

# Myositis News



SCIENCE REPORTS • FUNDRAISING  
RESEARCH • AGM & CONFERENCE UPDATE

# Winter/Spring 2021

Dear Member,

It could easily be said that last year was a trying and difficult time for everyone and no doubt the majority of you would agree and ask the question, "Why state the obvious?" I could even deliver a further observation that the year had been rubbish particularly with having to cope and worry about the biggest contributor to these opening words, Covid-19. We have all been affected by this disease and it has led to much sadness in some people's lives while others have lived in the fear of contracting it and living in near isolation with mental health issues compounding it.

It affected the charity in many ways and had the effect of being in deep water trying desperately to keep afloat in the hope of drifting and eventually being marooned safely, and living to fight another day would have been considered a bonus.

The charity has not been able to function due to all the restrictions about meeting people and congregating for the fear of spreading infection. This has meant our fundraising ability has been curtailed and the London Marathon event did

not take place in the usual manner. The Christmas card sales were down because people couldn't meet to sell them. Likewise, the Christmas charity draw, for similar reasons, could not take place. The previously successful charity regional meet-ups had to cease. The charity book stall had to close and, alas, has now closed permanently. Our mascot, talisman and seasoned traveller, Teddy-Bo, has been grounded and in hibernation. The biggest disappointment was our Annual General Meeting and Conference being cancelled. Added to the woes, the scientific community involved with medical research into myositis had to ease up on their projects to help in the bigger picture of fighting Covid-19.

However, grim as all this may appear, this is not the full story. People have been fundraising for the charity, people have been making donations, several anonymously, knowing that we most probably need help. People have been able to keep in touch through social media by means of the charity forums and pages. The wheels have not fallen off the wagon and Myositis UK has battled on. The issue with myositis is that you have to be careful for the majority living with

the illness are vulnerable and need to keep safe. Nevertheless, the charity trustees and friends of the charity continued to play their role knowing we had to push on and get back into top gear. Myositis has no definitive cure but that is because we do not have the funds to discover a cure and it is this reason that the drive and ambition has not been diminished. Just look at what has been achieved in such a short length of time in developing a Covid-19 vaccine. Focus, money, scientific skill and dedication made this possible.

We are pleased to publish our first news magazine of the New Year even though we are under national lockdown yet again. Unfortunately, towards the later part of last year, I was not able to sit at a desk to edit an edition. However, this is another story! I trust this edition of Myositis News will bring you up-to-date and hope that we can all do as much as we can in treating and beating myositis as well as being vaccinated and keeping safe.

Happy New Year.

Les Oakley MBE  
Chairman



**CHAIRMAN** *Les Oakley MBE*   **SECRETARY** *Paula Jordan*   **TREASURER** *Jo Goode*  
**TRUSTEE** *Laura Oakley*   **CHARITY CO-ORDINATOR** *Irene Oakley*



# Science Reports

**The following news we would have liked to have published when it was submitted last year. However, for myriad reasons it was not possible. The reports are very relevant today to what is happening and extremely interesting.**

Dr Janine Lamb writes,

I have attached a 'lay summary' [see page 4] for a short letter that we had recently published in Annals of the Rheumatic Diseases, and a press release that was written for The Myositis Association (USA) that funded this study.

This is part of a larger piece of work investigating exposure to infections in individuals with anti-TIF1 positive dermatomyositis, which is currently under review.

Dr Janine Lamb - Letter published in Annals of the Rheumatic Diseases: Ann Rheum Dis. 2020 May 22:annrheumdis-2020-217522.

Antibodies against immunogenic epitopes with high sequence identity to SARS-CoV-2 in patients with autoimmune dermatomyositis

Spyridon Megremis, Thomas D. J. Walker, Xiaotong He, William E.R. Ollier, Hector Chinoy, Lynne Hampson, Ian Hampson, Janine A. Lamb

Idiopathic inflammatory myopathies (IIM) are a group of diseases with inflamed skeletal muscles (myositis). The lungs, heart and skin may also be affected. We don't know what causes myositis, but genetic and environmental factors, such as viral or bacterial infection, may be involved. The immune system is involved in myositis, and two-thirds of affected individuals have antibodies, proteins produced by the immune system, that are specific to myositis. We recently used a high-throughput approach to identify antibodies that were enriched in 20 individuals with dermatomyositis compared to 20 healthy controls. These antibodies are produced against infections such as viruses or bacteria, and also against self-proteins

(autoantibodies), and accumulate throughout life.

A new coronavirus has recently emerged from bats, and caused a global pandemic of severe acute respiratory syndrome (SARS) in humans, called COVID-19. Due to this pandemic, we specifically searched for antibodies produced against coronaviruses. In dermatomyositis patients, we identified antibodies targeted against bat coronavirus proteins. Three specific sections of these bat coronavirus proteins that caused an immune response were very similar to human SARS-CoV-2 that causes COVID-19. These findings indicate particular regions of the SARS-CoV-2 protein that might cause an immune response, and suggest that exposure to coronaviruses might contribute over time to musculoskeletal autoimmune disease development.

## Simon Rothwell, February 2020

Dr Janine Lamb writes,

A brief note to let you know that after approximately ten years (!), Simon is leaving the Manchester Myositis Research Group at the end of this month to take up another position within the University working on RA and RA treatment response. Simon

has made an enormous contribution to the work of our group, and wider international efforts, over the last ten years and he will be greatly missed.

I hope that you will join me in wishing Simon well in his new role.

In the meantime, we are putting

plans in place to ensure that the MYOGEN data arising from the ImmunoChip and related genetic studies is still available to everyone (with appropriate permissions) within the MYOGEN Consortium, through Chris Amos at Baylor College of Medicine. Fred will send an email in due course.

## Potential Targets for Covid-19 Vaccine Found, 28 May 2020

Scientists from the University of Manchester have identified parts of the SARS-CoV-2 strain of coronavirus that activate an immune response and which could act as targets for vaccine development.

Writing in *Annals of the Rheumatic Diseases*, the small-scale study performed before the pandemic used new technology to analyse the total immune response in patients with the musculoskeletal disease dermatomyositis and identified a link to lifetime exposure to coronavirus infection.

Idiopathic inflammatory myopathies, such as dermatomyositis, are a group of diseases characterised by inflamed skeletal muscles that may also involve the lungs, heart and skin.

Although scientists do not know what causes myositis, they do know the immune system is involved and research suggests genetic and environmental factors, such as viral or bacterial infections, may contribute to disease risk.

method to identify antibodies produced by the immune system against all types of infection that were unique or enriched in individuals with dermatomyositis, compared to healthy patients, during their lifetime.

The work sheds new light on how microbial infections may contribute over time to this disease, although the team stress that identification of antibodies against coronaviruses in individuals with dermatomyositis does not necessarily mean the virus causes the disease.

Three specific sections of the bat coronavirus proteins that stimulated an immune response were highly similar to the human SARS-CoV-2 virus that causes COVID-19 disease.

Comparison of the 20 individuals with dermatomyositis to 20 healthy controls has shed some light on the immune response against coronaviruses, and could suggest targets for vaccine development against COVID-19.

The team used a novel unbiased

Dr Janine Lamb

## Pandemic Interrupts Research

Dr James Lilleker writes on behalf of Manchester Myositis Research Group,

At the start of 2020, nobody could have foreseen how much things would change in such a short space of time. Facing the precipice of the pandemic, the University of Manchester shut its doors in March. The clinical academics of the Manchester Myositis Research Group ([www.manchester.ac.uk/myositis/](http://www.manchester.ac.uk/myositis/)) were seconded to full-time NHS work and put their research on hold. In this initial period a lot of time was spent trying to keep our immunosuppressed patients as safe as possible, providing advice on shielding and making difficult decisions about changes to medication regimens.

