MYOSITIS UK

Autumn 2022

Myositis News

GCOM 2022 • FUNDRAISING • RESEARCH
AGM & CONFERENCE UPDATE

Autumn 2022

Dear Member,

This magazine, for many reasons, is long overdue.

It has been well over two years of stop and go because of the pandemic but at last society is getting back to some degree of normality.

As a charity we can now get back on track in improving the hope and aspirations of people living and coping with myositis.

However, during those uncertain times the charity has been ticking over, work is still being done and many members and friends of the charity have been raising funds.

Les Oakley MBE
Chairman

AGM & Conference

We are now very busy in the office preparing for our Annual General Meeting and Conference, which is being held on Sunday October 16th at the Oxford Belfry, Thame, Oxford.

It will be our first get-together conference since 2019 and we are really looking forward to seeing everyone again and also to meeting new members.

After much consideration and advice, we feel it is safe to travel and meet up after this dreadful pandemic.
As a result of this decision making, we have had full support from our medical professionals associated with the charity, including dermatology, will be attending for the first time. These are the leading experts in the field of treating and managing myositis in all its forms. They are giving their time at no cost to the charity for which we are extremely grateful.

The programme is still to be finalised which will be sent out and published online at a later date. The success of the conference will depend on you, the members, attending and making the occasion very worthwhile. 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 nearby or in the hotel. This is usually held in the room at the back of the hotel bar between 2pm and 4pm.

The conference venue is one which we have used many times before with adequate space. In the past we have had lunch in the restaurant but this year a buffet lunch will be served in the meeting room to avoid movement around the hotel.

We have secured accommodation with rooms with walk-in showers priced at £140 for double occupancy and £130 for single occupancy including breakfast. The conference is free to members and their partner/carer. Parents or guardians along with a child living with myositis are also free to attend.

As in previous years the Juvenile Dermatomyositis room is separate and there will be a play area for the children and siblings are welcome to attend at no charge.

This conference is an opportunity to talk to people with similar conditions, to share advice and generally obtain a better understanding of their condition. It is also a rare opportunity to speak to health professionals who are looking into and treating myositis.

The programme will include updates on research and treatment as well as an open question and answer session.

There will also be time to meet and talk to other members and perhaps make new friends.

This is an expensive event for the charity and we need to keep an eye on costs and expenditure as there is a cut-off date after which we will be liable for the full amount regardless of the numbers attending.

Please, write or email the office for a registration form or for further information. We trust you will give this conference your full consideration and support.

GCOM 2022

GCOM 2022
4TH GLOBAL CONFERENCE ON MYOSITIS 2022

congress prague

6th – 9th June 2022
Prague, Czech Republic

Information and on-line registration:
www.congressprague.cz/kongresy/myositis2022.html

Other good news is that the fourth Global Conference in Myositis has taken place in Prague in the Czech Republic. Irene and I had to leave it to the latest hour before we made the decision to attend in person. We had health issues to consider and, thankfully for us, it was not a problem.

Les Oakley reports: Fortunately, our flight to Prague was on time unlike much of the air travel industry on the day. We arrived on the evening of Sunday the 5th and set up shop the following morning in the venue. It was arduous work dragging the stuff about and it never ceases to amaze me how heavy paper and books can be along with display paraphernalia, etc.

Myositis UK in the world of myositis is almost unique in that we are a patient support charity sponsoring medical research as well. As such, we create much interest from all attending and the charity is much respected and appreciated for how we have managed to cope with the various demands that this can create. We are fortunate to have trustees who are invaluable with their input and aware of what is involved.

There is no doubt we have missed out over the last few years, because of the pandemic, these scientific and charity meetings. There is nothing like a face to face meeting with light-hearted banter to move an agenda along even during serious discussion. The same, I consider, cannot be so well achieved online. However, events evolved rapidly approaching the GCOM conference date and delegates, including us, were able to attend in person much to the relief of the organisers.

The world-wide lockdown had not, as was premised, diminished the ability for scientists to continue their work and the talks taking place in the conference room were extremely valuable, demonstrating the good progress that had been made. For us, we have been able to reconnect with the scientific community and as a charity we are developing some exciting plans and initiatives for all forms of myositis. We have also been talking to pharmaceutical companies present at GCOM where there may be opportunities to work together for mutual benefit soon. This conference

Meeting the Australian team, friends and delgates from the USA and some of our younger visitors to the stand.

has enabled us to reconnect with patient groups, particularly in Europe, and we will be involved with them where we can benefit from a united front and be part of an umbrella group. The evenings have been worthwhile too; because it is amazing how much can be achieved in a social setting enjoying a meal and a glass of wine.

Well, there has to be some benefits! Unfortunately, there had been some issues with communication before the conference and as such the "Speed Funding" for young scientists and research doctors could not take place. Also, there was much uncertainty about whether applicants for these grants could attend. This initiative proved so successful in Berlin 2019 and the resulting publications of the successful scientific work undertaken has shown beyond doubt to be funds well spent.

Our bronze sponsorship to this year's Global Conference included the prizes for scientific abstract posters presented. There was a large poster room where they were all displayed and reviewed. I can recall from years ago when I was excited to see just one poster about myositis on display at a national neuromuscular meeting. Research is certainly moving on at a pace. There were 189 posters displayed.

Because of the high quality of the submitted abstract posters, 22 instead of 10 were selected for the award.

The official award announcement took place on Thursday, 9th June, at the closing of the conference. The organisers were able to increase the number of prizes due to the funding given by Myositis UK. Although we could not fund the speed funding this year this was a way Myositis UK could continue to support young scientists.

