FLYER - AUGUST 2025

Myositis UK Conference

This year we had all the talks videoed and they are now available to watch via the following link. The link will also be on our website (myositis.org.uk). You will be able to click on individual links for each talk. I am sure you will all agree there is much good news and developments now taking place.
https://www.youtube.com/playlist?list=PL6VoLeSXZRk8JKRdxui4DWSPwbsvv_WhN

Talks:
1 - Myositis UK Grants scheme – Professor Lucy Wedderburn
2 - Disease pathways for IBM stratification and therapy – Nathan Routledge PhD Student
3 - New IBM diagnostic criteria - Dr James Lilleker
4 - Sleep disturbances and fatigue in children with Juvenile Dermatomyositis (JDM); do they relate to disease activity and pathology? Dr Charalampia Papadopoulou
5 - Patient and Public Involvement and Engagement in Research - Dr Shraddha Rane
6 - Exercise - Dr Gita Ramdharry
7 - Cancer Screening in Myositis - Dr Alex Oldroyd
8 - NAM/IMNM, emerging treatments - Dr Patrick Gordon
9 - CAR-T cell therapy in myositis - Professor Pedro Machado
10 - The importance of psychology in relation to myositis – Dr Rebecca Dow
11 - Question and Answer session -

Our thanks to all the speakers for making this such an informative and memorable day.

James Loud 38 mile run

James's story;
"I love running, I mean I hate running, I have a real love hate relationship with it like many out there but the person and reason I even tie up my trainers is now suffering. Ever since he was co-leader on "the couch to 5k course" I joined at my local running club, he has been there on many of my milestone runs, pacing me on a ParkRun, my first half marathon to a muddy trail cross country race.

Myositis which many of you won't have heard of is such a cruel condition, attacking the very thing we all take for granted in day to day life, our muscle function. Today, we can't cure it but we can damn try and do something to help rather than just ignore it.

On Saturday, September 13th, I am going to take on my biggest running challenge to date starting at the Myositis UK office in Southampton. I am going to run back to the village where I live, (Sherfield on Loddon) and a local pub, 'The Four Horseshoes'.

The route is close to 40 miles and a mixture of terrain. I will be running with a Myositis UK flag and rucksack to show the reason for my efforts. The Four Horseshoes' Pub will be hosting a village/Family Fun Day with a number of attractions including a raffle, bouncy castle, cake sale and fair ground style stalls etc.

There may also be a running club effort from Sherfield Park Runners on a treadmill outside the pub with a guess the distance event. (As well as a few pub regulars)

I can't just sit by and do nothing. I get times are hard right now, but they genuinely can be harder and however little amount you can spare is so appreciated.
Anything I can raise really will help. Thank you!"

James has raised £2,120 to date

You can sponsor James at https://www.justgiving.com/page/james-loud-1
Or send a donation to the office.

Fun Day Prize Draw at the Four Horseshoes

You can help James raise money and hopefully win one of the fantastic prizes below :

Bombay Sapphire Distillery Gin Tour for 2
The Barns at Wellington – class for you and 3 friends
The Barns at Wellington – 5 Cryotherapy sessions
10 Perform Classes
Four Horseshoes voucher
Body Reset Clinic voucher
Pet Portrait by Louise Hight
Wellington Riding Club House Breakfast for 2
Wellington Riding 2026 Horse Trials Family Ticket
Ocado £50 voucher code
2 Hornet Chilli Gift pack
Cupcakes by Carly
Coach and Horses £50 meal voucher
HDRC Drone S6
Two hour Alpaca Experience at Pennybridge Alpaca Farm
Weybrook Park Golf Club voucher for 2 (worth £100)

To enter for free by post please send your full name, mobile number, email address, country of residence to: 32 Bow Grove, Sherfield on Loddon, RG27 0D. Entries must arrive by Monday 8th of September 2025 ONE FREE ENTRY PER HOUSEHOLD.

To purchase tickets on jumblebee please follow this link:
https://www.jumblebee.co.uk/myositisukfundayprizedraw

You will then see the following where you can make your purchase.

Myositis UK Fun Day Prize Draw
Event Location: Four Horseshoes Pub , Reading Road , Sherfield on Loddon , Hampshire , RG27

Ticket Type	Price	Date	Quantity	Total
6 for £5	£5.00	13/09/25 18:30	⊖ 0 ⊕	£0
12 for £10	£10.00	13/09/25 18:30	⊖ 0 ⊕	£0

Total £0

Powered by stripe

GOOD LUCK EVERYONE!

