MYOSITIS UK

Spring 2025

Myositis News

NEWS & EVENTS • FUNDRAISING • RESEARCH
CLINICAL TRIALS • AGM 2025

Dear Member,

It is always a pleasure compiling the charity magazine. This format for information was the leading way for the charity to communicate with what was going on in myositis. In recent years, the website and myositis contact pages have proved to be, for the majority, the preferred way to view the charity and communicate what was going on in all aspects of living and coping with myositis. However, for me, the magazine is still a format that brings a brief overview of a period of time, pulling together all the activities and facets involving members family and friends as well as the scientific community.

I trust you will enjoy this edition.

Les Oakley MBE
Chairman

MYOSITIS UK

Conference 2024

The national conference held in Leamington Spa last year was very successful and I offer my grateful appreciation to all who attended. Members' feedback is always essential, and I thank all who made comment particularly where we can improve the programme content. As in all our conferences the medical speakers and scientists gave up their time freely to attend. The Woodland Grange conference centre was very accommodating and helpful making the effort to attend a pleasant and informative experience. It is a pleasure to catch up with members and swop notes and ideas. Topics at the conference covered, "Autoantibodies in Myositis" – Dr Sarah Tansley – University of Bath, "Understanding genetic risk in myositis" – Dr Janine Lamb – Manchester University, "The Gut Microbiome and Autoimmunity" – Professor Hector Chinoy – Manchester University, "Cancer Screening in Myositis?" - Dr Alex Oldroyd – Manchester University, "Update on new clinical trials in JDM" – Dr Charalampia Papadopoulou – GOSH – London, "Update on understanding mechanisms of myositis in children" – Professor Lucy Wedderburn, Institute for Child Health, UCL, London, "Optimise in IBM" – Dr Stefen Brady – Oxford, "IBM-Path: Identifying disease pathways for inclusion body myositis (IBM) patient stratification and therapy" - Nathan Routledge MSc (PhD student) – UCL, London, "Update on the Abcuro trial" – Professor Pedro Machado – UCL, London, "Rheumatology experience in Malaysia" – Dr Tara Mahadevan – Manchester.

To round off the conference there was the usual Q&A session which is always popular, producing a lively and helpful debate.

Bruce Cross

The charity has for some years now had friends who have kindly helped at our functions and conferences. Members who attend our national conference may recall their first point of contact when entering the building was usually with Bruce and Margaret Cross (pictured) on reception. They handed out name badges and conference packs as well as manned the charity merchandise table.

Sadly, I must inform you that Bruce passed away last October. We have lost that kind, caring, smiling face. He had health issues of his own unrelated to myositis but did not let these get in the way of helping other people.

Before Christmas 2023, I was holding a Christmas Luncheon and carol singing to raise funds for a local food bank. The lunch was heading for disaster because I was unfortunately let down by a master of ceremonies and a Father Christmas who could not attend. I saw Bruce about eight days before the event and said to him, “Didn’t you do Father Christmas years ago?” to which he replied, “Yes, for the kids in the street and the working men’s club.” So, I jokingly said, “You are doing it again in eight days’ time, mate!” He did not bat an eyelid for it was not an issue to him.

I managed to hire an outfit, and, on the day, he turned up at the function with Margaret and the pair of them sat at a table with other guests. At the appropriate time they discretely slipped out of sight with Margaret helping Bruce to get dressed up in his outfit and he returned to the hall resplendent with goody sack, ringing his bell to the delight of the children. He was fantastic with the kids, and they loved him.

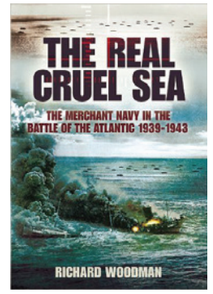
One little lad was coping with autism and when his name was called out and completely out of character he walked alone across the room and when Bruce offered him his present he politely and confidently said, “Thank you Father Christmas.” Well, Bruce was sat in a chair I looked down at him he looked up at me and we both had a tear in our eye! That was the sort of man Bruce was, quiet and compassionate. The event turned into a complete success raising a substantial sum of money, and everybody had a wonderful time. The amazing thing about this was Bruce, after getting changed, returned to the table, and sat down with Margaret and continued with the festivities. The other people sat at the table were completely unaware that he was Father Christmas. Amazing.

However, when you think about it, I reckon people who attend our conferences would appreciate the situation. Bruce just got on with what he had to do, made a significant impact, but discretely settled into the background when the job was done. Life was never about just him, but what he could do for others.

Bruce, I know, would be amused. The limelight was for others but when called on he could step up, make an impact and step back to plain old Bruce. I’m going to miss this old mate for we go back over fifty years. But life goes on and I have some great memories. However, for Maragaret and her family the losing such a loving and caring man must be heart-breaking and I feel for them in their great loss.

Captain Richard Woodman LVO

Captain Richard Woodman LVO sadly passed away in early of October last year. He was a naval historian and distinguished seafarer. He was also a successful novelist who retired from his nautical career in 1997. I expect many of you have read his books. It was in his later years that Richard became involved with the charity raising funds from his many speaking engagements. He may have been a prolific author, but I only ever received from him was a notelet with a few very brief words stating the enclosed cheque was from a talk he had given which he was forwarding to help with charity funds. These were regular gifts with some being very substantial and the background news to them have been published in the charity magazine over the years.



Institute of Child Health

On September 5th, 2024, at the Institute of Child Health, UCL GOS, celebrated the 25th anniversary of JDCBS. Established in 1999, this research study has now evolved into a national cohort study with 17 active centres, making it the largest of its kind for Juvenile Dermatomyositis (JDM) and related inflammatory myositis conditions.

The team said, “The event featured insightful talks reflecting on JDCBS’s growth and how standard healthcare practices in JDM have transformed over the years. We were especially grateful to have several key funders join us, whose presence helped make the event even more successful.”

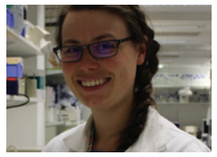
“A heartfelt thank you to all the patients and families who are part of JDCBS — none of this would be possible without your involvement. Finally, we extend our sincere thanks to everyone who participated in this special celebration.”

Parents Day at GOSH

Irene and I attended this meeting at Great Ormond Street Hospital for parents with children living with Juvenile Dermatomyositis. It was a pleasure to meet these families and listen to the talks relating to the disease. We were also invited to talk to the audience about the work of Myositis UK particularly in JDM and how, if they were not already members of the charity, they could join at no cost and be part of a bigger voice in getting research and a better understanding of the many issues of this miserable and often painful illness.

The event featured an introductory session covering JDM, the JDCBS, research initiatives, and ongoing trials. Charities hosted speaking sessions and information stands. Attendees participated in interactive Q&A sessions and age-group-specific parallel activities, including psychology, physiotherapy, art therapy, science and research games, and quizzes. This engaging day fostered community connections while providing valuable insights and resources to support families affected by JDM. The event was very well received, with positive feedback from both children and adults, highlighting the value of the activities and the supportive atmosphere.

Dr Meredyth Wilkinson



Congratulations to Dr Meredyth Wilkinson for being awarded a prestigious five-year Career Development Fellowship from Versus Arthritis.