Welcome from Jiří Vencovský

"We would like to welcome you to Prague for the 4th Global Conference on Myositis. Due to the COVID-19 pandemic, the conference had to be postponed by more than a year. I am very happy that we have finally managed to organize this meeting with two-thirds of the participants meeting in person. This will allow us not only to share and discuss the latest advancements related to myositis but also to interact face-to-face, especially during the informal parts of the meeting. This is important because it brings an immediate sense of authenticity and experience. I hope the collegial atmosphere will be felt, at least partly, also by those participating online. Since the 1st convention held in Stockholm in 2015, followed by meetings in Potomac in 2017 and Berlin in 2019, this conference has firmly established its place in the field of myositis research. Participation of researchers, clinicians and health professionals from the fields of rheumatology, neurology, paediatrics, dermatology, pathology, immunology, pulmonology, physiotherapy and other specialities offers a unique opportunity to meet and discuss the topics from different perspectives. From the outset of these conferences, strong attention has been paid to stimulating the active participation of young doctors and scientists. We hope that the spirit of GCOM 2022 will promote easy communication between the young and the more experienced participants and that it will further stimulate future activities in the field of myositis research. Finally, we hope you find some time to explore the city of Prague and its rich cultural heritage."

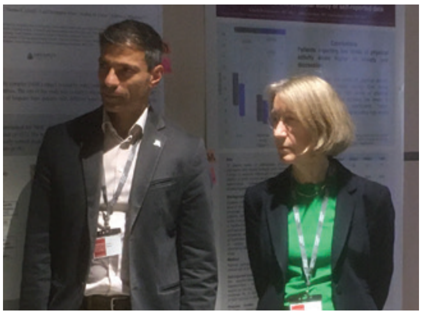
GCOM 2022

Unfortunately it is impossible for me to give a report on every presentation presented over the course of the conference but from the 189 posters displayed the following were chosen for presentation at poster sessions each day. From these titles you can see the amount of research that is now taking place in Myositis!

Poster Session 1 Tuesday

Leaders: Ingrid Lundberg, Kanneboyina Nagaraju

Spatial transcriptomic analysis of dermatomyositis muscle unveils a unique signature in atrophic perifascicular muscle fibers.
A SQSTM1 polymorphism confers risk for Sporadic Inclusion Body Myositis disease expression.
Description of macrophages in idiopathic inflammatory myopathies using in-situ RNAseq.
Efgartigimod restores muscle function in a humanized mouse model of immune-mediated necrotizing myopathy (IMNM).
Evaluation of major histocompatibility complex class II in idiopathic inflammatory myopathies.
Identification of anti-flagellin antibodies in juvenile dermatomyositis using an antibody profiling technology.



Professor Hector Chinoy and Professor Lucy Wedderburn

Some of the young scientist after receiving their poster prizes

Poster Session 2 Tuesday pm

Leaders: Victoria Werth, Albert Selva O'Callagan

COVID-19 severity and vaccine breakthrough infections in idiopathic inflammatory myopathies, other systemic autoimmune and inflammatory diseases, and healthy individuals: results from the COVID-19 Vaccination in Autoimmune Diseases (COVAD) study.
Power Doppler ultrasonography for the monitoring of patients affected by idiopathic inflammatory myopathies.
Immunogenetics features of Dermatomyositis-Associated Malignancies
Diagnosis accuracy of muscle MRI for autoimmune myopathies: Multicentric prospective study (DARWIM).
Achieving clinical remission in anti-HMGCR positive immune-mediated necrotizing myopathy with a corticosteroid-free treatment: report from a single center.
18-FDG PET-CT diagnostic value in immune checkpoint inhibitor induced Myositis.
Improvement in Disease Activity in Refractory Juvenile Dermatomyositis following Abatacept Therapy: Results of the Abatacept in Dermatomyositis (AID) Trial.

Poster Session 3 Wednesday am

Leaders: Lisa Rider, Mazen Dimachkie

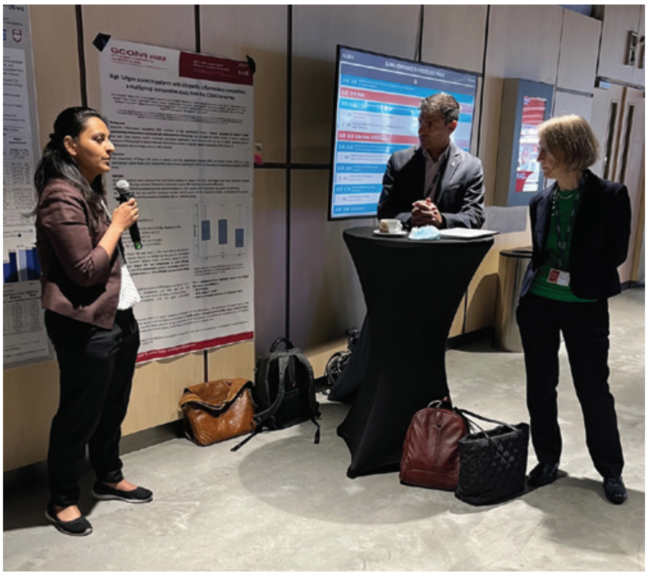
Using Smartphone-Based App Collected Daily Symptom Data to Identify and Investigate Characteristics of Myositis Flares - Towards Real-Time Flare Detection and Personalised Management.
Successful Management with Tofacitinib in Adult and Juvenile Dermatomyositis.
Recombinant human hyaluronidase-facilitated subcutaneous immunoglobulin for idiopathic inflammatory myositis: a multicenter observational study.
Comparing histopathology, transcriptomic and proteomic profiles of sporadic inclusion body myositis (sIBM) and polymyositis with mitochondrial pathology (PM-Mito): are we moving towards sIBM-spectrum disease (IBM-SD)?
IL-1 and IFN combined increase sarcoplasmic p62 puncta size but do not influence TDP-43 aggregation in healthy myotubes.

Phenotypical and Clinical Indications of a Lymphoproliferative Disorder of CD8+ T cell Large Granular Lymphocytes Among Inclusion Body Myositis Patients.
Cell type-specific transcriptomic trajectories underlying disease progression in inclusion body Myositis.

Poster Session 4 Wednesday pm

Leaders: Marianne de Visser, Hector Chinoy

High fatigue scores in patients with idiopathic inflammatory myopathies: a multigroup comparative study from the COVAD e-survey.
Validation of the 2016 ACR/EULAR Myositis Improvement Criteria in Adult Dermatomyositis and Polymyositis Clinical Trials and Consensus Profiles.
Patients with idiopathic inflammatory myopathies who report low levels of physical activity report higher levels of anxiety and depression - a cross-sectional study of self-reported data.
The Pattern of Major Histocompatibility Complex Class I Expression in Muscle Biopsies from Patients with Different Types of Myositis and other Neuromuscular Disorders.
Clinical characteristic defining antisynthetase syndrome: results from the univariate analysis on the class project’s dataset.



