MYOSITIS UK

Summer 2024

Myositis News

GLOBAL CONFERENCE 2024 • FUNDRAISING
RESEARCH • CLINICAL TRIALS

Dear Member,

Another year is rapidly moving on and I have much to report on developments in myositis. Much is happening in this country and around the world to benefit the issues of myositis and through these columns it is rewarding to give a brief overview of some of these developments. It is also an opportunity to express a collective ‘thank you’ from the membership to those people who have assisted the cause by raising and donating funds and for them to be recognised for the contribution they have made. The charity is actively involved with our myositis friends globally and has enabled us to keep up with these developments and as a charity to be contributing to the research.

Les Oakley MBE
Chairman

AGM & Conference 2024

The charity conference being held on Sunday 14th July is almost upon us and the programme is being put together to make it very worthwhile to attend. We will operate a similar format of the proceedings as last year that proved to be highly successful and appreciated by the members attending. There is always an atmosphere of goodwill, friendship and humour even though this conference is brought about by having to live and cope with a miserable disease. There is also much to learn from the progress over the past year and is well worth the time and effort to attend.

As in previous years, there is the ‘meet and greet’ on the Saturday for those staying the night before. Personally, I really enjoy this meeting because it is a chance to meet new members and chat informally about their issues and concerns as well as catching up on members who have been in the charity for some time. The ‘meet and greet’ is from 2pm-4pm on Saturday 13th July. The conference on Sunday 14th July starts with the AGM at 10am.

Myositis UK Research Grants

Dr Janine Lamb, University of Manchester - Biomarker identification for treatment response to the oral JAK 1/2 inhibitor, baricitinib, in adult idiopathic inflammatory myopathy £20,000

Dr Meredyth Wilkinson, UCL Great Ormond Street Institute of Child Health, London – “A mitochondrial gene signature to stratify juvenile dermatomyositis patients for targeted treatments” £19,973.70

Professor Pedro Machado - Department of Neuromuscular Diseases, UCL Queen Square Institute of Neurology, London - “MIRAGE: Myositis Inflammation Revealed through Advanced Magnetic Resonance ImaGing Evaluation - A Prospective Study” £19,908.65

GCOM – three “Speed Funding” grants of $15,000 each.

Global Conference 2024

Irene and I loaded up the car and drove to Heathrow airport. Unfortunately, it was raining and we had a lot of cases to move once there. However, as we were flying to the States from terminal five, she had booked the pod transport system to give us time to load and unload at the terminal. First experience for us but the choice of transport was to prove to be worthwhile and enabled us to move the cases without too much difficulty. They were full of all are charity display materials etc., as well as our personal luggage.

Pittsburgh, USA

We arrived in Pittsburgh at two thirty in the morning and it was a bit of an issue working our cases through the airport complex out to the taxi rank. The taxi driver scratched his head in trying to work out how to pack the cases, but he eventually achieved the almost impossible and off we went to the hotel/conference centre arriving at 3am UK time. Using the hotel trolley, we were able to get all the cases to our room because fatigue was becoming an issue and some sleep was certainly needed.

We set up our Myositis UK stand on the Tuesday morning ready for when the delegates arrived. There were over four hundred coming from around the world. The myositis research community is expanding and the poster hall was displaying dozens upon dozens of research papers. These are exciting times for medical research, and I am always amazed to witness the work taking place and the collective concern of these talented myositis researchers. There were also present pharmaceutical companies who see a viable future in the treatment of myositis and are developing trials. Those that are based in the States are keen to extend their projects and products overseas which is exciting news. However, they need myositis patients to step up and participate globally to achieve the numbers required to prove the efficacy of their products that will be used following strict research protocols.

Barriers to international studies are being removed and it is a worldwide collective that will unlock the door to these diseases. There is a noticeable buzz of confidence about this conference, building on the work of the previous four. With all this young enthusiastic presence it was a delight to see attending doctors and scientists who have made an impact

in the understanding of myositis for many years. It was a pleasure to meet up with Dr Fred Miller again and other eminent people from around the world still working and participating in the researching of myositis. Fred also paid tribute to the late Dr Paul Plotz who made a considerable contribution in understanding neuromuscular disease but also keen to let it be known that he was a very likeable person with many interests outside of his chosen profession.

Being a global conference there were speakers from China, Japan, Australia, Canada, Europe, Mexico as well as the States. People were also attending remotely too. Dana Ascherman on behalf of the steering committee welcomed everyone to the conference ending with the words, “We hope the spirit of GCOM 2024 will continue to promote easy communication between younger and more experienced participants, with the ultimate goal of stimulating future progress in understanding the pathogenesis, diagnosis and management of myositis.”