Her previous work identified potential drugs including anti-oxidants to stop the inflammation in juvenile dermatomyositis (JDM). In her fellowship she will investigate whether the drugs they have identified can improve inflammation using a 3D-mini-muscle model from JDM patient muscle.

“I am extremely grateful to receive this prestigious fellowship giving me the fantastic opportunity to continue my research into understanding the causes of inflammation in juvenile dermatomyositis and identifying new treatments. I would like to say a huge thank you to the Centre for Adolescent Rheumatology for their support throughout my academic career at UCL, but especially to the Centre Director Professor Lucy Wedderburn who has given me unlimited help, time, encouragement and advice.”

Alder Hey Children’s Hospital

Elaine Gorman writes,

We are pleased to invite you to the UK’s Experimental Arthritis Treatment Centre for Children’s Showcase Event on Saturday 22nd March 2025 at the Institute in the Park, at Alder Hey Children’s Hospital in Liverpool. The focus of the day will be on the children, young people and their families and hearing directly from them about their journey in research.
We will be highlighting the research taking place at the EATC for Children. We will also be discussing how together, along with our many charity partners, how we can better address the unmet needs of children and young people, as highlighted by the patients themselves.

Please find attached a leaflet with all the event details. You can register here for the event: EATC for Children Showcase Event: Registration Form

We would be delighted if you can attend the event yourself. Do please also circulate the details within your organisation to help us spread the word about this unique and informative event!

If you need anything further, please contact Jessica.Fitzgerald@liverpool.ac.uk

We will be attending and supporting this event and will have a table set up with our charity information.

Pharma Companies

We have been for some time now talking to pharma companies who are developing medications for myositis. These have been and are very fruitful and encouraging. I would like to thank members who have responded to the request to participate in the studies put forward. These are exciting times and as a charity we are hoping there will be a benefit for all sufferers of the different disease types. With progress being made in research and pharmaceutical companies making head way plus the fantastic support of our many supporters real progress is being made.

Myositis UK Grants

The Funding Process:
Funding opportunities are now advertised on our website and researchers working in the field of myositis are invited to apply. All applications are sent for independent review before a consensus decision is reached by our 'Scientific Advisory Committee' and 'Medical Advisory Board'. Once the outcome has been agreed by our 'Board of Trustees', the successful candidates are notified, and the award is made. The aim of this process is to ensure that funding is awarded to high quality research projects that deliver patient benefits, in an open, fair and transparent manner.

The funding process was introduced in March 2023, since when we have received fifteen funding applications and awarded ten grants. Of those awarded, three were large grants (£100,000 plus for both) and seven were for small grants (£10,000 - £20,000 for each) with around £460,000 awarded in total. Below is a summary of the research funded under this new process.

Project 1
Optimism – Rapamycin for Inclusion Body Myositis
Dr Stefen Brady (John Radcliffe Hospital – Oxford)
Awarded: May 2023, £111,247.75
Inclusion body myositis (IBM) causes progressive disability and a seven-fold increased risk of dying early. Unlike other forms of myositis, no treatment has been shown to affect the progression of IBM.

In 2017, a small pilot study of an anti-transplant rejection medication, Rapamycin, was the first to show benefit. We have been invited to join Optimism, an international collaborative study whose goal is to ascertain the benefit of Rapamycin.

We expect Rapamycin treatment to produce similar benefits as previously observed in the pilot study including slowing disease progression and weakness.

Rapamycin is cheap, widely used in the UK, and licensed for treatment of autoimmune disease. In the event of a positive outcome, it can easily be made available to people living with IBM, improving their quality of life through slowing or stabilising the progression of their disease.

Project 2
IBM – Path: Identifying disease pathways for inclusion body myositis (IBM) patient stratification and therapy.
Professor Pedro Machado (University College London – UCL)
Awarded: May 2023, £129,933
Inclusion Body Myositis (IBM) is a disease that causes progressive muscle wasting and disability. There is currently no known treatment, and the cause of IBM is unknown. It is believed that genetic and environmental factors may trigger inflammatory and degenerative pathways in the body, particularly as someone ages.

We are part of the IBM genetics collaboration and have completed a genetic study that found new genetic associations. Moving forward, we plan to expand our study by collecting genetic data from more IBM patients and comparing it with data from people with polymyositis or dermatomyositis.
We will investigate specific genetic regions in IBM using advanced techniques such as exome and genome sequencing to identify exact genetic variations associated with the disease. We will investigate altered and/or reduced protein production by sequencing IBM muscle samples.
Pathological studies and tissue culture investigation of muscle tissue and patient cells will be used to gain insight into disease mechanisms and potential drug targets.

Project 3
Improving clinician utilisation and data quality on the MYOACT patient register
Dr Saadia Ali (King's College Hospital – KCH)
Awarded: May 2023, £9,998,37

The idiopathic inflammatory myopathies (IIMs) are rare group of autoimmune conditions affecting 10,000 patients in the UK. There are two advanced treatments available for this condition in the UK, Rituximab and Abatacept. However, large clinical trials have failed to confirm a benefit from these drugs in the IIMs.

Further analysis of these studies suggested that some types of IIMs may benefit from these drugs. This represents a significant unmet clinical need and there is an urgent demand for further data to confirm these findings and elucidate which patients benefit from these drugs.
Real-life patient registries can be complementary to clinical trial data as they pool together patient information from across the country, increasing the amount of information available to analyse, making it an asset in rare diseases like IIMs. The MYOACT patient audit was set up with the aim of monitoring the safety of these drugs in the myositis population and confirming which patients are likely to benefit. As more drugs become available the registry will help us better select right drug for the right patient.

However, despite the audit being a requirement for NHS funding for these drugs, the audit has not been widely used by clinicians. A survey and focus group of myositis experts established that many clinicians found the MYOACT website too complicated and there was too much data to be completed in our busy clinical environments as the main reasons for underuse.

The aim of my research is to re-engage clinicians with the MYOACT audit by making it more user friendly and designing a smart phone application to input data quickly into the register ultimately improving data quantity and quality. This would make it easier to monitor the safety and clinical use of these important treatments in myositis ensuring their appropriate use in patients.

Project 4
MyGRATE – Supporting the migration of JDCBS to a Trusted Research Environment with dataset Quality Control
Dr Sokratis Varakliotis (Great Ormond Street Hospital – GOSH)
Awarded: May 2023, £9,680
The Juvenile Dermatomyositis Cohort Biomarker Study and Repository (JDCBS) is the largest cohort study with linked patient biological samples for JDM and related inflammatory myositis conditions that begin in childhood. Since 2000, sixteen UK centres have been contributing data and samples, supporting multiple national and international studies on genes, immune cells, and muscle in childhood myositis. The study has recently undergone two vital changes:

- migrated to using the internationally agreed set of data collected, called the JDM Consensus Dataset, designed for clinical use, to improve collaborative research and allow easier sharing of data between different researchers, and
- migrated its data collection away from a standalone system to a secure research environment, called the GOSH Digital Research Environment or DRE, which will be maintained long into the future.

