**Myositis UK**

**146 Newtown Road, Woolston, Southampton, SO19 9HR**

**Flyer - \\Summer 2025**

**AGM and Conference 6th July 2025 at the Woodland Grange, Leamington Spa**

It is now just four weeks to the AGM and Conference. Thank you to members who have registered to attend the meeting. If you have not yet registered and would like to attend a registration form and accommodation form were sent with the copy of “Myositis News” in February. Please complete the registration form and accommodation form, if required and return by post or email to the office msg@myositis.org.uk

If you have mislaid the form, please email the office with your details.

**CONFERENCE – Preliminary Programme ( order and timing to be arranged)**

**10.30 – 1.00** **Morning session 1.00 – 2.15Lunch - 2.15 - 4.15 - Afternoon session**

Professor Neil McHugh -DM/PM including IMNM and anti-synthetase syndrome.

 Dr Gita Ramdharry - exercise and devices/equipment

 Professor Pedro Machado – IBM

Dr James Lilleker - new IBM diagnostic criteria

Dr Patrick Gordon - NAM/IMNM, emerging treatments and ILD

Dr Alex Oldroyd- Cancer Screening in Myositis

Dr Dow- the importance of psychology in relation to myositis

Dr Shraddha Rane - Patient and Public Involvement and Engagement in Research

Group discussions led by delegates separated into IBM, DM/PM etc., depending on numbers attending in each form of myositis – an opportunity to talk to others.

Question and Answer session - speakers to sit on panel

4.15 – 4.30 Summary and Close

**London Marathon 2025**

The London marathon took place on Sunday 27th April and all seven runners of “Team Muscle” completed the run and raised over £14,000. A full report will be in the next edition of “Myositis News”. However, we would like to thank them in this flyer for all the effort they have made to help us. Also, a big “Thank you” to members who sponsored the team.

**The Inspire Project**

Martha Piper writes,

“I am a research assistant working alongside Melanie Sloan on the INSPIRE project at the University of Cambridge. Thank you to all those who shared our research team’s Challenges in Care and Inequalities survey earlier this year. With your help, we received over 6,000 responses from people living with autoimmune conditions from around the world. We are excited to announce a **webinar via Microsoft Teams to share our results on the 12th of June at 3pm BST**.

We would like to invite your charity communities and networks to attend and hear patients and researchers speak about our findings and how we are using them to improve the lives of people with autoimmune diseases. The joining instructions are below, please share them widely among your networks. A recording will also be available after the webinar for those who can’t attend live.”

[**Join the meeting now**](https://teams.microsoft.com/l/meetup-join/19%3Ameeting_ODU5MGVmN2UtYjY5NC00ZjJkLTk5Y2UtMjBlMGQyNzQzMmU5%40thread.v2/0?context=%7b%22Tid%22%3a%2249a50445-bdfa-4b79-ade3-547b4f3986e9%22%2c%22Oid%22%3a%2256d5f5ea-62c5-4f0f-86ff-6ecf03b4e0c2%22%7d)

**Meeting ID: 389 518 418 016 2**

**Passcode: E98hH7xa**

**New Survey**

**Rheumatology and other autoimmune diseases patient survey from the University of Cambridge**

This survey asks about how you define flares in your disease, what triggers and prevents flares and the order of symptoms in flares. It should take about 45 minutes to complete, and you can pause or stop at any time.

Everyone who takes part can choose to be entered into a **prize draw to win one of four £50 amazon vouchers** when the survey closes, which will likely be in June.

Please click on this link <https://bit.ly/4kOQeyg> to take part.

If you have any questions, please contact Martha Piper on mp2196@cam.ac.uk or Melanie Sloan on mas229@medschl.cam.ac.uk.

This study is part of the INSPIRE project, which is led by Dr Melanie Sloan, who is a rheumatology patient as well as senior academic. Her team includes senior rheumatologists, Prof David D’Cruz and Dr Arvind Kaul, and is well-known as leading the way in fully involving patients as research partners and changing care through the work they publish. This is only made possible by your involvement is studies such as this.

Please see below for some recent relevant articles they have published with your views and experiences:

Prevalence and identification of neuropsychiatric symptoms in systemic autoimmune rheumatic diseases: an international mixed methods study. <https://doi.org/10.1093/rheumatology/kead369>

Telemedicine in rheumatology: A mixed methods study exploring acceptability, preferences and experiences among patients and clinicians. <https://doi.org/10.1093/rheumatology/keab796>

**Inclusive Travel: What Travellers with Disabilities Need to Know About Their Rights**

<https://www.skyscanner.net/news/inclusive-travel-rights-for-disabled-people>

This booklet breaks down the current landscape of accessible travel in Europe; dives into the rights of disabled travellers spanning different areas such as mobility, service animals, and travel insurance; and offers practical advice for accessible holidays.

This guide aims to encourage more people with a disability to explore safely and enjoy travelling.

***This is a very comprehensive guide produced by Skyscanner***