, Leukemia & Lymphoma Society; and CEO, American Liver Foundation.



Carl Harrington

is the the Chair Emeritus for the IWMF and served as the volunteer president and CEO for eight years, from 2013 to 2020. During this tenure, he was key to creating the IWMF Strategic Plan – including the vision, mission, values, and global imperatives, as well as the IWMF-LLS Strategic Research Roadmap initiative. His leadership brought significant fundraising and revenue increases. Currently, as Chair of the IWMF Global Patient Initiative, he actively promotes the IWMF vision and mission worldwide. Carl was diagnosed with WM in 2006 and has been in watch-and-wait ever since.

In Birmingham



Dr Dima El-Sharkawi

is a haematology consultant at the Royal Marsden Hospital. Her specialist interest is lymphoma including WM, CLL and the mature lymphoid leukaemias. She is clinical lead for the SIHMDS (regional diagnostic laboratory) at the Royal Marsden Hospital. She is the lead for the clinical advisory board (CAB) for WMUK and is an author on the recently published guidelines for the diagnosis and management of WM.



Dr Shirley D'Sa

is a founder trustee of WMUK. She is a Consultant Haematologist with a special interest in WM and runs the largest WM clinic in the UK at University College London Hospitals (UCLH). She leads WMUK's Biobank and Rory Morrison WMUK Registry projects that collect and store clinical data about WM.



Will Franks

is WMUK's former Chair of Trustees and lives with WM. He has been a successful founder and entrepreneur in the tech world, as well as a Chariman, CEO, and Non-Executive Director for various companies. Will is currently taking a sabbatical to focus on having fun and living well.



Charlotte Bloodworth

is a Haematology Advanced Nurse Practitioner currently working within the Lymphoma service at the University Hospital of Wales in Cardiff. Charlotte qualified as a registered nurse from the University of Nottingham in 1995. Since joining the Cardiff team in 2003 she has worked on the general Haematology ward, the Bone Marrow Transplant Unit and the Day Unit before becoming Lymphoma Specialist Nurse in 2009. Then in 2017, she started in the new post as an Advanced Nurse Practitioner in Lymphoma, which enabled the service to continue develop and expand in ways not able to before.



Sandra Holstead

worked within the NHS for 27 years as part of a dental team. She was subsequently diagnosed with WM at the age of 44. She didn't require treatment straight away and had 6 years of active monitoring while coming to terms with her diagnosis. After developing symptoms, she had 8 cycles of chemo (RCP), which gave her a partial remission until 2019. She then started on ibrutinib which gave good control of her symptoms. Since 2021 she has been on the LOXO 305 clinical trial and considers herself to feel as well as she did before her diagnosis! She believes there are some exciting advances in the treatment of WM and passionately believes that everyone should have access to them.



Harriet Scorer

is a patient trustee of WMUK bringing her extensive experience of living well with WM to the Board. Diagnosed with WM in 1999 she has first hand experience of being a mother, carer and colleague whilst navigating the path of treatment options over the years which have included chemotherapy, a stem cell transplant, ibrutinib and now a clinical trial.



Vern Middleton

is a 57 year old Electronics Engineer living in the south of England. He was formally diagnosed with WM in May of 2018 and received 6 rounds of DRC from June to Sept 2018. He loves whilst navigating the path of treatment spending time exploring the great outdoors and has an active runner, mountain biker and sailor for most of his life. Having WM and associated fatigue and peripheral neuropathy has changed his abilities but not his passions. Since his diagnosis, he has strived to reduce the impact of WM on his life and focused on how to live well with WM. He still continues to engage in his outdoor hobbies but in an altered way.



Isabella Jones

is an Occupational Therapist, currently working at The Royal Marsden Hospital.

She has recently specialised with children and young people with cancer, although has a background of working with

adults in both inpatient and community settings. Common symptoms she works with are peripheral neuropathy, fatigue, deconditioning, adjusting to living with a chronic condition. Her main priority is what is important to individuals and enhancing their quality of life.