The programme was extremely varied covering all aspects of myositis. To demonstrate how the medical community on myositis has grown is demonstrated by a scientific committee of forty seven members. The leading sessions of the conference were headed under the titles of, “Pathogenesis of inflammatory myopathies : transcriptomic analyses - Genetic/ environmental - navigating through challenging cases in dermatomyositis - Inclusion body myositis - IIM classifications: different prospectives - advances in therapeutic development - Immune reset: achieving remission with CD19-CAR T cell therapy - Juvenile dermatomyositis: promising avenues for new therapies - clinical trials

- pathology workshop, disease models workshop - extramuscular manifestations - exercise and rehabilitation - speed funding - potpourri - governance - imaging and biomarkers and malignancy.

As well as the extensive myositis programme it was an immense pleasure to meet up again with other charities and pharma companies with an interest in myositis. The programme is arranged by iMyoS (International myositis society). This global conference is now the hub for the scientific community to share their work and their progress. For me It was very assuring to witness, and for the charity to participate by “speed funding” young scientists in this rapidly developing progress in the treatment and management of myositis.

Myositis UK is the longest established charity in the world representing people with myositis and during this time we have been fortunate to have witnessed the development of the worldwide myositis community. However, there were other larger charities such as The Myositis Association (TMA), Cure Juvenile Dermatomyositis (Cure JDM), who have invested millions of dollars to help the cause of myositis. Other patient advocacy organisations present were the Myositis Association of Australia, the Czech Myositis Working Group, the Dutch Myositis Group, the German Myositis Group, the Swedish Myositis Working Group, Myositis Support and Understanding (USA) and Myositis Canada. Everybody who attends these global meetings all comment on what a pleasure it is to be able to attend. They are very friendly and sociable occasions even though everybody is aware that the agenda and the reason behind it is

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to help people suffering from serious disease.

To get to the present day has taken over thirty years and during this time many of the scientists and doctors are still involved and some were present on this occasion, still presenting and working in the field of myositis. To mention a few names of the original group we owe much to the late Paul Plotz, David Isenberg, Bob Cooper, Lisa Rider, Fred Miller, Ingrid Lundberg and Jiri Vencovsky. Close on their tails are Chester Oddis, David Scott and Lucy Wedderburn and the myositis baton has been passed on to the growing list of equally dedicated members of the worldwide medical and research community.

Myositis UK were a Platinum sponsor and partner here. Thirty-five young investigators from around the world applied for our speed funding grants and were vetted by and scored by twelve reviewers from several countries. Seven were invited to Pittsburgh to present their work on stage in front of their medical peers. I expect it was a daunting experience, but one that will look good for all the right reasons on their academic history. The judging was particularly difficult because the standard was extremely high. Irene and I witnessed the adjudication by the panel and did not envy their position. However, three were selected and the winners announced to a packed auditorium.

They were:

Jorge Álvarez Troncoso - Capillaroscopy and Artificial Intelligence in Inflammatory Myopathies.

Emily McLeish - Deciphering Inclusion Body Myositis Heterogeneity: Integrating Immunophenotyping and Machine Learning for Co-morbidity Prediction.

Angeles Galindo-Freia -Identification and characterisation of Jo-1 autoreactive B and T cells in patients with interstitial lung disease.

Sara Sabbagh - Investigating MSP-RON signalling mechanisms of dysregulated macrophage polarisation in juvenile idiopathic inflammatory myopathy.