We found ourselves working outside of our comfort zones, covering for colleagues who had been called up to work on the 'front-line'. We adapted our working patterns and performed more remote consultations on telephone and video calls. If someone had told me in 2019 that in 2020 I would be wearing a headset microphone and running a remote first seizure clinic from my kitchen table using a new video consultation system, I certainly would not have believed them!

Professor Chinoy and I ran two webinars on Covid-19, providing information and a forum for discussion to members of Myositis UK and other people with myositis across the country. We received some great feedback on these sessions, and I am thankful to everyone who joined us so

enthusiastically. We are also indebted to Will Gregory, consultant physiotherapist at Salford Royal, who delivered a virtual physiotherapy session with exercises that could be performed safely within the home. Resources from these webinars and an exercise information leaflet from Will are still available on Myositis UK website (<https://www.myositis.org.uk/myositis-info/coronavirus-and-myositis/>).

Overall, the main memory I have of this period is how kind, supportive and understanding all the patients and families I interacted with were. It was so moving each week to see (and hear!) people standing on their doorsteps clapping for NHS staff and other key workers. Please can I personally thank you all for your support during this period – it would have been so much more difficult to get through without it.

Some of the research we have managed to complete recently has inevitably had a Covid focus. This has included an international survey of people with myositis, reflecting on how management of their condition has had to adapt during the pandemic. We completed this in collaboration with myositis researchers in India, with members of Myositis UK generously contributing their insights. The study provided important food for thought about how healthcare systems should organise themselves to ensure high quality care is delivered to patients with chronic conditions during a pandemic. The publication will be available for download soon.

More recently, our PhD students have been able to go back to their research work. Alex Oldroyd is due to submit his thesis on remote patient monitoring and Andrew Snedden is getting back to work on his Myositis UK funded project

investigating protein mishandling in inclusion body myositis. We managed to present some of our work (remotely) at the British Society for Rheumatology conference in April, including analysis of the link between the timing of cancer diagnosis and long-term survival in patients with myositis and examination of quantitative muscle testing data in inclusion body myositis from our collaboration with researchers in Newcastle.

We have also been able to restart clinical trials activity, such as the study of Zilucoplan for patients with immune mediated necrotising myopathy. Salford Royal remains the global leader for recruitment to this study. An exciting investigator-initiated study led from Manchester and spearheaded by Professor Chinoy investigating a potential new treatment for myositis (JAK inhibition) has also reached the final stages of setup.

We have restarted our work on producing clinical guidelines for the treatment of myositis. This collaborative project involves specialists, allied healthcare professionals and patient representatives from across the UK, and is facilitated by the British Society of Rheumatology. Once completed, these guidelines will drive up treatment standards and hopefully improve outcomes for people with myositis worldwide.

We sorely missed being able to meet with everybody at the Myositis UK AGM this year, but hope to see everyone again soon in more normal circumstances!

*James Lilleker is an NIHR Clinical Lecturer and Honorary Consultant Neurologist working at The University of Manchester and Salford Royal NHS Foundation Trust*

## UK Rare Diseases Framework

Rare Disease UK is a UK



charity that works with health departments across the UK to implement the UK Strategy for Rare Diseases to ensure that patients and families living with rare conditions have equitable access to high quality services, treatment and support.

They welcome the publication of the UK Rare Diseases Framework and are looking forward to working with the four nations of the UK to help to deliver its aims. This is once again an almost unique piece of health policy in that it represents a commitment from four health ministers from across the UK to deliver a shared aim for people living with rare conditions.

Overarching policy for people living with rare conditions is necessary now more than ever. We saw in our December 2020 publication: Rare Experience2020 that people with rare conditions are insufficiently served by the system.

For more information please visit the website <https://www.raredisease.org.uk/>

# Speed Funding Update

## Kyla Britson (USA)

### Project title: The Pathogenesis and Treatment of Inclusion Body Myositis in a Xenograft Model

When you are diagnosed with Inclusion Body Myositis (IBM), you are faced with two hard facts: there is no cure and the exact cause of the disease remains unclear. Those two facts are at the foundation of the Speed Funding Project I submitted to Myositis UK, which aims to study the cause and treatment of IBM using a xenograft model.

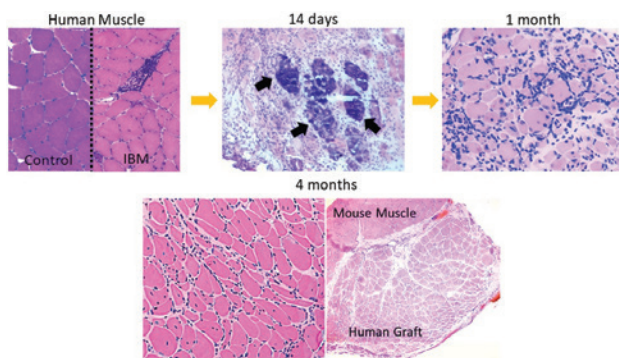
The cause of IBM has been a long standing debate due to the combination of degenerative and inflammatory pathological features seen in the skeletal muscle of patients with this disease. On one hand, the presence of rimmed vacuoles and an abundance of aggregated proteins

within muscle cells suggests that IBM is primarily a degenerative disease. However, the invasion of muscle cells by cytotoxic T cells and the fact that some patients have a particular autoantibody (Anti-NT5c1A) in their blood both indicate that IBM could be primarily autoimmune.

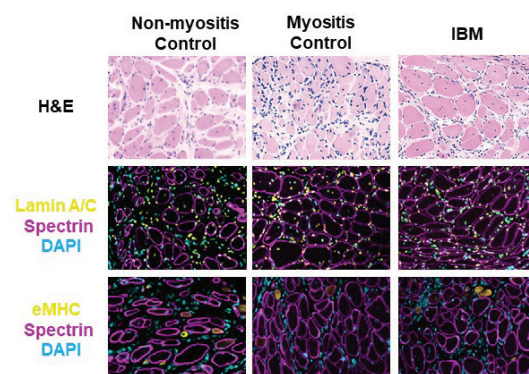
The absence of a laboratory model for IBM is one reason researchers have struggled to understand this disease and develop treatments. To address these challenges, I am developing a human skeletal muscle xenograft model of IBM in the laboratory of Dr Tom Lloyd at Johns Hopkins University. To make these xenografts, I receive IBM patient muscle and transplant it into the leg of an immunocompromised mouse host. As these host mice lack a functional immune system, the human

muscle can regenerate within the mouse to form a functioning human muscle called a xenograft (Figure 1). We were excited to find that IBM xenografts regenerate comparably to both non-myositis and myositis control xenografts (Figure 2), and our next step was to ask whether these xenografts showed pathological hallmarks of IBM.