Dr Catherine Ogilvie

is a consultant haematologist who has been based at Raigmore hospital in Inverness since October 2022. Prior to this, she worked as a consultant haematologist at the Beatson Cancer

Centre in Glasgow, 2012–2022. She completed her haematology training in Glasgow and her medical degree at the University of Newcastle upon Tyne. She has an interest in lymphoma and leads on lymphoma for NHS Highland. She is keen to improve access to clinical trials and nurse specialist support for patients living in more remote parts of the country.



Joy Ellery

was diagnosed with WM in July 2021 and has been taking Zanubrutinib since September 2021. She joined WMUK and the IWMF soon after her diagnosis and has been very grateful for the support

she has received from fellow WMers. Her background is in clinical research and she has been an advocate of involving patients in research and in the wider planning and delivery of health services since she joined the NHS in the 1980s. She retired from full time work in a London acute hospital in 2015 and is now a Patient Safety Partner at the Royal Marsden NHS Foundation Hospital.



Orlando Agrippa

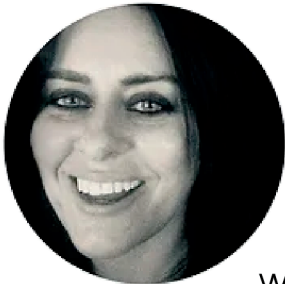
is the Founder and CEO of Sanius Health, established in April 2022. With over 16 years of experience in healthcare, including leadership roles in the NHS, Australia, and the Middle East, he is

dedicated to improving patient outcomes, quality of life, and access to care for those with haematological disorders, malignancies, rare diseases, and chronic conditions. Orlando is an expert in AI, Digital Health, Data Management, Remote Monitoring, and Advanced Analytics. He has a philanthropic spirit, supporting charitable causes and research in the UK, India, and Africa to enhance healthcare outcomes and patient well-being.



Jonathan Moshinsky

is CEO and Co-Founder at Stitch, working to improve the experience of patients on clinical trials, inspired by his father's WM journey. He has 15 years experience in Life Sciences technology, previously holding senior roles at Veeva, uMotif and IBM.



Jane Nicholson

is the CEO of WMUK. An experienced CEO in both the commercial and not-for-profit sectors, Jane has experience in shaping, driving and leading organisations. Jane joined WMUK in March 2021 and is passionate about improving WM patient outcomes.



Ask our speakers

We'll have roaming microphones at all our question times, or you can submit questions to speakers at any time through our event website.

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1. Scan the QR code below or type www.sli.do into your web browser
2. Enter 'PatientForum2023' into the event code box Select 'Join event'
3. When polls are activated, you will be prompted to take part and submit a response
4. Otherwise you may send in any questions you have for our panel and upvote those of your fellow audience members

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Here for anyone affected by WM

WMUK is the only charity in the UK focussed on supporting people with Waldenstrom's macroglobulinaemia, helping people to live longer, good quality lives. We provide personal support and expert information, whilst driving research to improve treatment, care, and outcomes.

We run the UK's only Support Line dedicated to helping people affected by WM. Our nurse spends on average 50 minutes talking with patients and family members, giving them a space to talk, helping them find answers and providing reassurance.



A phone call like this costs us £20. We rely solely on voluntary donations to keep this service running – can you spare £20 to fund a call to a patient who needs support and information?

Scan the QR code to sponsor
a phone call today:



Call our support line:

0300 373 8500



The International Waldenstrom's Macroglobulinemia Foundation (IWMF) is a patient-founded and patient-driven, nonprofit organisation.

Our Vision & Mission

Our vision is a World without WM (Waldenstrom's macroglobulinemia). Our mission is to support and educate everyone affected by Waldenstrom's macroglobulinemia (WM) to improve patient outcomes, while advancing the search for a cure.

Research ● **Patient support** ● **Awareness**

Education ● **HCP awareness**

Ways to give

Website: <https://iwmf.com/ways-to-give/>

Scan the QR code:



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Let us know how we did by scanning the QR code below and filling in the quick survey – it'll only take 5 minutes.



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Thank you for your feedback.



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volunteers and generous donors, who
have made this event happen.**



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