This proposal focuses on the crucial process of data migration from the old standalone database to the DRE, while providing continuous operation of the study, to make sure this happens smoothly. The aim is to apply quality control, eg, data cleaning, checking and recovery methods, using specialised software techniques.

This will ensure more accurate migration and will maintain twenty years of high-quality data continuity between the historic and the modernised version of the dataset, to the benefit of patients through all the current and future research projects which use this unique dataset.

Project 5
Biomarker identification for treatment response to the oral JAK 1/2 inhibitor, baricitinib, in adult idiopathic inflammatory myopathy
Dr Janine Lamb (University of Manchester).
Awarded: December 2023, £20,000

Inflammation in the muscles and other symptoms has a significant impact on quality of life of people living with myositis. While immune suppression drugs can help, there are often side-effects and not all individuals respond to these drugs. The applicants are currently completing a clinical trial of a new drug, baricitinib, in adult-onset myositis, a drug which blocks signalling of inflammatory chemicals.

In the proposed study, we aim to build on the clinical data and biological samples collected during this clinical trial to identify molecular predictors and markers of response to treatment with baricitinib.

We have collected biological samples (including blood, serum, DNA) from all patients in the trial at baseline (pre-treatment), and at three timepoints throughout the trial. Using these samples, we will apply a range of complementary experimental approaches to look at the levels of inflammatory markers and myositis autoantibodies (immune proteins), the relative frequency of different types of immune cells in the blood, and genetic differences between patients. We will compare the samples collected pre-treatment to post-treatment and at the different timepoints throughout the trial to look at changes over time and in response to treatment. We will correlate these molecular measurements to levels of inflammatory muscle enzymes, and clinical measures of response to baricitinib treatment and changes in disease activity.

We anticipate this research may identify molecular predictors and markers of response to treatment with baricitinib and disease activity in individuals with adult-onset myositis. This knowledge may help to develop more individually targeted treatment approaches and to improve future disease management in myositis. Characterisation of these molecular markers will also give insight into the biological mechanisms and causes of myositis.

Project 6
A mitochondrial gene signature to stratify Juvenile Dermatomyositis patients for targeted treatments.
(Lead Researcher Dr Meredyth Wilkinson (University College London).
Awarded: June 2024, £19,973.70

Juvenile dermatomyositis (JDM) is a rare autoimmune condition in which the body's defence system (designed to stop infections) attacks itself leading to muscle weakness and skin rashes. Some patients get damage to lungs, gut and even brain. Treatments used in JDM suppress the body's defence system, but do not work for all patients and can cause unwanted side effects. If we understood exactly which part of the body's defence system was going wrong it would help us target this with more effective medication. Our recent publication showed that genes (the human code) that code for mitochondria ('powerhouse' energy producers of the cell) were less active in JDM patients (even those already on strong treatment) than in healthy children of the same age. We believe that these discoveries allow us to develop tests to measure mitochondrial problems and identify better treatments for patients. Importantly, fatigue is one of the most common symptoms described by JDM patients and needs to be addressed. We believe that mitochondrial problems may relate to the levels of fatigue in children with myositis. In two groups of JDM patients measuring expression of thousands of genes in blood cells, we have identified a set of thirty seven genes that represent the mitochondrial problems seen in immune cells. Using a technology called nCounter made by NanoString (measure expression of a fixed set of genes), the mitochondrial gene signature (MGS) will be measured as a set to measure mitochondrial problems.

AIM1: Investigate if the MGS can characterise groups of patients, and predict disease type, severity or outcome.

AIM2: Establish if the MGS measured in blood relates to levels of fatigue experienced by JDM patients.

Project 7
MIRAGE: Myositis Inflammation Revealed through Advanced Magnetic Resonance ImaGing Evaluation A Prospective Study Amount requested.
Professor Pedro Machado (University College London).
Awarded: June 2024, £19,908.65

Our study focuses on understanding and better assessing a group of autoimmune muscle disorders called idiopathic inflammatory myopathies (IIMs), which can affect various body parts beyond muscles. To evaluate these conditions, we can use advanced imaging techniques, particularly magnetic resonance imaging (MRI), which helps us visualise muscle inflammation and damage. We aim to develop a new MRI method called T2-water quantifiable MRI (Q-MRI), which can accurately measure muscle inflammation in adults with IIMs. We hypothesise that this method will provide more precise and objective assessments of muscle inflammation compared to current MRI techniques. Our study involves two visits over a period of 3-6 months for sixteen adult patients with IIMs. During these visits, we will conduct various assessments, including MRI scans of the pelvis and thighs, evaluations of disease activity and damage, tests of physical function and mobility, and assessments of fatigue and organ involvement. We will also evaluate how patients respond to treatment using established criteria. By the end of our study, we hope to validate the new MRI method as a reliable tool for assessing muscle inflammation in IIMs. This could lead to better monitoring of disease activity, improved treatment decisions, and ultimately, better outcomes for patients with these challenging conditions. This study has the potential to advance our understanding and management of IIMs, ultimately improving the lives of individuals affected by these conditions.

Project 8
The UKMYONET study: Increasing accuracy of autoantibody testing in myositis using new approaches and exploring genotype-autoantibody associations
Professor Hector Chinoy (University of Manchester).
Awarded: December 2024, £97,724

This will help answer questions that matter to patients such as, 'what will happen to me?' and 'why me?'

Autoantibodies are a blood test used by doctors to diagnose myositis and to predict problems like lung disease or cancer. Testing happens routinely in the NHS, but hospital tests don't work well and often give the wrong result. Different autoantibodies are linked to different genetic markers. This in part explains why different people develop different types of myositis. Until now, myositis genetic studies have focussed on white people.

UKMyoNet is a large study of nearly 2000 UK myositis patients. Samples have been collected and stored. About 600 samples do not have reliable autoantibody and genetic data. We will accurately test these samples for autoantibodies. We will compare our findings to data from hospital testing and show where improvements are needed. We will also test the genetics of these samples to confirm links between autoantibodies and genetics and whether the same links are seen in non-white people. Importantly, we will show the value of a new version of what is currently the best autoantibody test. Going forwards, using the new test will increase access to accurate autoantibody testing and lead to new research prospects.

Project 9
Sleep disturbances and fatigue in children with Juvenile Dermatomyositis (JDM); do they relate to disease activity and pathology?
Dr Charalampia Papadopoulou (University College London).
Awarded: December 2024, £20,000

Desirable long-term outcomes in chronic childhood diseases include normal growth and development, participation in normal social, educational and sporting activities and a good quality of life. Sleep disturbance is often seen in rheumatological diseases and may contribute to the fatigue seen in many of these conditions, including Juvenile Dermatomyositis (JDM).

In JDM the frequency of sleep disorders and fatigue, as well as the contributing factors to their occurrence remain poorly understood. Sleep alterations in JDM have been associated with steroid treatment and disease markers in the blood.

The aim of this study is to assess how common sleep disturbances and fatigue are in children with JDM at the start of disease (at diagnosis) and over time, using developed patient-reported outcome measures (PROMIS) which are efficient, precise, and easy to use in routine clinical practice. We will then test how these relate to clinical measures of the disease and disease markers in the blood. We will measure interferon (an inflammatory protein) and mitochondria (powerhouse of the cell) markers in the blood to identify what is going wrong in the body and how these contribute to fatigue, sleep problems and also cause JDM disease specific symptoms.