IFN-I dependent impairment of muscle stem cell proliferation in dermatomyositis.

My Conference Talk – Les Oakley

At the end of the conference patient groups were invited to give an update on their work. Last time in Berlin, Irene gave the talk with an introduction into how the charity was formed and its progress over the years. So, it was my turn to give the update in Prague!
I took to the stage accompanied by charity mascot, Teddy-Bo, pointing out that we were a double act and if there were any mistakes, blame the bear! I thanked everyone for giving me the opportunity to give an update from Myositis UK and used slides to support my talk.

I reported that at the Global Conference on Myositis in Berlin, Myositis UK was the sponsor of the 'Speed Funding' for young scientists which was very popular and well supported with three very worthy winners who were the recipients of 15,000 euros each to continue their research into Myositis. Unfortunately, like with most things over the past two years Covid interrupted a lot of research. However, they continued with their projects when they were able too.

Kyla Britson (USA), who was one of our "Speed Funding" scientists presented her thesis seminar via zoom last September (2021) which we were invited to attend online. She has since finished her research which was published in the Journal of Science Translation Research. The cover image shows a regenerated IBM xenograft from her model. Kyla is now an ORISE Fellow in the Antivirals and Antitoxins Branch of Biomedical Advanced Research and Development Authority (BARDA).

Unfortunately, due to time restraints and a few communication problems, we were unable to sponsor the speed funding this year, but we are pleased to have been a bronze sponsor of GCOM 2022, including the sponsoring of some of the poster prizes.

We do hope to be able to sponsor the 'speed funding' again at the next GCOM meeting in Pittsburgh, Pennsylvania in the United States in two years time.

Over the last two years the pandemic has affected the myositis community worldwide with meetings either cancelled or changed to zoom meetings and research being put on hold. Myositis UK held zoom meetings with members and doctors. It has also been a very difficult time for many of our members, many of whom were shielding because of the medication they were on. Unfortunately, for some, even the immunisation did not give them the protection it has for many of us. Even so, our members were still able to find ways to raise funds for the charity during lockdown. The London Marathon in 2020 was cancelled but the 2021 marathon went ahead in October and although we were unable to meet our runners at the end, we were able to see them and shout encouragement on the way round. One of our five runners was Professor Hector Chinoy from Manchester who completed the course in 3hrs 32sec. which is a fantastic achievement. He also raised funds for Myositis UK. The runners' sponsorship totalled over

£11,000. This year's marathon is again in October and we have twelve runners taking part.

We are committed to our support of research and particularly after seeing and listening to the talks at this meeting over the past few days. It is really encouraging to see how things have progressed over the forty years since we, as parents, first heard the words, "Juvenile Dermatomyositis" in 1982. Since starting the charity in 1987 we have continued to help members with all forms of myositis. The one thing that matters to them most is finding a cure and with the use of new drugs and therapies there is much hope that their lives can improve.

We would like to thank and show our appreciation to the organising committee for this successful conference. Jiri and everyone involved with him deserve the highest praise and congratulations.

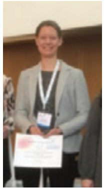
There is one very special person who has been the inspiration for all the work that we do and that is our daughter, Paula, who was diagnosed with JDM at the age of 5 in 1982. She still has some problems today but she is very determined and gets on with life. She is married and has a lovely husband and son.

Thank you for listening and I look forward, along with the bear, to the next GCOM meeting.

Teddy-Bo At GCOM

Research Updates

Kyla Britson – Speed Funding GCOM Berlin 2019



Kyla has sent the following update:

“I’m glad to say that I have a wonderful update for the outcome of the project you helped support with the Speed Funding grant. My work was published in the journal of Science Translational Medicine this past January. We were also very excited that the journal selected our paper to be featured on the cover. The cover image shows a regenerated IBM xenograft from our model. Myositis UK is credited in the acknowledgment section of paper as well.”

The full paper can be found at: Britson KA et al. Loss of TDP-43 function and rimmed vacuoles persist after T cell depletion in a xenograft model of sporadic inclusion body myositis. Sci Transl Med. 2022 Jan 19;14(628):eabi9196. doi: 10.1126/scitranslmed.abi9196. Epub 2022 Jan 19. PMID: 35044790

Or if you would like a copy please send a stamped addressed envelope to the office or email for an email copy.

Dr Janine Lamb, Manchester

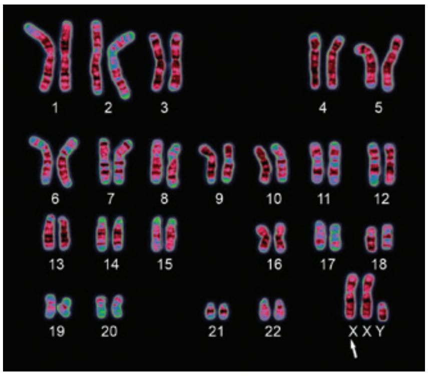
Janine has sent a brief summary referring to the following paper:

47XXY and 47XXX in Scleroderma and Myositis. Scofield RH et al. ACR Open Rheumatol. 2022; 4(6): 528–533.

More women than men are affected with autoimmune rheumatic diseases such as dermatomyositis, systemic sclerosis and systemic lupus erythematosus. This may be due to sex hormones or the sex chromosomes. Women have two X chromosomes compared to men with one X chromosome (46,XX vs 46,XY), so genes on the X chromosome might have more effect in females.