Using a variety of experimental approaches, we have found that IBM xenografts share features of the human disease, including both inflammatory and degenerative features. IBM xenografts frequently show fibers with rimmed vacuoles, and occasionally fibers with protein aggregates. In addition, we observe endomysial inflammation, primary invasion of non-necrotic fibers by T cells, and mitochondrial dysfunction



**Figure 1: Overview of xenograft regeneration.** Following the xenograft surgery, the existing human muscle fibers from control or IBM patients undergo necrosis and are replaced in their entirety by newly regenerated myofibers which are spontaneously innervated and vascularized by the mouse host. At 14 days post surgery, there are areas of necrosis indicated by the black arrows. Then by 1 month there is an abundance of small regenerating fibers, and by 4 months a robust, mature human skeletal muscle xenograft has formed



**Figure 2: IBM xenografts can regenerate robustly.** Representative images of non-myositis control, myositis control, and IBM xenografts stained with H&E, human spectrin (magenta) to label muscle cells, human lamin A/C (yellow) to label human nuclei, embryonic myosin (eMHC) (yellow) to label regenerating fibers, and DAPI (cyan) to label DNA. Both control and IBM xenografts show comparable regeneration.

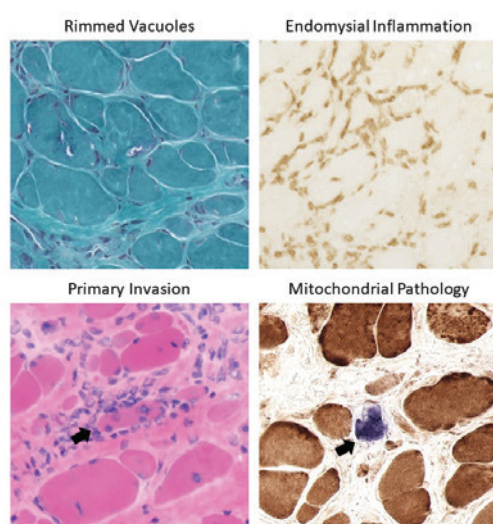


as indicated by COX-deficient fibers (Figure 3). Recently, we have started to carry out T cell depletion experiments in our IBM xenograft model to help answer the question: what role do T cells play in IBM pathology?

We are confident this xenograft model of IBM will help us better understand the cause of IBM and provide a platform to



test potential therapies for the disease. We are extremely grateful to Myositis UK for the support they have given this project, and the results from our study will be published soon.



**Figure 3:** IBM xenografts recapitulate hallmarks of the human disease, including rimmed vacuoles, endomysial inflammation, primary invasion of non-necrotic fibers (arrow), and mitochondrial pathology (arrow indicating a COX-deficient fiber).

## Erin Wilfon (USA)

In collaboration with the Bonami lab, we have been able to identify Jo1 specific B cells circulating in the blood, and we are working on a manuscript with this data at present.

We also looked to see if B cells invaded the inflamed lungs of patients with anti-Jo1 positive IIM, and this does not appear to be the case based on the patient samples available to us.

Finally we continue to work on transcriptional profiling of B cells in IIM and are tweaking the protocols for our transcriptional analysis.

We did have some substantial delays in research with COVID-19, but hopefully I will have some transcriptional data to share before too long.

I want to thank Myositis UK for funding this award and I look forward to sharing additional findings.

## Saskia Lassche (Netherlands)

We have made great progress in optimizing the skeletal muscle on chip model. We have started with experiments with IBM and control serum to investigate the effect of anti-cN1a antibodies on the muscle-on-chip model. We are currently optimizing this protocol.

Another aim is to start contractile experiments at the Ottenheijm lab in

Amsterdam to measure the contractility of the muscle bundles. So, as you can see, we have already achieved several of the aims outlined in the project proposal.

We hope we will be able to continue our experiments as planned, unfortunately Covid-19 cases are rising in the Netherlands and our government has already imposed new restrictions.

# Dr Frederick Miller MD PhD Is Retiring



When Irene and I first knew about Fred it was through researching doctors and scientists who had an active interest in myositis. This

was in the days when the internet was in its infancy and awareness of any activity was through their written and published papers. At this time, and it must be over thirty years ago, other names also cropped up in the United States such as, Dr Lisa Rider and Dr Chet Oddis, names so familiar and friendly to us now.

However, once the internet took off we were able to contact these people directly and since those days they have all visited this country and Fred and Chet have spoken at our national conferences.

We first met Fred at a scientific meeting and took the opportunity of inviting him to speak at our national conference being held in Birmingham. He kindly accepted and as a result of his participation it encouraged many other medical professionals to also attend for he was, and still is, very much respected for his understanding and contribution into research of neuromuscular disease.

Since those early days and with the driving force of Professor David Scott in the United Kingdom the association between Myositis UK

and the International community of myositis based research has gone from strength to strength and we now have the benefit of international conferences that have been held in Sweden, United States and Germany and if we can get past Covid-19 The Czech Republic in the future. These have all involved participation from eminent medical representatives worldwide.

**Fred was at the start of these events and this is his biography to the background to his work.**

Dr Frederick Miller is Chief of the Environmental Autoimmunity Group in the National Institute of Environmental Health Sciences at the NIH, Bethesda, MD. He oversees investigators in his group as well as others in national and international consortia that evaluate and conduct a wide range of basic and clinical studies on adult and juvenile autoimmune diseases.

He obtained his MD and PhD from Case Western Reserve University, went on to medical residencies at Emory and Stanford, and then did rheumatology and immunology training at the NIH. His work in the field of autoimmune diseases spans three decades and involves many aspects of the environmental risk factors, epidemiology, immunology, genetics, pathogenesis, evaluation

and treatment of immune-mediated diseases.

He has focused much of his work on autoimmune muscle diseases. He is leading a number of studies to identify environmental and genetic risk factors for autoimmunity and systemic autoimmune diseases.

To allow him to explore his many other interests, Fred Miller has announced that he will be stepping down as an International myositis assessment and clinical studies group (IMACS) Co-ordinator and Deputy Chief of the Clinical Research Branch at NIEHS. He will be retiring to become a Scientist Emeritus at the NIH in March 2021, with Lisa Rider taking over many of his oversight and administrative roles. An IMACS Advisory Committee was recently formed to address future planning and needs for IMACS. These needs include additional coordinators, as well as considering what would be the optimal future administrative housing of IMACS. Candidates for future IMACS coordinators have now been vetted by the Advisory Committee and will come to a vote by IMACS members in the annual ballot/survey.

*This is all rather heady stuff and you would expect Fred to be so wrapped up in his work he would not be a character who could be witty and amusing with interests*



*outside of his scientific career. I can recall a conversation when he told me as a young man he wanted to be an engineer!*

*In 2002 Irene, Paula and I attended the Myositis Association conference in Atlanta, USA. We booked in for the meeting at the venue in an orderly and friendly manner at 5pm and by 6pm we were standing outside the hotel in the pouring rain caught up in the final stages of Hurricane Isidora. There was a fire alert with an urgency to vacate the hotel. I would mention we did not need any prompting! Atlanta fire service and the police turned out in full force. An air conditioning extractor was faulty and pumping smoke into the fourth, fifth and sixth floors. Fortunately, the situation was not serious and by 6.30pm we were back in the hotel taking refuge in the bar. Fred was already standing there, glass in hand, in bare feet. He had left his hotel room to have a brief reconnoitre when the door shut behind him, locking him out! I suppose it could have been worse because he was decently attired.*

*Mind you, Fred is the sort of character who would be completely unfazed by the sequence of events and the fact he had nothing on his feet was not an issue for him and rectifying the situation could wait.*

*I am sure Fred will continue to be an influence in the understanding of myositis for many years to come.*

## Research Grants

The trustees approved funding of £31,982 to the Manchester Myositis Research Group to support the ongoing research programme in Myositis.

The grant awarded previously for £12,000 to Dr Pedro Machado for IBM and AD amyloid PET imaging has, at his request, had an extension approved by the trustees.