Project 10
Developing a dietary intervention to address muscle loss in inclusion body myositis (IBM).
Dr Paul Morgan (Manchester Metropolitan University)
Awarded: December 2024, £20,000

Sporadic inclusion-body myositis (IBM) is a common type of muscle disease in people over 50 years of age. Sufferers experience muscle weakness, particularly in the arms and legs, which gets worse over time and results in disability. Most people lose their ability to walk independently within seven years. IBM does not respond well to medication, and the costs of this for our healthcare system are large. While physical therapy is recommended, little is known about how diet, particularly how much protein these people eat, affects the progression of IBM. Protein intake is important for maintaining muscle mass and strength, but there are no specific guidelines for people with IBM. In healthy individuals, eating protein helps build muscle, but in people with low muscle, this process doesn't work as well. It is unclear if this happens in people with IBM, and finding out information about this will help us to understand whether providing more protein to IBM sufferers will help them. If so, we can also provide dietary advice for them about how they might achieve this increase in protein intake. We will study the dietary habits, nutritional status, and measure chemical processes that occur in the muscles of IBM patients, which has not happened before. We will also assess how well people with IBM function, how much fat and muscle they have and investigate how their muscles respond to protein intake, compared with healthy people of a similar age. We will do this by:

1. assessing dietary intake and physical activity habits, challenges to good nutrition, energy use, muscle and strength, swallowing difficulties and markers of quality of life in people with IBM.

2. studying how IBM patients' muscles respond to protein consumption. 3. identify dietary factors that influence muscle health, strength, and quality of life in people with IBM.

Next funding call
The next funding call deadline is Friday 28th March 2025 where two small grants of up to £25,000 are available to UK researchers working within the field of myositis. Details on how to apply are on the Myositis UK website

MELODY Study

Research results show the importance of COVID vaccination and a personalised approach for RAIRD patients

A study published in the Lancet has revealed that blood tests can predict the severity of Covid-19 infection in Rare Autoimmune Rheumatic Disease (RAIRD) patients, which could lead to individualised approaches to vaccination.

The MELODY study was supported by a collaboration of research charities and medical funders including RAIRDA member charity Vasculitis UK, to ensure better representation of at-risk groups in pandemic research.

MELODY is the largest research study to date in people with rare diseases, including 6,516 people living with a RAIRD.

Key findings from the study:
• COVID-19 antibodies provide strong protection for people with RAIRDs.
• Regular vaccinations are crucial for people living with RAIRDs to maintain immunity.
• Antibody tests can guide personalised prevention plans.

How COVID-19 vaccines helped people with RAIRDs during the Omicron wave: the MELODY* Study

Background on the study:

People with RAIRDs, like lupus, vasculitis, scleroderma, and myositis, are more likely to get seriously ill from COVID-19. This is because their immune systems don't work normally, and people with these conditions often take medications that weaken their immunity.

In the UK, people living with RAIRDs were offered three initial COVID-19 vaccine doses and regular boosters. The MELODY study looked at whether people with RAIRDs who didn't develop detectable COVID-19 antibodies after receiving three or more vaccines were at a higher risk of catching the virus or experiencing more severe illness, during the Omicron wave.

How the study worked:
From February to June 2022, 6,516 people with RAIRDs across England joined the study. They had all received at least three COVID-19 vaccine doses. Participants did at-home antibody tests, filled out health surveys, and their health was tracked for six months using NHS records for COVID-19 infections, hospitalisations, and deaths.

What the study found:
• Out of the 6,516 participants with RAIRD, 37% had lupus, 21% small vessel vasculitis, 13% systemic sclerosis, 9% large vessel vasculitis, and 7% had myositis. 13% did not specify which RAIRD they had.
• Many (71%) were on treatments that suppress their immune system, and 42% were on steroids.
• After at least three vaccine doses, 86% of participants had COVID-19 antibodies.
• People on certain medications — like anti-CD20 drugs (e.g. rituximab), cyclophosphamide, or mycophenolate — were less likely to have antibodies. Steroids also reduced antibody levels, but methotrexate and azathioprine didn't seem to affect them.

Over six months:
• 1,024 participants caught COVID-19. Younger people and those living with children had more infections.
•Having COVID-19 antibodies reduced the risk of infection by 43%.
• 140 participants were hospitalised with COVID-19. Antibodies lowered the risk of hospitalisation by 68%.
• Older participants and those with other health issues were more likely to be hospitalised, but antibodies still helped protect them.
• There were only four COVID-19-related deaths.

What does this show us?
COVID-19 antibodies provided crucial protection for people with RAIRDs, reducing their chances of getting infected or seriously ill during the

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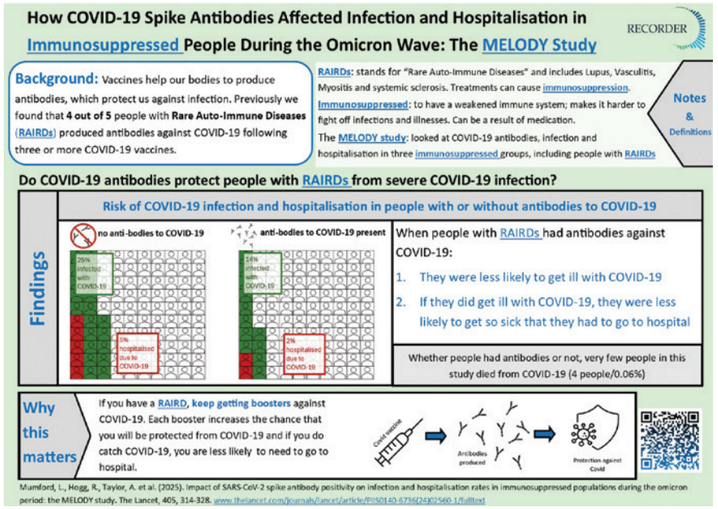
Omicron wave. COVID antibodies decrease over time since your last vaccine; and the study shows that having antibodies reduces your chance of infection with COVID by half, and of hospitalisation with COVID by two-thirds.

Therefore, it is key that people with RAIRDs get their booster COVID vaccines, to increase their chances of having COVID-19 antibodies.

Further, we know that some people who are immunosuppressed remain at risk of serious illness from COVID-19. The study shows that a simple blood-test which can be deployed at scale, would enable those at greater risk to be identified, and have individual support directed to them, to protect them from COVID-19.

This graphic is a summary of the results relevant to rare autoimmune rheumatic diseases from Impact of SARS-CoV-2 spike antibody positivity on infection and hospitalisation rates in immunosuppressed populations during the omicron period.



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Dear Myositis Community Member,

Collecting data on people living with rare diseases including myositis has provided critical insight about these conditions. However, collecting data is not as simple a task as it sounds and can pose many different challenges in attaining success.

MIHRA has founded an initiative across many myositis organizations to help facilitate feasible and meaningful global data sharing/harmonization. The cornerstone of this effort is to understand what are the aspects and items that clinicians and patients perceive as important in data collection.