In this study, we investigated the X chromosome in individuals with idiopathic inflammatory myopathies (myositis) and systemic sclerosis. We found an increased number of X chromosome alterations in systemic sclerosis and myositis. In systemic sclerosis, 3/70 men had an extra X chromosome; 47,XXY (see Figure). 8/709 men with polymyositis or dermatomyositis, and 6/147 men with inclusion body myositis, had 47,XXY. 1/114 women with inclusion body myositis had an extra X chromosome; 47,XXX. The frequency of these X chromosome alterations was significantly higher than in healthy individuals with no autoimmune disease in our study. The increased rate of 47,XXY or 47,XXX was also seen in individuals with polymyositis or dermatomyositis from Japan.

47,XXY is known as Klinefelter syndrome and typically occurs in 1 in 500 males at birth. 47,XXX occurs in 1 in 1000 females at birth. The frequencies we observed in myositis and systemic sclerosis are therefore higher than expected from the live birth rates. A higher frequency of Klinefelter syndrome and 47,XXX has also been found in individuals with systemic lupus erythematosus or Sjögren syndrome.



Chromosome karyotype of a male with an extra X chromosome; 47,XXY (Klinefelter syndrome).

These findings may suggest the involvement of interferon genes on the X chromosome in these diseases. Further research is needed to investigate the biological mechanisms involved.
The full paper is freely available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9190224/

The Genetics of Autoimmune Myositis

The idiopathic inflammatory myopathies (IIM) are rare, heterogeneous systemic autoimmune disorders, characterized by inflammation of skeletal muscle and multi-organ involvement. Studies to identify genetic risk factors and dysregulated gene expression in IIM aim to increase our understanding of disease pathogenesis. Genome-wide association studies have confirmed the HLA region as the most strongly associated region in IIM, with different associations between clinically-defined subgroups. Associated genes are involved in both the innate and adaptive immune response, while identification of variants reported in other autoimmune disorders suggests shared biological pathways. Targeted imputation analysis has identified key associated amino acid residues within HLA molecules that may influence antigen recognition. These amino acids increase risk for specific clinical phenotypes and autoantibody subgroups, and suggest that serology-defined subgroups may be more homogeneous. Recent data support the contribution of rare genetic variation to disease susceptibility in IIM, including mitochondrial DNA variation in sporadic inclusion body myositis and somatic mutations and loss of heterozygosity in cancer-associated myositis. Gene expression studies in skeletal muscle, blood and skin from individuals with IIM has confirmed the role of interferon signalling and other dysregulated pathways, and identified cell-type specific signatures. These dysregulated genes differentiate IIM subgroups and identify potential biomarkers. Here, we review recent genetic studies in IIM, and how these inform our understanding of disease pathogenesis and provide mechanistic insights into biological pathways.

Introduction

The idiopathic inflammatory myopathies (IIM) are a rare heterogeneous group of systemic autoimmune disorders. IIM are characterized by chronic inflammation of skeletal muscle resulting in muscle weakness, and multiple other organ systems may be involved. Individuals with IIM can be classified into different disease subgroups based on clinical and/or serological criteria. Our understanding of disease pathogenesis in IIM is limited, and some individuals respond poorly to treatment, with consequently poor health outcomes. Research to identify genetic risk and protective factors, and dysregulated gene expression, has been facilitated by rapid advances in biotechnology and computational approaches. These studies can identify genetic similarities and differences between IIM subgroups, and how these 'myositis spectrum disorders' relate to other connective tissue diseases and autoimmune diseases more generally. This knowledge increases understanding of disease pathogenesis, and yields mechanistic insights into biological pathways and potential drug targets. Knowledge of genetic risk factors that contribute to different myositis phenotypes may enable more precise classification and inform clinical decision-making for targeted disease management and treatment. Here, we review our current knowledge of myositis genetics gained from genome-wide and targeted studies of both common and rare genetic variants, and studies of gene expression. For the purposes of this review, we consider the following IIM clinical subgroups: dermatomyositis (DM), polymyositis (PM), anti-synthetase syndrome (ASS), sporadic inclusion body myositis (sIBM), cancer-associated myositis and immune-mediated necrotising myopathy (IMNM) (1). We highlight key findings and suggest potential avenues as future research priorities.

The full paper is available at: https://www.frontiersin.org/articles/10.3389/fimmu.2022.886290/full

Advisory Board

The charity has now established two advisory boards from the medical profession. We have a medical advisory board (MAB) consisting of four members and a scientific advisory board (SAC) comprising of seven members. These boards will oversee applications for grant funding into myositis. The trustees are very grateful to these board members who all play a very significant and well documented role in all aspects relating to myositis. These new procedures are now in place and are evaluating their first application for small grant funding to further characterise the genetic architecture underlying idiopathic myopathies ultimately to make drug development faster and more precise.

Fundraising

London Marathon 2021

It has been briefly reported in our News Flyer about the fantastic effort made by the runners in Team Muscle. The team members were: Julia Raymond, Stephen Bailey, Eigen Helpin, Hector Chinoy and Mark Emms. They all did excellent times ranging from, 3hours 45 minutes, to 5hours 30minutes.

You may recall from the News Flyer they raised over £11,000. What was a bit special about the team is that Hector Chinoy is a professor working in the field of treating myositis and leading myositis research. I'm sure the others in the team knew of his involvement which must have given them every reason for crossing that finishing line.

Helen's Fibre 4 Fibres

Helen Kurtz writes: "I'm raising money through creative activities for Myositis UK because more research is needed to fight this disease."

Helen Kurtz has become a champion fundraiser during lockdown while coping with illness, raising nearly £30,000 and still rising! When you consider this was achieved against a back ground of helping a little known charity with no celebrity influencers, or media publicity, or the mass influence by support workers of a large organisation. Quite remarkable! She would be the first to admit she set out to raise £1000 and it took off. It has to be recognised and appreciated that much time and effort was put in by Helen.

Helen has raised £29,574 to date.

https://www.justgiving.com/fundraising/Helen-Kurtz

The Richard Kirkman Trust

Secretarial Law Limited, who administer the Trust, has made two donations to the charity amounting to £3.500 since our last magazine. It is with pleasure to be able to acknowledge this wonderful support to the charity. Myositis UK is particularly grateful for their help given over the years particularly these donations during this difficult period.