Two of the three grants for 15,000 Euros awarded at the GCOM meeting in Berlin have been paid and one is in the process of being paid.

A grant of £5000 has been approved to fund a database manager for four months for the IMACS core set measures online training tool. Dr Hector Chinoy and Dr James Lilleker, The University of Manchester and Prof Raashid Luqmani, University of Oxford.

A grant of £30,000 has been approved by the trustees to Professor Lucy Wedderburn for the UK Juvenile Dermatomyositis Cohort and Biomarker Study. (£20,000 contribution towards the salary costs of the JDM Study Co-ordinator and £10,000 contribution towards the cost of consumables required for the study.)

A grant of £12,800 to fund the salary of Experimental Officer Hazel Platt for six months at The Faculty of Biology, Medicine and Health, University of Manchester.

Due to the Covid-19 pandemic some of the above grants have had to be put on hold as most research could not continue as the doctors were seconded elsewhere. Hopefully, they will all resume this year.

# Consensus Exercise Guidelines

Paula Jordan writes,

At the beginning of April 2020, I received an invitation to participate in an international research project as a patient representative (PR) to develop evidence-based, consensus exercise guidelines for juvenile myositis.

This project has been established by the IMACS<sup>1</sup> Rehabilitation and Exercise Special Interest Group (SIG) and in addition to the JDM arm which I am a PR on there are also other adult arms looking into DM/PM and IBM.

The lead of the JDM SIG is Dr Helene Anderson and she expertly led our Zoom meetings. The first part of the project was to review the current literature on exercise for myositis and for the group I was in specifically JDM. The main input

for this project was time. Prior to a meeting a published exercise paper had to be read and analysed through a guided checklist. It was anticipated that each participant would read 2-5 publications and would involve 6-10 hours in total over several weeks.

The papers were interesting and Helene was excellent at explaining the checklists when it came to discussion on Zoom. At first it was quite daunting to be on a Zoom meeting with experts in the field (from across the globe too) but there was another PR present and our views were always welcomed and even on occasion gave real food for thought. At the start of the project the time taken to review and discuss took longer than anticipated, but this was accommodated and improved upon. During the first COVID-19 lockdown I was able to give the time to participate and reviewed 3

papers in the phase 1 of the project. Unfortunately, I was unable to make Zoom meetings scheduled for October and thereafter in 2020 but the next is set for the end of January, which I plan to attend where I believe the project has moved onto the next stage of Assembly meetings for all groups.

It will be interesting to participate again and give input where I can as well as see the project through the next phases. I know an ultimate aim of the project and this SIG is to develop educational materials on exercise for patients and health-care providers. As a patient myself I know how important this would be to everyone, both children and adults with myositis.

<sup>1</sup> International Myositis Assessment and Clinical Studies Group

## Webinars

In March 2020, when the pandemic started, Professor Chinoy and Dr James Lilleker, along with physiotherapist Will Gregory, held webinars over zoom for our members. These were very interesting sessions and we are hoping to start them again on a regular basis either bimonthly or quarterly. The dates and joining information will be put on the Myositis UK website and on social media.

Dr Lilleker has shared his slides from these webinars and they are available on our website along with Will Gregory's exercise sheets.

# Fundraising

**JustGiving™** £43,761.52 was raised through JustGiving for the charity during 2020.

Donating through JustGiving is simple, fast and totally secure. Your details are safe with JustGiving – they'll never sell them on or send unwanted emails. Once you donate, they'll send your money directly to the charity. So it's the most efficient way to donate – saving time and cutting costs for the charity.

## Ashley & Pete Trudgeon

Ashley writes,

My Dad and I had been planning on cycling from Land's End to John O'Groats for a few years now and something had always got in the way. As he turned 50 this year, it seemed like a good time to get out and get on our bikes! We cycled without company or support vehicle and averaged just under 100 miles everyday, all the way from Land's End in Cornwall up to John O'Groats in Scotland! The cycle was physically challenging and equally a mental battle through the storms and heavy rain we encountered on the way.

We chose to raise money for Myositis UK as you've supported a bubbly, young girl that I had been lucky to teach in my class last year. The resilience that I saw day in, day out was inspiring. Hopefully, this money will help Myositis UK to continue to support children with Juvenile Dermatomyositis (JDM) and continue to fund much needed research.

We managed to raise the grand total of what is now £755 by posting daily updates of our cycle and many of our friends and family followed our cycle, sponsoring us along the route. The initial target of £500 was smashed on our last day, taking us hundreds of pounds over the target! We cycled from Land's End to John O'Groats in 9 days, averaging just under 100 miles a day.

<https://www.justgiving.com/fundraising/trudgeonsontour>





# Tour de France 2020

Colin McNab writes,

Three years ago, my big brother Andrew was diagnosed with dermatomyositis. It has turned his life upside down and he has had to adapt to this new way of living, whilst experiencing ups and downs along the way. My sister raised a lot of money for Myositis UK as she took on the challenge of the Edinburgh marathon, my mum raised a lot of money taking on a 24-hour golf challenge, so it was my turn to do something!

About a year and a half ago, it was announced that the Tour de France 2020 would start in Nice. I have lived in Cannes for the last 10 years and one of my closest friends out here, David Derham, came up with the mad idea of attempting to complete the Tour de France.

We had been training for the best part of a year on the local hills in our area. France had a fairly strict lockdown from March to May so we both had to invest in home trainers. We changed our original plan and decided to start our tour at the end of July.

We had to book hotels and, more importantly, find a support team for our bags and transporting us from the finish of one stage to the start of the next. Thankfully, my mum and uncle were keen to help any way they could, so they signed up to be our support team for our first week. David's wife then supported us for the next 9 days or so, before my uncle came back out as he wanted to see us finish it!



We set off at the end of July on what would be an epic 3 weeks of cycling and exploring France. We kept a steady pace throughout the first week, enjoying a coffee stop in the morning and a lunch stop in some suitable restaurant en route. The days were long and the relentlessness became apparent early on. We would start at 7am or so, finish at roughly 6pm, pack the bikes onto the car, drive to the next start town, wash our clothes and ourselves, find somewhere to eat, reply to messages, stretch and then get some sleep before repeating the same process the next day.

We were delighted to reach Paris. Riding down the Champs-Elysees

was an unforgettable moment and the sense of achievement was overwhelming. In total, we cycled 3,548km with over 58,000m of climbing.

I'm overwhelmed by the generosity of people. They have raised a fantastic amount of money for a very worthy cause and I hope that Myositis UK continues their great work in helping my brother and others who have suffered at the hands of this disease.

**Colin and David have raised £7,131**

<https://www.justgiving.com/fundraising/colin-macnab1>

## A Man With A Van

Peter Marshall writes,

I am offering a man with a van service to raise money in support of Myositis UK, a charity that has provided support to a good friend, Andrew Macnab, over the past three years. This is a great small charity, that requires funding for ongoing

research and to help improve treatments and diagnosis.

**Pete has raised £787 to date**

<https://www.justgiving.com/fundraising/petermarshall22>



## Land's End To John O'Groats Virtual Run

Billy-Joe Davies writes,

I am running 874 miles virtual Land's End to John O'Groats for Myositis UK (between September 2020 and September 2021) because I got diagnosed with polymyositis in 2019. Polymyositis affects many different muscles, particularly around the neck, shoulders, back, hips and thighs.