MIHRA Myositis International Health & Research Collaborative Alliance

Follow this link to the Survey: https://tulane.co1.qualtrics.com/jfe/form/SV_eaL8Sb0O5zAAD3w

Sincerely,
Chris Mecoli, Didem Saygin, Pedro Machado & Lesley Ann Saketkoo
MIHRA Data Harmonization Group

AGM & Conference 2025

This year's meeting will be on Sunday 6th July at the Woodland Grange Hotel, Near Leamington Spa.
We have taken into consideration the valuable feedback from last year's conference. We are still in the process of putting the programme for the day together but there will be less scientific content and more focus on "Living with Myositis". This will include physiotherapy, mental health and wellbeing and table discussions for different types of myositis. We hope to include a slightly longer lunch giving more time to enjoy your lunch.

This conference needs you, its members, to attend and show support to the speakers from the medical profession for the work they are doing to improve the quality of your lives. The charity is fortunate that we have dedicated teams collaborating with us in this country and globally as well.

The conference is a place to meet up with other members and chat about your condition, share news and encouragement and even make new friends in the process. It is also a great opportunity to ask questions about your illness to a medical panel in an informal relaxed way. This interaction has benefits for everybody, improving the way you live and cope with myositis.

Booking details are enclosed with this edition of "Myositis News". There will be an informal meet up and chat on the Saturday afternoon of the weekend with tea, coffee and biscuits provided for those staying at the hotel or living or staying nearby. It will be held between 2pm and 4pm.

Prescription Charges Coalition

Share your experience with your MP
We need to get the message out to every MP we can across England, so we're encouraging anyone living with a long-term condition to speak to your MP. We've produced a guide that can help you speak to your MP.

Briefing MPs about the impact of prescription charges
We met with some English MPs to share the impact on people with long-term conditions of paying for their medicines.

Survey reveals prescription charges are a barrier to keeping people well and in work
The latest Coalition survey shows that 1 in 10 people with long term conditions can't afford their prescriptions, which is impacting their physical and mental health and making them rely on NHS services more.

https://www.prescriptionchargescoalition.co.uk/

Fundraising & JustGiving

Glanrhyd Methodist Chapel

On behalf of the chapel, E Jones sent to the charity a donation for £175 as a result of a collection held at their Christmas service.

Secretarial Law Limited

The Richard Kirkman Trust administered by Secretariat Law have continued to find us worthy of their support with a gift of £2000.00. The trust has been following and helping our charity for many years and seen it grow into a position where it is now making a significant contribution in every aspect relating to myositis. Alison Leggett of Secretarial Law and the Trust management have been very kind and helpful to Myositis UK. Through the years there have been people, such as Alison, who the majority of us will never meet and never get to know. However, the contribution they have made by supporting and contributing to our charity funds has been essential in our progress so that Myositis UK can initiate advancement in the treatment and understanding of this group of miserable diseases.

Bradley Dearnley

Leicester Tang Soo Do and Bradley Dearnley held a fundraiser for Myositis UK and over a hundred attended raising £1,427!

Bradley had JDM as a child and he used the martial art Tang Soo Do as part of his physio for recovery. Thanks to everyone who took part in this event.

Fair Oak 8191 Hampshire's Party Night

We were invited to attend this nautical party on Saturday 26th October and what an enjoyable and authentic night it was! The invitations went out reading, "Please join us on the cruise ship SS Fair Oak, for a night of ship based entertainment and experience everything which a cruise can offer without leaving port."

We then attended their Christmas Carolokee evening on 10th December where I was presented with a cheque for the charity for £1,000.

Masons and Buffaloes around the country have been very supportive of Myositis UK. Fair Oak Lodge in particular have kept us on their radar and I offer them my gratitude for supporting us for many years.

Birkacre Garden Centre

Stephen Ainscough of Birkacre Garden Centre, Chorley, writes, "We basically have quite extensive and elaborate Christmas displays, featuring many animations and including a Santa's Jazz Band. This year we dressed them up as "Irish" Santas to incorporate them in our Irish pub setting, which was one of our main themes, and had them playing stuff like, "The fairytale of New York" and "Whisky in the Jar". It went down very well and the band is always good for raising donations. £1066.80 was raised for the charity.

We are using the band in a summer theme this year, so, hopefully, there'll be a chance to raise a bit more.

Emily Baker

Emily's Challenge, 30Before30 for Myositis UK

Emily writes, "Unfortunately, my beautiful mum was diagnosed with Polymyositis in April 2024. We are now, as a family, on a road to adapting and testing treatment options, although this will be a long road ahead. Thankfully, my mum has been, so far, responsive to her treatment, and we hope that soon she'll be able to have more of a quality of life back."

"As many of you may know, I also have many disabilities myself. Some of you may also know that I was told, "if you are lucky enough to make it to thirty years old, you have a chance of surviving" - well I will be thirty and I have lived already and will continue to live and prove the medical professionals wrong. So, I'm not only doing this for charity, but for myself too, to prove to myself that I CAN do what I've been told that I can't."

https://www.justgiving.com/page/challenge30before30

Emily has raised £545 of her £1000 target to date.

Christina Gittins

Christina's family and friends organised a surprise birthday party for her with donations to Myositis UK. £2700 was donated including a donation from Christina. Her brother also held a fundraising event at Birkacre Garden Centre.

Rachel Cole of Fothergill's writes,

"Just wanted to let you know that the staff draw for Myositis UK has taken place today. Fothergill's stumped up a top prize of two tickets to see Wicked the Musical with Dinner & Drinks, and we raised £230 for the charity. Here is my colleague, who won the top prize, who looks VERY pleased with himself."

JustGiving

Rachel Tucker – Wreath Workshop

Rachel writes, “Having attended many Christmas wreath workshops over the years to design and create my own Christmas door wreath, I decided back in September 2024 that I’d love to organise my own workshop for my local community. With a village pub down the road and a bunch of very hospitable punters and charitable landlady already with a huge marquee attached to the pub hosting all sorts of events, I knew it would be the perfect place to host the night I had visualised.

I pulled in the support of a dear neighbour with a background in design and between the two of us we spent weeks planning the Christmas grotto AKA ‘pub marquee’.

Our local wildlife centre donated bird of prey feathers and I purchased catering size cinnamon sticks from the Indian food wholesalers! Suzie made individual gift bags for every guest - we had forty people attend the workshop and each gift bag contained a bag of cinnamon sticks, dried oranges, pears and apples, a Ferro Roche, literature of our chosen charities and a Myositis pen and shopping trolley token, along with a miniature bottle of prosecco, and a homemade Christmas card.

The Marquee was a festive delight! Decorated with Christmas trees, hand made ceiling decorations and Christmas produce to sell which was kindly donated by Supplies Garden

For a nonprofit making event we were able to raise a total of £775 in total from ticket sales and selling the donated decorations! I have been asked to put together another wreath night this year in December, how can I say no”.

JD Mike Ford

On 26th September 2024, a determined Mike Ford in his 90th year embarked on a trek to climb Pen y Fan, the highest peak in South Wales, using an All-Terrain Vehicle. This inspiring endeavour is in support of Myositis UK.