Ultra Challenge

Chris Meekings writes: “I am doing the ultra challenge 100km (62miles) Jurassic coastal walk on the 14th May 2022 in one hit over one day. I am doing it for Myositis UK as it’s a savage illness with little known about it. My step daughter, Kristal, was diagnosed with Juvenile Dermatomyositis in 2019 when she was eight years old.”

Chris completed his challenge and this is his report: “Well what can I say, that was emotional, mentally and physically draining but an amazing activity. Definitely the hardest thing I’ve ever done and very over whelming. This applies to both the support and the money raised to be honest. Thanks to everyone that have donated and have been supportive during my training. Even more so on the day, especially in my dark moments at 51 miles, when I was a wreck. Coffee and pulled pork and a good phone call saved me!

Big thanks to my wife who made some massive phone calls to me to get me through. And to Sarah who was my wing man providing me with fresh shoes, clothes and support throughout. I now need new feet! I finished in just under 18 hours moving time, which was amazing for my first go at one of these. I kept up a solid 3.46 miles an hour or something throughout. My watch died at 52 miles which was annoying, but it was brutal with many steps, burning over 10,000 calories. 62 miles in the bag, love it.”

https://www.justgiving.com/fundraising/Christopher-Meekings

Hale 10K

Chio Mafunga ran the Hale 10K for Myositis UK in February 2022 because, in his words, “My son Tad is such an inspiration me!”

Hi everyone! Thank you for your amazing support. ♥ I managed to run within 1hr 13mins.

Chio raised £1,100.

https://www.justgiving.com/fundraising/Chio-Mafunga

JustGiving™

Carnegie American Football’s Yorkshire 3 Peaks Challenge

Their story: “On Tuesday the 21st of June, the Carnegie American Football team will be doing the Yorkshire 3 peaks challenge to raise money for Myositis UK. This is a charity our club holds to heart due to one of our coaches suffering from the condition, and we hope to raise money to make a positive impact on research into this field!”

Here is a message from the coach himself, Will Babbington, regarding the charity: “The Myositis charity is an excellent organisation that helps with research and help to people to deal with the lifelong complications of the very rare conditions that fall under the Myositis umbrella. Huge strides have been made with regards to treatments that improve the lives of those diagnosed as a result of funding that the charity has been able to provide.”

The team raised £530
https://www.justgiving.com/fundraising/CarnegieAF3Peaks

Antonio ‘Jacko’ Giacchino

Sam Whyley-Smith writes: “Antonio ‘Jacko’ Giacchino was loved in many different ways by many different people. He was a son, a brother, a husband, an uncle, a colleague and a friend. Most of all, for anyone who was lucky enough to have met Jacko, he was a kind, caring and friendly person who always greeted you with a smile. Jacko will be sorely missed by all. He unfortunately suffered from a rare autoimmune condition called dermatomyositis with associated interstitial lung disease. With Antonio’s condition being rare there is currently limited research to support diagnosis and treatments. This Just Giving page has been set up in loving memory of Antonio ‘Jacko’ Giacchino as a way for those that knew him to offer a donation to commemorate his life and for others to at the very least offer a donation towards a very worthy cause.

All funds raised through this Just Giving page will be securely donated directly to Myositis UK. Myositis UK is a small national charity that provides information to patients like Antonio that have been affected by myositis. Myositis UK also provides vital funding into research to improve diagnosis and treatments.

Please follow the link below to make a donation and please feel free to share this page with others.”

In loving memory of Antonio ‘Jacko’ Giacchino. ‘Fly high brother’. 10th May 1986 - 27th October 2021.

£3,667 was donated in his memory.

https://www.justgiving.com/fundraising/Antonio-Giacchino

The following fundraising event was also in memory of Jacko:
“We have created a musical event in Ragusa, Italy in memory of Antonio Giacchino and €3,000.00 was raised to contribute to the research for myositis and we hope it will help those who are struggling.

Lebowski Music Network and Maniacreativa are pleased to present a charity event in memory of Antonio “Jacko” Giacchino on Sunday 29 May starting at 4:00 pm at the City Park of Ragusa. This is the only possible way to pay homage and honour to this great friend and musician who died prematurely due to a rare disease.

The music festival will involve twelve local bands and artists whose purpose is to raise funds for Myositis UK. There will also be organic and craft markets throughout the day. We look forward to seeing you for such a good cause!”

Other Just Giving pages in memory of a loved one have raised £8,476.

Great Manchester Run Half Marathon

22nd May 2022, Kelly Shaw & Claire Maddocks

Kelly's story: "Three years ago, my mum was diagnosed with a rare muscle and skin disease, dermatomyositis, which causes muscle inflammation and weakness. My mum is the most kind, caring, supportive person and always puts everyone else before herself. Over the past few years, it has been hard to see the huge impact this has had on her life. On the outside, due to her medication, she looks absolutely fine. However, this cruel disease limits her daily activities significantly and she is in constant pain. I would like to raise as much money as I can for the Myositis charity to say thank you for supporting people with this disease and to help fund vital research projects. This May, I will be pushing myself out of my comfort zone, both mentally and physically, by running the Manchester Half Marathon. I am running this half marathon not only to raise money for a wonderful charity but also to celebrate my mum and the incredibly brave and inspiring woman she is."

Kelly and Claire raised £1,660.
https://www.justgiving.com/team/runlittlelegsrun

Walking 125 miles

Natalie Erskine is walking the equivalent of NE Coast NE38-HU18, 125.64 miles, for Myositis UK

Natalie Erskine's story: "We all have a charity or charities close to our heart, something which we support due to being impacted by or someone we know being impacted by and that's why I've decided to fund raise for Myositis UK.

I lost my dad recently to an extremely rare disease called Dermatomyositis which we hadn't heard of and everyone we spoke to hadn't heard of either. This disease impacts roughly 9 in 1,000,000 people! My dad had no idea he had this disease and he never had chance to find out about it. It took his body very quickly and quietly which is all the more reason I feel like I need to share information and spread awareness.

I have decided to walk/jog the equivalent of the north coast from here to Hornsea (125.64mile over the course of the next 6-8 weeks) a place my dad loved and where he spent the last years of his life. He loved nothing more than a walk along the beach.