Symptoms of polymyositis include: muscle weakness, aching or painful muscles, feeling very tired, finding it hard to sit up or stand after a fall, swallowing problems, finding it hard to hold your head up, feeling unhappy or depressed. You may find it difficult to get up from a chair, climb stairs,

lift objects, and comb your hair. The muscle weakness can become so severe that even picking up a cup of tea can be difficult.

Now feeling well with medication keeping it under control and with help of me keeping fit I've decided to do a virtual running challenge to raise money for Myositis UK.

I will be running the length of the UK, Land's End to John O'Groats. 874 MILES!

**Billy-Joe has raised £280 to date**

<https://www.justgiving.com/fundraising/bjdfitness>

## Half Marathon Of Doom

Adam Sheppard writes,

Against all odds and common sense, I've signed up to run a half marathon in May. And, unless films and TV have lied to me, all I now need is a cracking training montage, a cynical coach who dares to dream and one snarky competitor to beat.

All that aside, I also thought this was a great opportunity to raise money for Myositis UK. This charity does great and important work supporting people diagnosed with this rare disease and funding research to improve diagnosis and treatment. I believe that this is a very worthy cause and if my staggering through 21km can help raise a little money for them, then that's awesome.

Adam has raised £700

<https://www.justgiving.com/fundraising/adam-sheppard6>



## Ross Mabbott's Birthday

Ross writes,

I'm raising money for Myositis UK as this is the charity my late mum used to support. I lost my dear mum in September 2018 and she suffered lots with muscle pain and just wanted to do a little bit to support the charity my mum used to support. It would be very much appreciated if you could spare just a little amount. Thank you very much for reading my fundraiser. Have a lovely day.

**Ross raised £149**

<https://www.justgiving.com/fundraising/ross-mabbott>

## Hang Gliding in Loving Memory of Pam Meacham

Sally Cargill writes,

My dear friend Pam recently passed away after a long struggle with myositis. To raise donations for Myositis UK in her memory, I am flying into my first tandem hang gliding experience at Airways Airsport, near Ashbourne, on Tuesday 22nd September at 10.30am. Please donate generously to support Myositis UK and in loving memory of Pam.

**Sally has raised £770 to date.**

<https://www.justgiving.com/fundraising/memory-of-pam-meacham>

Sally adds,

I'm so very sorry to have to tell you that I can't do my hang gliding for Pam on Tuesday 22nd September, as planned. After a meeting my pilot had with her chief flying officer, it was decided that under current conditions around Covid-19 a tandem flight would be untenable. She also says 'after Covid' she's more than happy to take me up! As you can imagine I'm bitterly disappointed but in view of the present situation it's understandable and absolutely the right thing to do.

*We hope that Sally can get airborne and wish her every success for the future in her fundraising.*

## Beach Masonic Lodge of Hampshire & IOW

President of the Lodge Jim Steel writes,

Although 2020 has been a very difficult year with lodges unable to hold their usual scheduled meetings, we have still been actively fundraising.

It therefore gives me great pleasure to enclose a cheque for the sum of £500 on behalf of the members. We know that during these exceedingly difficult times many charities are finding it difficult to raise much

needed funds and we hope that our donation will help you to continue the very important work that you do.

We hope you stay safe and well as we look forward to better times ahead.

Over the years Freemasons around the country have been very generous and supportive of the charity, raising thousands of pounds for us. However, it is not just the gift but the kind and supportive words that are so very heartening, as well.



# The 2.6 Challenge

When the 2020 London Marathon was cancelled the organisers launched the 2.6 Challenge to help charities recoup some of the monies that would have been raised by the London Marathon.

The event was open to anyone and for any charity. The challenge was anything based on the number 2.6 or 26 and those performing the challenge asked friends and family to support their effort.

The 2.6 Challenge was launched nationally on 26th April, appeared on all media including the BBC news.

Myositis UK trustees and members took upon themselves varied challenges to raise funds.

In the past Flyer we reported on some of these challenges which included Irene and me dressing up and performing a daily 26 challenge, Paula Jordan who whilst shielding ran 2.6 miles on her cross trainer for 26 days in a row and then on completion carried on walking and recording her walks to reach 260 miles. Also involved were Lizi Williams who performed personal training workout of 26 reps of 26 exercises (raising £35) and Alison Belshaw who walked up and down her garden 26 times and raised £443. Alison said on her JustGiving page at the time, "My mobility is not great but I will try to do this without my stick." Brilliant efforts by all!

There is yet no information whether another official 2.6 challenge will be happening this year, but, given that the London Marathon date has been moved to October this year and our much favoured and familiar fundraising activities may not return to normal for a while, the 2.6 challenge is a simple way to raise funds.

Collectively £1862 was raised for Myositis UK last year via the challenge and this is vital money that otherwise would not have been received.



If there is any member who has been inspired to take on the 2.6 challenge for 2021 to help Myositis UK continue fundraising through the COVID-19, pandemic then please on the 26th April set up a challenge and JustGiving page. Information from the 2020 event can still be found online. Visit, [www.twopointsixchallenge.co.uk](http://www.twopointsixchallenge.co.uk)

If you are stuck for ideas, a simple google search or browse on [www.fundraising.co.uk](http://www.fundraising.co.uk) may help; run 2.6 miles, 26 handstands, row 26 miles, bake 26 cookies, build 2.6 metre tower of Lego, 26 rotations of 26 exercises, run and draw 26 using a running app, 2.6 cycle ride, 26 times flight of stairs, 26 minutes of dancing, 26 hours of silence, read 26 pages of a book a day for 26 days.

We would love some of you to have ago and report on your effort with photos for publication in a later edition of Myositis News.



## GV HARRISON BUILDING CONTRACTORS LTD

Claire of the Cambridgeshire company writes,

We are a building contractor who choose a charity each year to donate to. This year we have chosen you because someone close to us has myositis. The amount will vary each time we make a donation as it depends on the jobs we do.

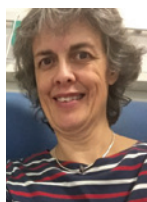
*G V Harrison Building Contractors Ltd are a family-run business, established in 2008, which has delivered hundreds of projects – commercial and domestic – and who pride themselves on delivering the highest quality of service and are meticulous about the standard of their work. They are the only contractor in their area solely dedicated to VELUX installations. For each VELUX window they replace they make a donation towards their charity of the year.*

**The company donated a generous £1,110 for jobs completed in 2020.**

## Fibre 4 Fibres Fundraiser

Helen Kurtz writes,

Last year I was diagnosed with myositis. It has had a huge impact on my life as I have been unable to work and it limits my daily activities significantly. I have had a lot of support from Myositis UK and would like to raise as much money as I can, through creative activities, to say thank you.



**Helen has raised £11,807 to date and is still fundraising!**

<https://www.justgiving.com/fundraising/helen-kurtz>



*Helen must have the title “fundraiser of the year” for Myositis UK. This sum of money is quite remarkable when you consider she raised it during lockdown and is still continuing.*

## Ann Lucas

Ann has continued her fundraising in memory of her dear dad, John Williams, because he was a sufferer of Inclusion Body Myositis.

Ann writes,

We are determined to do all we can to help others with this disease and those who care for people with this disease. We look forward to the day when there is a cure and Inclusion Body Myositis

is something everyone has heard of. Please help that journey for current and future sufferers and their carers. This is the greatest way we can honour the memory of our Dad.