Despite being diagnosed with Inclusive Body Myositis in 2006 and facing physical limitations, Mike remains resolute in his mission to conquer Pen y Fan again. The unwavering support from independent carers, personal friends, family, and the generous assistance from Beamish Ltd, manufacturers of the Tramper, have made this ambitious feat possible. With his beloved border collie, Darcy, by his side, they have covered over 15000 miles using the Tramper,

showcasing their enduring love for the outdoors.

Mike completed this challenge and raised £365

Dundee Kiltwalk

Hannah Swan writes, “I’m walking twenty miles for the Kiltwalk on 11th August from St Andrews to Dundee, to raise money for Myositis UK, a charity leading the way through funding research and treatments for myositis.

In 2020, my daughter Holly, who is now twelve, was very unwell and after lots of tests she was diagnosed with Juvenile Dermatomyositis.

She, like all other JDM patients, have to endure hardcore treatment to keep them in a

stable condition. This means daily medication, weekly injections and monthly infusions in hospital.

I’m doing this for Holly, and for the future children, in the hope they can cure myositis and/or find less brutal treatments for them too. Let’s do this, for my girl and all the myositis warriors.”

Hannah raised £405

Heather Morrison

Quiz/Live Music Fundraising Evening, 27 September 2024

Heather writes, “We have lupus in the family and I have polymyositis which is a rare, debilitating, horrible, life limiting condition which currently has no cure. Research is constantly needed but money is scarce. Please, please, come along and support us. Live Music by local band Lais Pzazz and a fun quiz too.”

Heather raised £736

Lakes In A Day

Charlie Kay writes, “As some of you may know, towards the end of last year I entered Lakes In A Day, a 50 mile run from the north of the Lake District in Caldbeck to Cartmel in the south. Primarily, my entry was driven by the thought of a cracking day out in the hills combining my enjoyment of running with a place I love.
When I first entered, I had no notion of fundraising as part of this, however, following the loss of my lovely, creative and caring mum, I have decided to attempt to raise some money for Myositis UK in the hopes of what I raise may make a little difference to any other loved ones who suffer from myositis diseases. For those who didn’t have the opportunity to meet my mum, it’s hard to describe the person she was - creative, funny, encouraging, selfless and caring, if I was to attempt to throw a few words at it. She truly was one of a kind. And for those who did know her, I’m sure you’ll agree with me, that we were all grateful and lucky to know her and I am and will continue to be very proud to call her my mum.

London Marathon 2025

This magnificent event is quickly looming up on us again. The marathon is a major fundraiser for the charity and I trust you will all as usual get behind our, "Team Muscle" runners, featured here. For them the training is ongoing and no doubt they are preparing themselves physically. We are already making plans to get all the charity gear to London for the day. Perhaps some of you may wish to attend and seek us out and say hello! Will be pitched in St James's Park. I really enjoy this day. It is long and tiring for us but well worth the effort.

Kelly Gearing

Kelly's story: "Hi everyone, I have been given the opportunity to run the London Marathon 2025. I'm hugely excited and training hard. However, the most important challenge here will be to raise some much needed money for the Myositis UK charity. Please consider making a donation, no amount will be too small. Your support will help keep up the fight against this rare muscle disease and strive for a future free from all forms of myositis.

https://www.justgiving.com/page/kellygearing-londonmarathon4myositisuk?utm_medium=FR&utm_source=CL

Steve & Adelaide Bailey

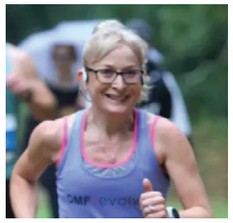
Steve writes: "This will be the third London marathon for which I've raised money for Myositis UK as a member of Team Muscle!

We've never met anyone from the charity before because my previous marathons were in the Covid affected years of 2020 and 2021 so we're really looking forward to meeting everyone involved.

We got married in Cyprus a few months ago and this is Addy's first London marathon so we'll be running it together and we want to meet all the Myositis cheer leaders along the way.
I will be wearing my Myositis shirt when I run the Liversedge half marathon on March 2nd as part of my marathon training."

https://2025tcslondonmarathon.enthuse.com/pf/adelaide-seymour

Nikki Brown



Nikki writes: "Thank you for visiting my fundraising page for Myositis UK. I am very privileged to have been given the opportunity to run the London Marathon for this very important charity.

Myositis affects people of all ages including children and there is currently no cure.

Myositis UK is a charity that supports people affected by myositis and funds research to improve diagnosis and treatment.

As someone who has always loved to run it has been a lifetime ambition of mine to be able to take part in the London Marathon. I feel very lucky to have this opportunity, and am very grateful for any donations to this wonderful charity."

https://2025tcslondonmarathon.enthuse.com/pf/ nikki-brown-8237f

Mohammad Ursani

Clinical Rheumatologist in the United States (Houston, Texas) and chairman for the American college of rheumatology.

Mohammad writes: "I am excited to announce that I will be running the 2025 London Marathon to raise funds for Myositis UK. As a clinical rheumatologist, I treat patients suffering from myositis. This cause is deeply personal to me as I witness first-hand the impact myositis has on my patients' lives and their families.

Myositis UK is dedicated to funding research, raising awareness, and providing support for those affected by this challenging condition.

By running this marathon, I hope to contribute in a meaningful way to the ongoing efforts of Myositis UK. Your support, no matter the size, will go directly to help fund research and improve the lives of those living with myositis.

Thank you for your generosity and encouragement."

https://2025tcslondonmarathon.enthuse.com/pf/mohammad-ursani

Kelly Morris

Kelly's story, "I am running the London Marathon in memory of our very dear friend Gav, who sadly lost his life last September to a very aggressive form of myositis.

Gav was a larger than life character who was loved by so many and once you met him you never forgot him, from his role as lead singer in Glitterball and various other bands along with carpentry, rugby coaching and all the other things he was involved in.

Hopefully by raising funds for this little known about disease, we can raise much needed awareness so it can be diagnosed and treated early by the medical community and to also fund research for treatments."

Thanks everyone, Lots of love Kelly / Mini Team Gav

https://www.justgiving.com/page/kelly-morris-2

India Egbunike

India's story: "I am running the London Marathon on 27th April (what a way to celebrate our wedding anniversary weekend!) to raise money for Myositis UK. This is a charity very close to my heart as my mum was diagnosed with Myositis 10+ years ago and has been living with it ever since. It has affected mum's skin, muscles and lungs. She has been in and out of hospital, pricked and prodded; but always does it with a smile on her face.

Last year, mum was in hospital after a particularly bad flare-up. It was an extremely difficult time for everyone, but mum stayed strong throughout finding support in her family and friends, especially those she had met through Myositis UK. This charity has been a particular source of comfort, help and knowledge for mum from diagnosis to present day, and I think it's time to give something back to them!"

https://www.justgiving.com/page/indiaegbunike

Appreciation and thanks for the donations we receive in other ways including private donations, in memory donations and to members who donate through regular standing orders. These donations make up a substantial amount of our income and contribute to the charity being able to fund and support the research into myositis.