Bryan and I have also decided to turn lost lb's into £'s for the charity so for every lb we lose we will donate £1 - and we've got a lot of lbs to lose. So whether you are able to donate or just share to raise awareness of this disease and the signs this disease presents it would be greatly appreciated."

Natalie has raised £494 to date.
https://www.justgiving.com/fundraising/Natalie-erskine

Exeter Half Marathon

Rebecca Box: Exeter's Great West Run Half Marathon 2022, on May 22

Rebecca Box's story:
"I am running (I use that word loosely) the Great West Run in Exeter, my first ever half marathon, on 22nd May.
I am raising money in memory of a wonderful, selfless, caring, hilariously funny (the list goes on) Auntie.
Auntie Jane was an amazing sister, mother, wife, nanny (too briefly), auntie and all round human being and is missed very much. She suffered with this largely unknown disease which took her from us too early. Myositis UK are a relatively small charity so will benefit from anything you can give."

Rebecca raised £735
https://www.justgiving.com/fundraising/Rebecca-Box1

Scott’s Running 2022-23

Scott Oakes’s story: “My dad was always active; he had a manual job (stonemason), loved long bike rides, and even completed the London Marathon. Early 2021, he very suddenly became weak and unmotivated and began to worry. It wasn’t long before he was diagnosed with Myositis, and everything went downhill from there. The side effects from his treatment, combined with his already low mood, completely changed him as a person. He lost all hope.

Then, on the 18th of April 2021, he sadly passed away. I then decided I wanted to do something for Myositis UK. I’ll be participating in several running events over the next year to raise a bit of money for them. Anything you can give would be massively appreciated.

There’s still so much to learn about Myositis; the condition is rare, and the effects of the medications used to treat it are still not widely understood. In the weeks and months after losing my dad, we found out about similar cases with other Myositis patients who had also lost their lives due to poor mental health during the treatment process - maybe the money we raise can help to change the narrative.

Rather than create a new page for each event I participate in, I’ll keep this one going for the year and post regular updates about what I’m getting up to.

This is my current diary for the rest of the year:

1. Conqueror Run Virtual - Angkor Wat 32.2km - 14 day time limit - FINISHED (COMPLETED IN 12 DAYS)
2. Sun 11th Sept - Pizza Run Manc 5k
3. Sun 30th Oct - Chester Zoo 10k
4. Sat 12th Nov - Alton Towers 10k

Early next year, I’m hoping to take part in a Rock N Roll Running series event in America. It’s looking like this will be Las Vegas, but I’ll confirm as soon as I know.”
https://www.justgiving.com/fundraising/scott-oakes-running
Scott has already raised £572

Endure24

Janet Downes - Endure24, June 24-25, 2023

Janet’s story: “I am doing Endure24 solo in 2023, to raise money for Juvenile Dermatomyositis. My son was diagnosed with it in 2009 at LGI and was treated by Dr Wood and his staff for seven years. They did an absolutely fantastic job in looking after my son and all their patients. Luckily, by 2015, he could stop all the medication and was in remission once again and still is. He is now 22 years old and doing really well and just finished his masters at university.”

https://www.justgiving.com/fundraising/Janet-Downes3

Christmas Cards

We have a selection of Christmas cards available for sale this year. Please see the enclosed order form.

Other Ways To Raise Donations

amazonsmile
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 over £2,000 this year to date 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 to benefit from their donations.

London Marathon 2022

The following are members of Team Muscle who are taking part in this year's London Marathon on 2nd October.

Gareth Roberts

"I'm really proud to be part of Team Muscle! Myositis can be a debilitating condition and as someone who gets so much joy out of being active, I can only imagine how tough it must be for those living with it. It's only with the help of Myositis UK that those suffering from the disease can get the support they need, and also fund much needed research. I'm passionate about supporting smaller charities that are underfunded and underrepresented, and where you know every penny of your support is going towards a great cause."

https://tcslondonmarathon.enthuse.com/pf/gareth-roberts

Tara Bracher

"I am running because my daughter was diagnosed with JDM in 2020. The information I was able to get from Myositis UK was key to helping myself and my husband understand the disease as well as find support. I hope the money I raise can help other families and get us a step closer to finding a cure."

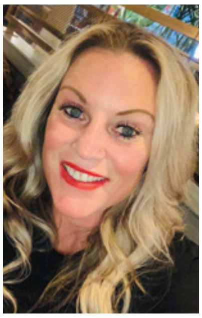
https://tcslondonmarathon.enthuse.com/pf/tara-bracher-e0e1a/post/1607850

Alistair Gould

"To mark my 50th birthday this year, I have decided to do a series of running events. One of these events is the London Marathon and I have chosen to support Myositis UK as it is a charity very close to my heart. In October 2020 my nephew, Harry, was diagnosed with Juvenile Dermatomyositis. Myositis UK has provided vital support to Harry and continue to research Myositis which in turn benefits JDM sufferers like Harry."

http://www.justgiving.com/fundraising/Alistair-Gould3

Michelle Dean



"Being a group exercise and fitness instructor, I am very passionate about helping people keep fit and promoting exercise. Exercise is a very important part of treatment for all types of myositis. It can help reduce swelling, give you more energy, and build up or restore your muscle strength. I'm so excited to be part of Team Muscle and being given the opportunity to run London marathon."

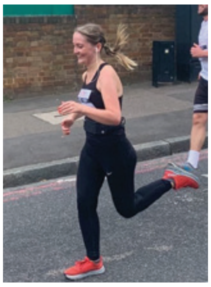
https://tcslondonmarathon.enthuse.com/pf/michelle-dean

James Collins

“My name is James Collins and running the London marathon has always been something I’ve aspired to do, but running it for such a personal reason is driving me harder. My mum was diagnosed with myositis about ten years ago and has had such a huge affect on her and our family as a dynamic. To watch her struggle day to day breaks my heart, but also drives me on to live my life as best I can.”

https://www.justgiving.com/Jimicol

Rachael McMurray



“I’m 28; I’m a fashion designer and live in London. I’m running for Myositis UK as my partner’s dad has been battling Polymyositis since 2018. I want to raise as much money as I can to support the charity and everyone it helps!”

https://tcslondonmarathon.enthuse.com/pf/rachael-mcmurray

Zawar Khan

“Rather than a personal story, this stems from my personal ambition to complete the London Marathon. This has led me to discover the ambition of Myositis UK as a charity, as well as those suffering from Myositis.