Ann, Mark and Neil Williams

**To date they have raised £4,270.**

<https://www.justgiving.com/fundraising/annlucas-fordad>

# JP's Gym, Inflatable 5K, Glasgow

Gym members taking part on March 3, 2020: Derek Budd, Suzanne Robinson and Sheila Moug

Their story,

We are a group of staff and members from JP's Gym in Coatbridge. The ethos of our community is to support each other in living a rich, fun, active life for those we care about as much as for ourselves, so we are taking on

UK Running Events Inflatable 5k obstacle course to raise money for an important but underfunded charity close to our hearts. A young member of our community and their family is affected by Juvenile Dermatomyositis or JDM. Being such a rare condition, the main charity for the condition, Myositis UK, receives no funding from the Government, National Lottery or pharmaceutical grants, so we have decided to take on this fun

fitness challenge together to support this charity and the people it helps.

**Derek raised £40, Suzanne raised £60, Sheila raised £35 to date**

<https://www.justgiving.com/fundraising/jpsinflatable5k>  
<https://www.justgiving.com/fundraising/suzannerobinson14>  
<https://www.justgiving.com/fundraising/mightymougie>

## Other Ways To Raise Donations

**amazon**smile  
 You shop. Amazon gives.

Thank you again to everyone who used Amazon Smile to raise funds for the charity. Amazon Smile is a programme that donates 0.5% of your eligible purchases on Amazon to a charity of your choice. All you need to do is start your shopping at smile.amazon.com. The donation will be made at no extra cost to you. You just need to select Myositis UK as your chosen charity.

 **easyfundraising**  
 feel good shopping

Thank you to everyone for raising donations for Myositis UK with easyfundraising. If you haven't signed up yet, it's easy and completely free. Some 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/myositissupportgroup/>

**PayPal**  
 Giving Fund

We have received £1,600 from the PayPal Giving Fund. These funds are a grant that was made possible by donors who gave to PayPal Giving Fund and chose Myositis UK as their choice of charity.



## In Memory Of Loved Ones

Also, on the JustGiving Pages, there have been people raising thousands of pounds in memory of very dear family and friends requesting it will help the work of Myositis UK.

Myositis in all its forms can be very cruel and yet the way people have coped with it is very inspiring. Some of the words that are expressed are: 'Lived his life to the full with dignity'; 'Never let it get the better of her'; 'Unflinching optimism and good humour'; 'Grit and determination'; 'Coped with patience and dignity'.

Words can never express the gratitude of Myositis UK to all these people who have shown nothing but kindness and affection during times when they have had to endure such great sorrow.

## Virtual London Marathon 2020

One of our Gold Bond runners took part in the virtual marathon held by the London Marathon.

As you will probably know, due to the pandemic, the race was cancelled in April and then again in October, except for elite runners who took part in a special course in London without spectators.

Runners who took part in the 'virtual' marathon ran the 26.2 miles in October on their own in their home towns. To do this must have taken great determination and dedication.



Stephen Bailey took on this challenge and, in a message, said: "I enjoyed the virtual in October and the fundraising is going well!"

Stephen is also taking part in the 2021 London Marathon as one of our Team Muscle runners.

## Merchandise

We have a selection of items available for purchase and to help with fundraising.

Re-usable cups with lids (dishwasher safe) £8 each  
Shopping Trolley Key £1.50  
Metal Pin Badges £1  
Pens 2 for £1  
Wristbands £1  
Teddy-Bo Badges 2 for £1  
Teddy-Bo £5  
Teddy-Bo Book £5

Postage & packaging is £2 for the cup, £3 for Teddy-Bo, £2 for Teddy-Bo Book and £1 for other items. (If you wish to order more than one item please email the office for postage



cost.) Please make cheques payable to Myositis UK; for other ways to pay, please email the office for details.

If you are holding a fundraising event and would like some of the items to sell, please contact the office.

# London Marathon 2021

Team Muscle is gearing up for this great event with fingers crossed, will take place on Sunday 3rd October.

We hope the team will comprise of some of the runners that should have participated last year. Their resolve has not been beaten, they are back in training hopefully forming part of the biggest team Myositis UK has ever had for the event.

They are, as usual, raising their own sponsorship and I know you, dear readers, will be helping them as well when the sponsor forms are sent out as well as on line.

All our runners have a story to tell for the reasons why they are running for Myositis UK.

The following is a story about a former sufferer of myositis who, along with her husband, who has fundraised for the charity before, are taking on this superb challenge together.

Prior to his wife being diagnosed, Stuart Dillingham said: "We, like many of you, had never heard of this rare disease that affects about 1 in 10,000 people. Myositis causes inflammation of the muscles resulting in pain and



weakness of the muscles. When muscles are used they produce CK (creatinine kinase); the normal person has levels between 60-174. It would be expected an athlete after completing an Ironman event (2.4 mile swim, 112 mile bike ride followed by a marathon run, all in 17 hours) to have levels of 1500. Joanne was diagnosed with levels of 5800. This meant the pain she felt was similar to completing nearly 4 Ironman events just from completing day to day tasks and chores. There have been many lows and stresses over the past few years, we, as a family, have had to deal with just to try to have a 'normal' life. There is at present no cure for myositis. The best we can hope for is periods of remission. In a way Joanne has been very lucky, as although her symptoms have been horrific and life changing, they have disappeared into insignificance when reading what others are suffering in the hands of myositis. Many are unable to walk or live alone as they are unable to do much for themselves. We now know

why Joanne's doctor advised right at the start to be careful what you read. A cure needs to be found for myositis. Please, please, dig deep, and help us in our fight against myositis."

In 2020 we had 13 places available in the London Marathon. These have been reallocated over the next three years by the London Marathon. Five places in 2021, seven places in 2022, one place in 2023. These are in addition to the five places for each of these years. This gives us 10 places for 2021.

These places have been offered first to our 10 runners who should have taken part in 2020 along with one other who had gained a ballot place. This would make a team of 11 runners for 2021. We also gave these runners the option of deferring their place until 2022. Three of the runners have at the moment opted for 2022.

This leaves the charity with three places available for October this year. If you know of anyone who would like a place in this fantastic event and be part of a great team, please email the office.



# 4th Global Conference On Myositis (GCOM)

Due to Covid-19 pandemic, this meeting cannot be organised in the originally planned time. It has been postponed to 2022. The new dates are 16 -19 March 2022 in the same location.

Jirí Vencovský writes,

It is a great privilege to host the 4th Global Conference on Myositis in Prague, the Czech Republic. Since the 1st convention in Stockholm in 2015, followed by meetings in Potomac USA 2017 and Berlin 2019, this conference has firmly established its place in the field of myositis research. Idiopathic inflammatory myopathies are heterogeneous diseases requiring multidisciplinary approach. Participation of researchers, clinicians and health professionals from rheumatology, neurology, paediatrics, dermatology, pathology, immunology, pulmonology, physiotherapy and other sub specialities offers a unique opportunity to meet and discuss the topic from different perspectives. The open and welcoming character of the meeting is further potentiated by participation of leading experts in other diseases to provide thought-provoking state-of-the-art lectures.

Since the very beginning of these conferences strong attention has been paid to stimulate active participation of young doctors and scientists. We would like to further encourage communication between young and more experienced experts by intentionally removing any barriers that might exist. We also hope for active participation of patient representatives and their organisations.

With its accessible location and cultural heritage, Prague has recently become a frequent destination for conferences and congresses on immune mediated systemic diseases. We are looking forward to welcome you in our city in the spring of 2021 (now 2022); however, we are painfully aware, that the unfolding Covid-19 pandemic may still disrupt our plans.