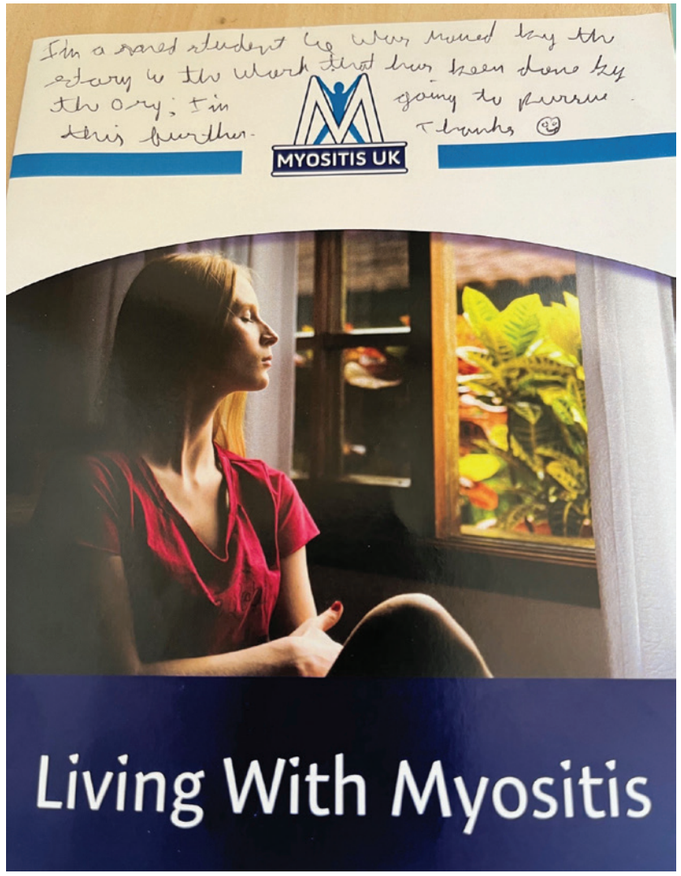
Christopher Nelke - Mitochondrial membrane permeabilisation as pathophysiological feature in inclusion body myositis.

Andrew Wilson - Rescue of TDP-43 function in in vitro and in vivo models of Inclusion Body Myositis (IBM).

Shannon O'Connor - Revealing the genomic factors of severity in juvenile dermatomyositis.

They were all acclaimed finalists and all their work is of value and worthy of being investigated and developed further. However, Sarah, Andrew and Christopher were the three winning projects.

Myositis UK coordinator Irene Oakley and Dr Dana Asherman were pleased to present the seven finalists with a small, engraved trophy of the occasion as a memento of their excellent presentations.



At our stand we had many visitors, particularly young investigators, talking to us about myositis and our involvement. These chats would also take place in the evening in a social setting and I consider my role is to encourage these people, if it is possible, to follow a career in muscle disease. I get all sorts of serious comments and a lot of banter too! However, one morning turning up to our stall I noticed that someone had penned a comment on one of our leaflets which I found quite moving. I do not know who this person is but it made my day. Written at the top of the leaflet were these words, "I'm a med student who was moved by the story of the work that has been done by the organisation. I'm going to pursue this further. Thanks."

The Myositis Association (USA)

The TMA have kindly sent me a report of their time at the conference.

TMA recently returned from a high-profile week in Pittsburgh, Pennsylvania at the Global Conference on Myositis (GCOM)! Along with the almost four hundred attendees for the scientific program, TMA helped lead a group of twelve worldwide patient advocacy organizations (PAOs) facilitating international collaborative efforts that included networking, sharing best practices, and brainstorming solutions to common issues. Here are some of the significant takeaways from this important biannual gathering.

Patient-Centred Programming

With a special Patient/Patient Advocate registration category, TMA's efforts supported a parallel program for PAOs that featured nine PAO posters and representation from ten countries, both in person and virtually. Our parallel program was a highlight of the week for all of us, as we brainstormed about national research agendas, with inspiration from the Netherlands; consumer panels in research, with inspiration from the Myositis Association of Australia; and World Myositis Day, with inspiration from the German Myositis Group.

Highlights from the patient contributions to the scientific program included a Meet the Patient Experts panel, featuring six patient experts sharing about their disease, and a session on Patient-Centred Research Collaborations with case studies from Cure JM Foundation, InspireNMD from the Netherlands, Myositis UK, and Myositis Support and Understanding.

Research and Posters

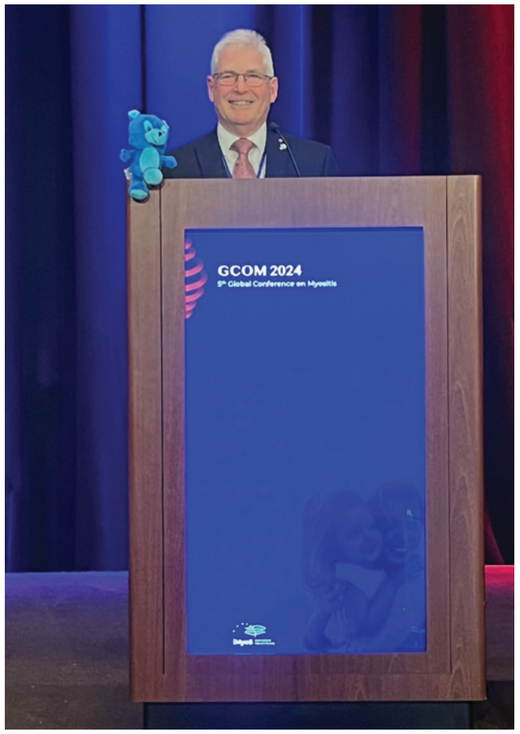
TMA was well represented by presentations from current and former members of our Medical Advisory Board. Dr Merrilee Needham and Dr Adam Schiffenbauer, for example, moderated a set of sessions about environmental and genetic risk factors associated with myositis. Dr Robert Hallowell talked about "When ILD goes bad," and Dr Elie Naddaf presented on diseases that mimic IBM.