GCOM Lisbon 2026

23 – 26 March

The organising of this conference is well underway. We will keep you updated when we have further details. For your diaries, pencil in 2028 Montreal, Canada for the following GCOM meeting.

World Myositis Day

This year will be the third “World Myositis Day”

This special day is now celebrated every year on September 21. 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.

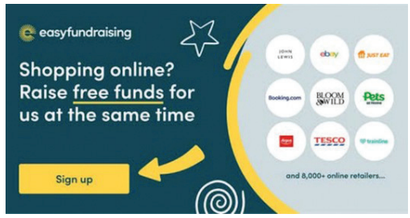
World Myositis Day 21 Sept

Share this information and join us in celebrating World Myositis Day every September 21!

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

Carers

As a charity we are aware that carers are often overlooked during a myositis journey. I would appreciate hearing from you and how it has affected you through good times and bad. Perhaps we can publish your article on your experience in Myositis News because many are unaware of the time, energy and emotion that is involved in this role. – Thank you



Easyfundraising

Thank you to everyone for raising donations for Myositis UK with easyfundraising. You have raised £1,993.17 to date.

If you haven’t signed up yet, it’s easy and completely FREE. 4,400 shops and sites will donate to us when you use easyfundraising to do your everyday online shopping - at no extra cost to you! Every donation you raise makes a difference to us so please sign up and share today.

https://www.easyfundraising.org.uk/causes/myositisuk/

PayPal Giving Fund

We have received a further £648.26 in donations from the PayPal Giving Fund. These donations are made possible by donors who gave to PayPal Giving Fund and chose Myositis UK as their choice of charity to benefit from their donations.

Pen Friend Wanted

“Hello, I am a 67-year-old female with Inclusion Body Myositis. I live in a small country town in Western Australia and am housebound due to my mobility problems. If possible, I would like a UK pen pal with similar problems. Cheers.”

Please get in contact with the office if you wish to get in touch with this lady. I know some of you do correspond like this and have made good friends in the process.

Literature Update

Distinct Cytokine and Cytokine Receptor Expression Patterns Characterize Different Forms of Myositis.
Kirou RA and others. Published in medRxiv [Preprint]. 2025 Feb. PMID: 40034760 Free PMC article.

Challenges in international investigator-led rare disease clinical trials and the case for optimism in inclusion body myositis.
Needham M, and others. Published in Clin Exp Rheumatol. 2025 Feb PMID: 40018747

Optimism in inclusion body myositis: a double-blind randomised controlled phase III trial investigating the effect of sirolimus on disease progression in patients with IBM as measured by the IBM Functional Rating Scale.
Badrising UA and others. Published in Clin Exp Rheumatol. 2025 Feb.PMID: 40018746 Clinical Trial.

Ultrasensitive interferons quantification reveals different cytokine profile secretion in inflammatory myopathies and can serve as biomarkers of activity in dermatomyositis.
Bolko L and others. Published in Front Immunol. 2025 Feb PMID: 40013143 Free PMC article.

Treatment guidelines for idiopathic inflammatory myopathies in adults: a comparative review.
Paik JJ and others. Published in Rheumatology (Oxford). 2025 Feb PMID: 39999025

The Myositis Clinical Trials Consortium: an international collaborative initiative to promote clinical trials in adult and juvenile myositis.
Bishnoi A and others. Myositis Clinical Trials Consortium investigators. Published in Clin Exp Rheumatol. 2025 Feb PMID: 39977016 Review.

Imaging evaluation of the upper limbs in inclusion body myositis: an unmet need.
Salam S and others. Published in Clin Exp Rheumatol. 2025 FebPMID: 39977010 Review.

Determining patient and carer priorities in inclusion body myositis: a patient-led research study.
Austin KL and others. Published in Clin Exp Rheumatol. 2025 PMID: 39946183

The classification of myositis: setting the stage for a universal terminology.
Giannini M and others the International Myositis Society (iMyoS). Published in Clin Exp Rheumatol. 2025 FebPMID: 39932802 No abstract available.

The utility of muscle magnetic resonance imaging in idiopathic inflammatory myopathies: a scoping review.
Paik JJ and others. Published in Front Immunol. 2025 Jan PMID: 39931069 Free PMC article.

Efficacy and safety of pharmacological treatments in inclusion body myositis: a systematic review.
Santos EJF and others. Published in RMD Open. 2025 Jan PMID: 39843353 Free PMC article.

Quantitative muscle magnetic resonance imaging as a biomarker for inclusion body myositis in clinical trials: exploring the in vivo effects of arimoclomol.
Salam S and others. Published in Clin Exp Rheumatol. 2025 FebPMID: 40018748 Clinical Trial.

Current biomarkers in inclusion body myositis.
Daniel E and others. Published in J Neuromuscul Dis. 2024 NovPMID: 39967427 Review.

Association of HLA-DR, HLA-DQ, and HLA-B alleles with inclusion body myositis risk: A systematic review, a meta-analysis, a meta-regression and a trial sequential analysis.
Dhaouadi T and others. Published in Int J Immunopathol Pharmacol. 2025 Jan. PMID: 39959993 Free PMC article.

Emerging mechanisms and therapeutics in inflammatory muscle diseases.
Wischnewski S and others. Published inTrends Pharmacol Sci. 2025 Feb PMID: 39939222 Review.

Serum creatine kinase elevation following tyrosine kinase inhibitor treatment in cancer patients: Symptoms, mechanism, and clinical management.
Zhang H, To KKW. Published in Clin Transl Sci. 2024 Nov.PMID: 39473122 Free PMC article.

Inclusion body myositis: an update.
Anderson NC, Lloyd TE. Published in Curr Opin Rheumatol. 2025 Jan.PMID: 39469805 Review.

Myositis-specific and myositis-associated autoantibodies: their clinical characteristics and potential pathogenic roles.
Ogawa-Momohara M, Muro Y. Published in Immunol Med. 2024 Oct. PMID: 39394957

Recent Updates on the Pathogenesis of Inflammatory Myopathies.
Musai J and others. Published in Curr Rheumatol Rep. 2024 Dec.PMID: 39316320 Free PMC article.

Inclusion body myositis: Correcting impaired mitochondrial and lysosomal autophagy as a potential therapeutic strategy.
Brady S and others. Published in Autoimmun Rev. 2024 Nov. PMID: 39306221

Pathogenic mechanisms of disease in idiopathic inflammatory myopathies: autoantibodies as clues.
Wu Y and others. Published in Front Immunol. 2024 Aug. PMID: 39281689 Free PMC article.

Effect of sirolimus on muscle in inclusion body myositis observed with magnetic resonance imaging and spectroscopy.
Reyngoudt Hand others. Published in J Cachexia Sarcopenia Muscle. 2024 Jun. PMID: 38613252 Free PMC article. Clinical Trial.

Calcinosis in dermatomyositis.
Davuluri S and others. Published in Curr Opin Rheumatol. 2024 Nov.PMID: 39120537 Free PMC article.

Brepocitinib, a potent and selective TYK2/JAK1 inhibitor: scientific and clinical rationale for dermatomyositis.
Paik JJ and others. Published in Clin Exp Rheumatol. 2025 Feb. PMID: 39008325 Review.