GCOM is the premier global event dedicated to various forms of inflammatory myopathies. Currently, we are in the process of programme development. We identified topics that will be in focus of the conference. Rather than aiming to individual myositis subtypes, we plan to discuss problems that are common to the many forms of myositis.

We plan to include:

1. Genes and environment
2. Pathogenesis, including mitochondrial biology
3. Antibodies & Biomarkers
4. Pulmonary & Cardiac involvement
5. Skin in myositis
6. Imaging in myositis
7. Drug induced myositis
8. Juvenile to Adult transition
9. Towards personalized medicine (treatment of myositis)
10. Repairing damage

We also will introduce 'Great Debate' with the topic of Inclusion Body Myositis. We plan to hold several workshops, similar to those in Berlin. Also, similar to previous GCOM meetings, we will pay great attention to patients' aspects. We have formed a separate organizing committee that is working hard to organize and harmonize the program for patients, including the poster session. In our preliminary programme, we also assigned the time for parallel workshops with time for patients organisations.

*Myositis UK will endeavour to help in funding this very important international conference and in particular the speed funding of young scientists.*



# AGM & Conference 2021

It is with much regret that the conference we were hoping to hold in June 2021 has been cancelled. The date is too soon to be sure of the completion of second vaccinations and the desire for members to feel confident enough to attend. Also, our medical teams may find that they are not in a position to have the time with a backlog of clinics, etc, due to Covid-19.

The venue for the conference, the Oxford Spires hotel Oxford, have been very kind and helpful during all the uncertainty. There is no doubt the charity will be using this venue in the future.



## Annual General Meeting

We are looking into the possibility of holding the AGM on Zoom. We have looked at the advice and guidance on the Charity Commission website and although we do not have a clause in the Governing Document that specifically allows us to meet virtually or to use telephone facilities, there is also no mention that meetings have to be in person. However, the Charity Commission advice is that if generally there is no such clause in the governing document and we decide to hold meetings over the phone or using digital solutions, they will understand as long as we record this decision and that we have done this to demonstrate good governance of the charity. The trustees have recorded this decision.

Our Governing Document was originally set up in 1988 and has only had a couple of amendments since that time. We are therefore seeking professional guidance to bring our Governing Document up to date.

## Welfare Advice

Janet Horton can be contacted at: 1 Fellstone Vale, Withnell, Chorley, Lancs, PR6 8UE. She will be pleased to help Myositis UK members regarding welfare advice. You can also speak to her by telephone on a Monday or Friday between 10am and midday on 01254 832463.

If you telephone please tell Janet you are a Myositis UK member for she helps members of other organisations as well. Janet cannot give any medical advice. Any member requiring information of this nature should get in touch with Irene or Les Oakley.

# 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 it is preferred you email rather than use Messenger within Facebook.

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 a Twitter presence, but we do not tweet 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 many Myositis UK members have found this Facebook Group an invaluable source of support.

To find the pages on Facebook simply type the name (in bold) 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 (Trustee). 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 whatever your activities are. 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.

**Myositis UK Community Forum** 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.

# Published Research

A medical literature search on PubMed since the last Myositis News has revealed again a large body of published work including that by doctors and institutions supported by the charity. To conserve space we have only reprinted the title and basic details of publications. By entering the PMID number on pubmed.com you can read the abstract and in some instances even the full paper.

On this website you can also perform your own searches of the medical literature. However, if you do not have access to a computer and would like to read a paper copy of a publication listed, please get in contact with the office, enclosing a stamped addressed envelope, and we will print and send it to you.

## Pitfalls in the diagnosis of myositis.

Chinoy H, Lilleker JB.

*Published in Best Practice & Research: Clinical Rheumatology, Abstract only. February. 2020 PMID: 32063440*

## Differential Diagnoses of Inclusion Body Myositis.

Vivekanandam V, Bugiardini E, Merve A, Parton M, Morrow JM, Hanna MG, Machado PM.

*Published in Neurologic Clinics. August 2020. Abstract only. PMID: 32703477.*

## Myositis autoantibodies: recent perspectives.

Riddell V, Bagby S, McHugh N.

*Published in Current Opinion in Rheumatology. November 2020. Abstract only. PMID: 32890028.*

## Up-to-date treatment and management of myositis.

Pipitone N, Salvarani C.

*Published in Current Opinion in Rheumatology. November 2020. Abstract only. PMID: 32890030.*

## The promise, perceptions, and pitfalls of immunoassays for autoantibody testing in myositis.

Tansley SL, Snowball J, Pauling JD, Lissina A, Kuwana M, Rider LG, Rönnelid J, McHugh NJ; International Myositis Assessment and Clinical Studies (IMACS) Group Myositis Autoantibody Scientific Interest Group.

*Published in Arthritis Research. May 2020. Free article. PMID: 32414409.*

## Treatment of calcinosis cutis in systemic sclerosis and dermatomyositis: A review of the literature.

Traineau H, Aggarwal R, Monfort JB, Senet P, Oddis CV, Chizzolini C, Barbaud A, Francès C, Arnaud L, Chasset F.

*Published in Journal of the American Academy of Dermatology. February 2020 PMID: 31302187.*

## The myositis clinical phenotype associated with anti-Zo autoantibodies: a case series of nine UK patients.

Tansley SL, Betteridge Z, Lu H, Davies E, Rothwell S, New PP, Chinoy H, Gordon P, Gunawardena H, Lloyd M, Stratton R, Cooper R, McHugh NJ.

*Published in Rheumatology (Oxford). July 2020. Free article. PMID: 31665469.*



## Calcinosis Biomarkers in Adult and Juvenile Dermatomyositis.

Chung MP, Richardson C, Kirakossian D, Orandi AB, Saketkoo LA, Rider LG, Schiffenbauer A, von Mühlen CA, Chung L; International Myositis Assessment; Clinical Studies Group (IMACS) Calcinosis Scientific Interest Group.  
Published in *Autoimmunity Reviews* June 2020. Abstract only. PMID: 32234404.

## Long-term safety and tolerability of bimagrumab (BYM338) in sporadic inclusion body myositis.

Sivakumar K, Cochrane TI, Sloth B, Ashar H, Laurent D, Tankó LB, Amato AA.  
Published in *Neurology*. October 2020. Abstract only. PMID: 32690797.

## The reliability of immunoassays to detect autoantibodies in patients with myositis is dependent on autoantibody specificity.

Tansley SL, Li D, Betteridge ZE, McHugh NJ.  
Published in *Rheumatology (Oxford)*. August 2020. Free article. PMID: 32030410.

## Association of Ultraviolet Radiation Exposure With Dermatomyositis in a National Myositis Patient Registry.

Parks CG, Wilkerson J, Rose KM, Faiq A, Noroozi Farhadi P, Long CS, Bayat N, Brunner HI, Goldberg B, McGrath JA, Miller FW, Rider LG  
Published in *Arthritis Care Research (Hoboken)*. November 2020. Abstract only. PMID: 31478597.

## Long-term strength and functional status in inclusion body myositis and identification of trajectory subgroups.

Oldroyd AGS, Lilleker JB, Williams J, Chinoy H, Miller JAL  
Published in *Muscle and Nerve*. July 2020. Abstract only. PMID: 32134516.

## Polymyositis: is there anything left? A retrospective diagnostic review from a tertiary myositis centre.

Loarce-Martos J, Lilleker JB, Parker M, McHugh N, Chinoy H.  
Published in *Rheumatology (Oxford)*. December 2020. Abstract only. PMID: 33367878.