Steve Makin is fundraising for Myositis UK

Steve writes, “I was diagnosed with antisynthetase syndrome a couple of years ago. As with other forms of Myositis this is a very rare disease, which means there is limited awareness, limited funding and so very limited research and help available to sufferers. At the moment, I am in good health, but for many people the disease is life-changing and life-limiting. It is considered progressive and incurable.

On 20th September (eve of World Myositis Day) I will attempt 100 push-ups and 20 pull-ups in 30 minutes - 120 in 30. I hope my exertion will persuade you to part with some money 😊 . I will (hopefully!) perform this incredible feat 😂 at the Pavilions gym in Horsham, under the scrutiny of one of their personal trainers.”

You can sponsor Steve at https://www.justgiving.com/page/steve-makin-1
or send a donation to the office.

World Myositis Day 21 Sept

This special day is now celebrated every year on **September 21st .**
On the WMD, special attention should be paid to the disease of myositis. Myositis – which can affect adults and children - is a progressive inflammatory muscle disease leading to weakness, muscle loss, fatigue, and sometimes heart and lung involvement. Myositis is a pooling of different diseases and/or symptoms. The public should be made aware of Myositis and the disease should be brought into the focus of research and medicine. Share this information and join us in celebrating **World Myositis Day** every September 21!

Please share this on social media platforms or perhaps have a coffee morning or any other event to raise awareness!

Welcome to the 6th Global Conference on Myositis – GCOM

The organisers write, “We are thrilled to invite clinicians, researchers, healthcare professionals, patients, and industry partners from around the world to attend GCOM 2026, the premier international forum dedicated to clinical care and research in myositis. *This is a science based conference but patients are welcome to attend but there is a cost to attend*.
For more information, please visit https://imyos.org/ *then click on GCOM Meetings.*

Organized by the International Myositis Society (iMyoS), this biennial meeting provides a unique opportunity to share groundbreaking science, foster collaboration across disciplines, and engage with leading voices in the field of inflammatory myopathies.”

🔬 **Scientific Highlights Include:**

Pathophysiology, imaging, diagnosis, and treatment of myositis
Clinical trials and outcome measures
Juvenile and adult myositis, including all subtypes (DM, IMNM, PM, IBM, ASyS, OM)
Patient perspectives and patient-led research
Rehabilitation, organ involvement, and treat-to-target approaches
Interactive clinical cases and transition care
Do not miss this chance to be part of a global community shaping the future of myositis care and research!
We look forward to welcoming you to Lisbon!” **The Organising Committee and the iMyoS Board**

RAISE has been looking at what support is needed by people living with rare autoimmune rheumatic diseases and whether an intervention can be designed that addresses these needs.

“We are currently recruiting for the second part of the project - a UK wide survey to ask people what they would like to see in a support intervention from their NHS teams in terms of content and structure . We have ethics permission to share adverts via patient charity websites, and social media (we are also separately recruiting via NHS sites to get a range of participants).

Recruitment is going well so far but we have some conditions, including Myositis, which are under represented in the responses. We would love to hear more about people's experiences of living with Myositis.

I have attached the poster for the survey which includes a QR code and the direct link. If you are able to share on your social media and/or on the research section of your website, it would be much appreciated. Please do let me know if you need more information or the media in another format.

For context, in the first part of the study we held six face-to-face focus groups with community groups in Bristol, Weston-super Mare and Leeds. The aim of these was to explore the support needs and potential design of an NHS intervention for patients with RAIRDs. We collaborated with patient research partners and community organisations to hear from people who do not usually participate in research. The analysis from these focus groups helped to inform the questions for the survey.”

See enclosed leaflet

Documentary for a Masters degree

Hannah Clubley Writes, “I am Hannah, a Masters student at Bournemouth University, currently working on my final project for my Multimedia Journalism degree.

I am making a 12 minute documentary, raising awareness for JDM, something close to my heart as my cousin was diagnosed with this condition a few years ago. I came across Myositis UK and thought it would be great to include a representative from the charity in my work. I was wondering if I was able to interview someone from your team to help inform my documentary, including more about the condition and the work that you do.

It would entail a 15 minute sit down interview (on camera), but I would need to allow around 45 minutes including set up and pack down. I can send questions over in advance, and you are welcome to have access to the footage at the end of my project if you would like. I am fairly flexible with filming dates but need to get this done in the next two or three weeks. If there is somewhere quiet and light where you are based, I am happy to travel to you and do this at your office if that works?

Irene agreed to be interviewed and the interview took place in the office on the 10th July. It was a pleasure to meet such a lovely young lady with such empathy. We wish her every success with her final project and are looking forward to viewing the documentary.

Please may I have your news and articles for inclusion in the next edition of “Myositis News”.

Please email les@myositis.org.uk