Idiopathic inflammatory myopathies related lung disease in adults.
Sehgal S, and others. Published in Lancet Respir Med. 2024. PMID: 39622261

Current efforts and historical perspectives on classification of idiopathic inflammatory myopathies.
Glaubitz S, Saygin D, Lundberg IE. Published in Curr Opin Rheumatol. 2024 Nov. PMID: 39132766

Management and outcomes of interstitial lung disease associated with anti-synthetase syndrome: a systematic literature review.
Kouranloo Kand others. Published in Rheumatology (Oxford). 2025 Jan. PMID: 39083028

Review of Pulmonary Manifestations in Antisynthetase Syndrome.
Ghanbar MI, Danoff SK. Published in Semin Respir Crit Care Med. 2024 Jun. PMID: 38710221

A Review of Antisynthetase Syndrome-Associated Interstitial Lung Disease.
Patel P and others. Published in Int J Mol Sci. 2024 PMID: 38674039 Free PMC article. Review.

Cardiac involvement and anti-striational antibodies in immune-mediated necrotizing myopathy.
Sumi K and others. Published inJ Neurol Sci. 2025 Mar. PMID: 39914165

Anti-SRP Antibodies and Myocarditis in Systemic Sclerosis Overlap Syndrome with Immune-Mediated Necrotizing Myositis (IMNM).
Alexandru C and others. Published in Medicina (Kaunas). 2024 Oct. PMID: 39596941 Free PMC article.

Elicitation of expert prior opinion to design the BARJDM trial in juvenile dermatomyositis.
Papadopoulou C and others. Published in Rheumatology (Oxford). 2024 Dec. PMID: 39073903 Free PMC article. Clinical Trial.

A Review of Myositis-Associated Interstitial Lung Disease.
Kannappan R and others. Published in J Clin Med. 2024 Jul. PMID: 39064092 Free PMC article.

Anti-MDA5 autoantibodies predict clinical dynamics of dermatomyositis following SARS-CoV-2 mRNA vaccination: a retrospective statistical analysis of case reports.
Klein CR, and others. Published in Rheumatol Int. 2024 Oct. PMID: 39190200. Free PMC article.

Baricitinib for anti-melanoma differentiation-associated protein 5 antibody-positive dermatomyositis-associated interstitial lung disease: a case series and literature review on Janus kinase inhibitors for the disease.
Harada H and others. Published in Rheumatol Int. 2024 May PMID: 38456909 Free PMC article.

Patients with anti-small ubiquitin-like modifier activating enzyme-positive dermatomyositis resembling antisynthetase syndrome with poor prognosis: a bicentric international retrospective study and literature review.
De Carvalho and others. Published in 2024 Oct 9; PMID: 39382310 Free article.

Cardiac involvement and anti-striational antibodies in immune-mediated necrotizing myopathy.
Sumi K, and others. Published in J Neurol Sci. 2025 Mar 15 Epub 2025 Jan. PMID: 39914165 Free article.

Understanding the Role of Type I Interferons in Cutaneous Lupus and Dermatomyositis: Toward Better Therapeutics.
Hile GA, Werth VP. Published in Arthritis Rheumatol. 2025 Jan. PMID: 39262215 Free PMC article.

An update on autoantibodies in the idiopathic inflammatory myopathies
Nur Azizah Allameen Published in Nat Rev Rheumatol 2025 Jan. PMID: 39609638

Inclusion body myositis and immunosenescence: current evidence and future perspectives.
Allameen NA and others. Published in Rheumatology (Oxford) 2025 Mar. PMID: 39504446 Free PMC article.

Holiday Insurance

Myositis UK does not endorse or accept responsibility if you use any of the following companies. However, they are worthy of a look to see if they can cater for your requirements.
https://www.insurancewith.com/medical-conditions/
https://www.staysure.co.uk/medical-travel-insurance/
https://www.avantitravelinsurance.co.uk/pre-existing-medical-conditions-travel-insurance
https://www.allcleartravel.co.uk/medical-conditions/
https://www.travelinsurance4medical.co.uk/
https://www.insureandgo.com/travel-insurance/medical/
https://www.freedominsure.co.uk/travel-insurance/medical-travel-insurance/
https://www.medicaltravelcompared.co.uk/

Social Media

If you use social media, then this is a simple way to keep up-to-date. We currently have four Facebook Pages: Myositis UK, Team Muscle, Juvenile Dermatomyositis, and Teddy-Bo, his friends, adventures and Juvenile Dermatomyositis.

Facebook is always modifying the group and page platforms, not always in the user's favour! Meaning many posts are not easily visible and direct messages are not received. If you need to contact the charity, please email rather than use Messenger within Facebook. We do have an account on X, but we do not post often. In the future it may be a suitable time to amalgamate our pages together or change to another Facebook format. How we deliver our social media is under continuous review. We do have an account on X, but we do not post often.

If you do not use these social medias but use the internet, then our own website still retains an online community forum (Healthunlocked).

The traffic on our community forum is quiet as many prefer to use a forum that is inside one of their already open social medias. For this reason, Treasurer Jo Goode set up a Facebook myositis community forum group a few years ago. This Group is very active, self served by its users and Jo administers the page to welcome new people and ensure correct and safe discussion. We know Myositis UK members have found this Facebook Group an invaluable source of support. To find the pages on Facebook simply type the name into the Facebook search browser.

Myositis UK Facebook Page is our main charity Page. It allows posting of messages in real-time (rather than wait for a Myositis News) and re-post suitable messages from other organisations. However, our website is much more up-to-date thanks to Laura Oakley. The Myositis UK Facebook Page acts as the hub for our other Facebook Pages and is administered by Paula Jordan (Trustee) and Jo Goode (Treasurer).

Team Muscle Facebook Page is for anyone fundraising and the event can be added to the calendar linked to the JustGiving Page. Initially set up for our Gold Bond London Marathon runners, this Page is now for all fundraisers. Paula and Jo administer this Page.

Juvenile Dermatomyositis Facebook Page was initially set up by former trustee, Nikki Coleman, to raise funds for JDM (namely the Teddy-Bo Project) but has evolved as a general Page for JDM. Due to Facebook changes its user interaction has been diminished and now mainly serves as a signposting page. It is administered Paula.

Teddy-Bo, his friends, adventures and juvenile dermatomyositis Facebook Page is administered by Paula. This Page allows any Facebook user to follow Teddy-Bo on his adventures as he meets his friends and raises awareness of the inflammatory muscle disease. Again, Facebook changes have meant its difficult to see posts by others of their Teddy-Bo photos and stories unless reposted by the admin so limiting its friendly usability. This may change again soon, so please keep your Teddy-Bo snaps coming in.

The Myositis Community of Great Britain & Ireland Facebook Group administrated by Jo. A large community of users some of which may also be members of Myositis UK. It serves as self-help and support for anyone at any stage of their myositis journey. If you use social media then this is a simple way to keep up to date.

Postscript

I would like to thank you for taking the time to read this edition of Myositis News and for supporting the work of Myositis UK. If you have any articles or news you would like included in the next edition, please email the office (msg@myositis.org.uk).

– Les Oakley MBE, Chairman

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