## Assessing the content validity of patient- reported outcome measures in adult myositis: A report from the OMERACT myositis working group.

Esfandiary T, Park JK, Alexanderson H, Regardt M, Needham M, de Groot I, Sarver C, Lundberg IE, de Visser M, Song YW, DiRenzo D, Bingham CO 3rd, Christopher-Stine L, Mecoli CA.  
Published in *Seminars in Arthritis and Rheumatism*. October 2020. Abstract only. PMID: 32906029.

## Antibodies against immunogenic epitopes with high sequence identity to SARS-CoV-2 in patients with autoimmune dermatomyositis.

Megremis S, Walker TDJ, He X, Ollier WER, Chinoy H, Hampson L, Hampson I, Lamb JA.  
Published in *Annals of the Rheumatic Diseases*. October 2020. Free Article. PMID: 32444414.

## Expression of interferon-regulated genes in juvenile dermatomyositis versus Mendelian autoinflammatory interferonopathies.

Kim H, Gunter-Rahman F, McGrath JA, Lee E, de Jesus AA, Targoff IN, Huang Y, O'Hanlon TP, Tsai WL, Gadina M, Miller FW, Goldbach-Mansky R, Rider LG.  
Published in *Arthritis Research and Therapy*. April 2020. Free Article. PMID: 32252809.

## Cytokines and inflammatory mediators as promising markers of polymyositis/ dermatomyositis

Cerezo LA, Vencovsky J, Šenolt L

Published in *Current Opinion in Rheumatology*. November 2020. Abstract only. PMID: 32941247.

## Performance of the new EULAR/ACR classification criteria for idiopathic inflammatory myopathies (IIM) in a large monocentric IIM cohort.

Barsotti S, Dastmalchi M, Notarnicola A, Leclaire V, Dani L, Gheorghe K, Ekholm L, Bottai M, Tjärnlund A, Lundberg IE.

*Seminars in Arthritis and Rheumatism*. June 2020. Abstract only. PMID: 32024593.

## Monitoring disease activity and damage in adult and juvenile idiopathic inflammatory myopathy.

Gupta L, Chinoy H

Published in *Current Opinion in Rheumatology*. November 2020. Abstract only. PMID: 32890032.

## Identification of a novel autoantigen eukaryotic initiation factor 3 associated with polymyositis.

Betteridge Z, Chinoy H, Vencovsky J, Winer J, Putchakayala K, Ho P, Lundberg I, Danko K, Cooper R, McHugh N

Published in *Rheumatology (Oxford)*. May 2020. [Free Article](#). PMID: 31728542.

## Line blot immunoassays in idiopathic inflammatory myopathies: retrospective review of diagnostic accuracy and factors predicting true positive results

To F, Ventín-Rodríguez C, Elkhalfa S, Lilleker JB, Chinoy H.

Published in *BMC Rheumatology*. July 2020. [Free Article](#). PMID: 32699830.

## CARRA Juvenile Dermatomyositis Quality Measures Workgroup for the CARRA Registry Investigators. Patient and physician discordance of global disease assessment in juvenile dermatomyositis: findings from the Childhood Arthritis & Rheumatology Research Alliance Legacy Registry.

Tory H, Zurakowski D, Kim S.

Published in *Paediatric Rheumatology Online Journal*. January 2020. [Free Article](#). PMID: 31941511.

## COVID-19 and myositis- unique challenges for patients.

Gupta L, Lilleker JB, Agarwal V, Chinoy H, Aggarwal R.

Published in *Rheumatology (Oxford)*. November 2020. [Free Article](#). PMID: 33175137.

## Patient insights on living with idiopathic inflammatory myopathy and the limitations of disease activity measurement methods - a qualitative study.

Oldroyd A, Dixon W, Chinoy H, Howells K

Published in *BMC Rheumatology*. September 2020. [Free Article](#). PMID: 32974608.

## Insights into the knowledge, attitude and practices for the treatment of idiopathic inflammatory myopathy from a cross-sectional cohort survey of physicians.

Gupta L, Muhammed H, Naveen R, Kharbanda R, Gangadharan H, Misra DP, Lilleker JB, Chinoy H, Agarwal V

Published in *Rheumatology International*. December 2020. Abstract only. PMID: 32880031.

## Teleconsultation experience with the idiopathic inflammatory myopathies: a prospective observational cohort study during the COVID-19 pandemic.

Naveen R, Sundaram TG, Agarwal V, Gupta L.

Published in *Rheumatology International*. November 2020. [Free Article](#). PMID: 33150493.

## Identification and prediction of novel classes of long-term disease trajectories for patients with juvenile dermatomyositis using growth mixture models.

Deakin CT, Papadopoulou C, McCann LJ, Martin N, Al-Obaidi M, Compeyrot-Lacassagne S, Pilkington CA, Tansley SL, McHugh NJ, Wedderburn LR, De Stavola BL; Juvenile Dermatomyositis Research Group.

Published in *Rheumatology (Oxford)*. November 2020. Abstract only. PMID: 33146389.

## MicroRNA and mRNA profiling in the idiopathic inflammatory myopathies.

Parkes JE, Thoma A, Lightfoot AP, Day PJ, Chinoy H, Lamb JA.

Published in *BMC Rheumatology*. June 2020. [Free Article](#). PMID: 32529172.

## A Valid and Reliable Functional Outcome Assessment Measure in Patients With Dermatomyositis and Polymyositis

Ernste FC, Chong C, Crowson CS, Kermani TA, Mhuircheartaigh ON, Alexanderson H. Functional Index-3:

Published in *Journal of Rheumatology*. January 2021. Abstract only. PMID: 32295854.

## Juvenile Dermatomyositis Research Group (JDRG). Retrospective analysis of infliximab and adalimumab treatment in a large cohort of juvenile dermatomyositis patients.

Campanilho-Marques R, Deakin CT, Simou S, Papadopoulou C, Wedderburn LR, Pilkington CA;

Published in *Arthritis Research and Therapy*. April 2020. [Free Article](#). PMID: 32293539.

## New insights into the treatment of myositis

Stefanie Glaubitz 1, Rachel Zeng 1, Jens Schmidt 2

Published in *Therapeutic Advances in Musculoskeletal Disease*. January 2020. [Free Article](#). PMID: 31949477

## An international survey of developing classification criteria for juvenile dermatomyositis-scleroderma overlap.

Parichat Khaosut 1 2, Clarissa Pilkington 2, Lucy R Wedderburn 2 3 4, Sandrine Compeyrot-Lacassagne 2.

Published in *Rheumatology (Oxford)*. November 2019. [Free Article](#). PMID: 31199482.



# Memory Lane



The Barnettts with Tony Hindle (past treasurer)



1987: The first Myositis patient meeting at Hammersmith Hospital



Mary Adams and Les Oakley (Myostis UK founder) in 1990



June Patterson and her sister-in-law, Yvonne, taking part in the Great South Run



1990: D&P Support Group (Myositis UK) 'Team' at the Southampton annual Round Table Wheel Barrow race. I think they won the best fancy dress!



Sue, Nick and Mick Clarke (former trustee) taking part in the London Marathon

## Postscript

Thank you to everyone who has helped the charity and for making this magazine an interesting and helpful read and let us hope we can get Teddy-Bo travelling with you again soon!



**146 Newtown Road, Woolston, Southampton, SO19 9HR**  
**t 023 8044 9708 e [office@myositis.org.uk](mailto:office@myositis.org.uk) [www.myositis.org.uk](http://www.myositis.org.uk)**

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