Prior to coming across this charity, I like many of you had admittedly NEVER heard of this rare disease that affects approximately 1 in 10,000 people.

A cure NEEDS to be found for Myositis. Therefore, I would like to use this platform to request you to donate ANY amount, share this page, and help in the fight against Myositis as I do my part by completing the London Marathon.”

https://www.justgiving.com/fundraising/zawar-khan5

Kevin Lloyd

“I’m running for Myositis UK as my daughter Mari was diagnosed with JDM in 2015. I was originally entered in 2020 having attended one of the GOSH JDM family days and hearing about the fantastic work Myositis UK does in raising funds for research and support and was two thirds of the way through a training plan and fundraising when that was cancelled due to covid. Mari is now doing well thanks to the ongoing shared treatment and care she receives from GOSH and our local NHS trust. This will be the first marathon I’ve ever run and I’m looking forward to the day although also slightly apprehensive!”

https://tcslondonmarathon.enthuse.com/pf/kevin-lloyd-6bca5

Other members of Team Muscle are:
India Allen - *http://www.justgiving.com/India-Allen95*
Sam Harper - *https://tcslondonmarathon.enthuse.com/pf/sam-harper-239a8*
Hayley Brown - *https://tcslondonmarathon.enthuse.com/pf/hayley-brown*

Published Research

A medical literature search on PubMed since the beginning of the year 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 would like to read a paper copy of a publication listed, please get in contact with the office enclosing a stamp addressed envelope and we will print and send it to you.

Glucocorticoids in Myositis: Initiation, Tapering, and Discontinuation

Didem Saygin, Chester V Oddis

Published in Curr Rheumatol Rep March 2022. PMID: 35275363. Abstract only

Current and new targets for treating myositis

Siamak Moghadam-Kia, Chester V Oddis

Published in Curr Opin Pharmacol. August 2022. PMID: 35724455. Abstract only

Update on Myositis Therapy: From Today's Standards to Tomorrow's Possibilities

Stefanie Glaubitz, Rachel Zeng, Goran Rakocevic, Jens Schmid

Published in Curr Pharm Des. 2022. PMID: 34781868 Abstract only

Myositis-associated interstitial lung disease: a comprehensive approach to diagnosis and management

Robert W Hallowell, Julie J Paik

Published in Biomolecules. January 2022. PMCID: PMC8855729. Free PMC article

Update on Malignancy in Myositis-Well-Established Association with Unmet Needs

Aleksandra H Opinc, Joanna S Makowska

Published in Biomolecules. January 2022. PMID: 35053259 PMCID: PMC8773676. Free PMC article

Inclusion Body Myositis and Neoplasia: A Narrative Review

Laura Damian, Cristian Cezar Login, Carolina Solomon, Cristina Belizna, Svetlana Encica, Laura Urian, Ciprian Jurcut, Bogdan Stancu, Romana Vulturar

Published in Int J Mol Sci. July 2022. PMID: 35806366 PMCID: PMC9266341. Free PMC article

Association of various myositis-specific autoantibodies with dermatomyositis and polymyositis triggered by pregnancy

Chikaho Akiyama, Tsuyoshi Shirai, Hiroko Sato, Hiroshi Fujii, Tomonori Ishii, Hideo Harigae

Published in Rheumatol Int. July 2022. PMID: 33837447. Abstract only

Measuring change in inclusion body myositis: clinical assessments versus imaging

Lindsay N Alfano, Kendrea L Focht Garand, Georgia A Malandraki, Sharfaraz Salam, Pedro M Machado, Mazen M Dimachkie

Published in Clin Exp Rheumatol. February 2022. PMID: 35225227. Free article.

Update on Biomarkers of Vasculopathy in Juvenile and Adult Myositis

Kirsty McLellan, Charalampia Papadopoulou

Published in Curr Rheumatol Rep. June 2022. PMID: 35680774. Abstract only

Inclusion body myositis and associated diseases: an argument for shared immune pathologies

Christopher Nelke, Felix Kleefeld, Corinna Preusse, Tobias Ruck, Werner Stenzel

Published in Acta Neuropathol Commun June 2022. 35659120 PMCID: PMC9164382. Free PMC article

The role of protein aggregation in the pathogenesis of inclusion body myositis

Andrew M Snedden, Katherine A B Kellett, James B Lilleker, Nigel M Hooper, Hector Chinoy

Published in Clin Exp Rheumato February 2022. PMID: 35225225. Free article

Diagnostic and prognostic value of anti-cN1A antibodies in inclusion body myositis

Sharfaraz Salam, Mazen M Dimachkie, Michael G Hanna, Pedro M Machado

Published in Clin Exp Rheumatol February 2022 PMID: 35225226. Free article

Diagnostic delay of myositis: protocol for an integrated systematic review

Tergel Namsrai, Jane Desborough, Anita Chalmers, Christine Lowe, Matthew Coo, Christine Phillips 5, Anne Parkinson

Published in BMJ Open June 2022. PMID: 35697457 PMCID: PMC9196154. Free PMC article

Myositis-specific autoantibodies and their associated phenotypes in juvenile dermatomyositis: data from a German cohort

Svea Horn, Kirsten Minden, Fabian Speth, Tobias Schwarz, Frank Dressler, Nadine Grösch, Johannes-Peter Haas, Claas Hinze, Gerd Horneff, Anton Hospach, Tilmann Kallinich, Jens Klotsche, Katharina Köstner, Christian Meisel, Martina Niewerth, Prasad Thomas Oommen, Catharina Schütz, Frank Weller-Heinemann, Nadine Unterwalder, Claudia Sengler.

Published in Clin Exp Rheumatol February 2022. PMID: 33124555. Free article

Myositis-associated Interstitial Lung Disease: Clinical Characteristics and Factors Related to Pulmonary Function Improvement: A Latin-American Multicenter Cohort Study

María Laura Alberti, Verónica Wolff, Felipe Reyes, Ernesto Juárez-León, Leandro Fassola, Gabriel Carballo, Ivette Buendía-Roldán, Jorge Rojas-Serrano, Fabián Caro, Matías Florenzano, Francisco Paulín

Published in Reumatol Clin (Engl Ed) May 2022. PMID: 35568443. Free article

The origins, evolution and future of the International Myositis Assessment and Clinical Studies Group (IMACS)

David A Isenberg, Hector Chinoy, Mazen M Dimachkie, Frederick W Miller, Lisa G Rider

Published in Clin Exp Rheumatol February 2022. PMID: 35225220. Free article

Anti-Cortactin Autoantibodies Are Associated With Key Clinical Features in Adult Myositis But Are Rarely Present in Juvenile Myositis

Iago Pinal-Fernandez, Katherine Pak, Albert Gil-Vila, Andres Baucells, Benjamin Plotz, Maria Casal-Dominguez, Assia Derfoul, Maria Angeles Martinez-Carretero, Albert Selva-O'Callaghan, Sara Sabbagh, Livia Casciola-Rosen, Jemima Albayda, Julie Paik, Eleni Tiniakou, Sonye K Danoff, Thomas E Lloyd, Frederick W Miller, Lisa G Rider, Lisa Christopher-Stine, Andrew L Mammen, Childhood Myositis Heterogeneity Collaborative Study Group

Published in Arthritis Rheumatol February 2022. PMID: 34313394 PMCID: PMC8792092. Abstract only

Association with HLA-DR 1 position 37 distinguishes juvenile dermatomyositis from adult-onset myositis

Claire T Deakin, John Bowes, Lisa G Rider, Frederick W Miller, Lauren M Pachman, Helga Sanner, Kelly Rouster-Steven, Gulnara Mamyrova, Rodolfo Curiel, Brian M Feldman, Adam M Huber, Ann M Reed, Heinrike Schmeling, Charlotte G Cook, Lucy R Marshall, Meredyth G Ll Wilkinson, Stephen Eyre, Soumya Raychaudhuri, Lucy R Wedderburn, Juvenile Dermatomyositis Cohort and Biomarker Study, the Childhood Myositis Heterogeneity Study Group, and the Myositis Genetics Consortium (MYOGEN)

Published in Hum Mol Genet July 2022. PMID: 35094092 PMCID: PMC9307311. Free PMC article

Complement in autoimmune inflammatory myopathies, the role of myositis-associated antibodies, COVID-19 associations, and muscle amyloid deposits

Marinos C Dalakas

Published in Expert Rev Clin Immunol April 2022. PMID: 35323101. Abstract.

A cross-sectional study of memory and executive functions in patients with sporadic inclusion body myositis

Kirsty Lu, Keir X X Yong, Iwona Skorupinska, Stephanie Deriziotis, Jessica D Collins, Susie M D Henley, Michael G Hanna, Martin N Rossor, Basil H Ridha, Pedro M Machado

Published in Muscle Nerve January 2022. PMID: 34605039. Abstract only

Juvenile dermatomyositis. Where are we now?

Liza J McCann, Polly Livermore, Meredyth G Ll Wilkinson, Lucy R Wedderburn

Published in Clin Exp Rheumatol February 2022. PMID: 35225221. Free article

Idiopathic inflammatory myopathies: CT characteristics of interstitial lung disease and their association(s) with myositis-specific autoantibodies

Amandine Laporte, Kubéraka Mariampillai, Yves Allenbach, Nicoletta Pasi, Victoria Donciu, Dan Toledano, Benjamin Granger, Olivier Benveniste, Philippe A Grenier, Samia Boussouar

Published in Eur Radiol May 2022. PMID: 35022809. Abstract only

Prescription Charges Coalition

Laura Cockram writes: “A brief update from the last coalition meeting: I just wanted to update you on a few things following our last meeting.

- We have checked in with all organisations about whether they still want to be involved with the coalition and are awaiting confirmation from a small number, we hope to have this completed, along with understanding the prevalence of conditions the coalition represents during the summer.
- Lord Kamall confirmed he would not meet with us to discuss prescription charges.
- We still haven’t had a response from Jeremy Hunt and I’ll continue to chase the health and social care committee clerks.
- The Public Accounts Committee came back saying they don’t intend to revisit their penalty charge notices in healthcare, but they did share the most recent update they have had from the Government about their inquiry.
- We have written to some influential individuals and organisations asking that they mention prescription charges when they talk about the cost of living.
- We have managed to secure some recent media coverage on prescription charges in The Express with a case study of Zoe who cuts her tablets in half and also National Pharmacy Association research and a case study of Denby with glaucoma.
- We are working with 38 degrees to get a very brief survey out to their supporters on prescription charges and the cost of living - we’ll also share it with the coalition so you can share it with your supporters too. We’re hoping we can use the results in the media before we put together our more comprehensive survey next year.”

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.

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. 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.

Postscript

For more than the past two years during difficult times many members have been in touch to offer encouragement and help. Fundraising through the membership has been amazing with several saying it has helped with their mental health to focus on our cause and help relieve their isolation. It would be much appreciated if I can have your news and views and other relevant information or items for the next magazine. I would like to see, particularly, children taking Teddy-Bo on their travels or even showing the bear in a home setting. We have made the meeting for those attending the National Conference as safe and secure as we can. We trust that you will endeavour to join in and even though many of us are living and coping with these miserable conditions, we can as a group move forward knowing the effort has been well worthwhile.

MYOSITIS UK

146 Newtown Road, Woolston, Southampton, SO19 9HR
t 023 8044 9708 e office@myositis.org.uk www.myositis.org.uk

The opinions expressed in this Myositis News are not necessarily those of Myositis UK. We do not endorse any product or treatment mentioned in Myositis News. Our aim is to keep you informed on latest issues. You should always consult your doctor before changing any medication. Whilst every effort is made to ensure the information contained in Myositis News is accurate, Myositis UK accepts no responsibility or liability where errors or omissions are made.