Many investigators who collaborated with TMA or received research grant funding from TMA also presented posters, including Dr Lisa Christopher-Stine, Dr Celinda Johnson, Dr Chiseko Iwanaga, and Dr Begum Horologium.

One poster, "Improved physical function using a power enhancing glove in persons with IBM," presented by TMA medical advisor Malin Regardt, PhD, described a study conducted during TMA's 2023 International Annual Patient Conference (IAPC). Read about the outcomes of this successful study that showed people with IBM were able to perform activities, such as lifting objects, grocery shopping, and stabilizing the hand, more independently when using Carbon hand as an assistive device.

TMA presented a poster summarizing our impact: "Advancing research, supporting patients, and raising awareness of myositis: Representing the entire myositis community worldwide since 1993." And we participated in a joint poster about "Patient Impact on Myositis Research" with twelve other patient advocacy organizations from around the world.

Unfortunately, there was no mentioning of the 'Speed Funding' in this report.



Teddy-Bo

We took Teddy-Bo with us to Pittsburgh and to those who had never met the endearing little bear before he proved to be as big a hit as the day he was introduced to the charity. One of the patient groups in the States want him to become part of their community and we are more than delighted to let him work his magic and be a comforter to children. We are in the process of developing new ways that the accompanying Teddy-Bo book can be electronically distributed to make it more accessible. We know from schoolteachers that he is extremely useful to explain to all children in a classroom what children living with Juvenile Dermatomyositis and how the illness affects them every day of their life. They also value the idea of filming the bear in interesting and amusing places as well as getting those important publicity shots with celebrities from all walks of life.

For children in the United Kingdom and Northern Ireland who are diagnosed with JDM the bear and book are given free to help them understand their condition, particularly when they are in hospital. Email or write to the Myositis UK office and we will dispatch a bear and book to you.

Clinical Trials

NIAMS Remembers Scientist Emeritus Paul Plotz, M.D.

January 18, 2024

NIAMS is saddened to share the news that Paul Plotz, M.D., who dedicated nearly four decades of service to science at the NIH, passed away on January 13, 2024, at the age of 86 after a long illness.
Credit: Rhoda Baer

Dr. Plotz was a world-renowned rheumatologist, immunologist, and researcher known internationally as an expert in myositis, an inflammatory muscle disease and rare autoimmune condition.

He retired from NIH in 2011 after serving in a variety of leadership roles, including as chief of the NIAMS Arthritis and Rheumatism Branch, as well as acting scientific director and acting deputy director. He also was senior advisor to the NIH deputy director for intramural research, Dr. Michael Gottesman.

As a scientist emeritus at NIAMS, Dr. Plotz was awarded the 2013 Presidential Gold Medal from the American College of Rheumatology, which recognizes outstanding achievements in rheumatology over an entire career and is the highest award the ACR can bestow.

A fourth-generation physician, Dr. Plotz conducted groundbreaking immunology and muscle disease research and was instrumental in advancing understanding of autoantibodies, autoimmune disease, and inflammatory muscle diseases.

Among his many accomplishments, Dr. Plotz helped redefine how physicians think about and manage myositis, which helped lead to the first clinical trials in the field for myositis patients.

Early in his career, Dr. Plotz worked to advance understanding of systemic lupus erythematosus, a systemic autoimmune condition, as well as autoantibodies and other components of the immune system as part of our understanding of disease mechanisms in these autoimmune diseases.

He later investigated clinical, immunologic, and genetic aspects of several muscle diseases.

Dr. Plotz earned his undergraduate and medical degrees from Harvard University and completed a residency at Beth Israel Deaconess Medical Center in Boston. He joined NIH in 1965 as a clinical associate in the Arthritis and Rheumatism Branch at the National Institute of Arthritis and Metabolic Diseases, now known as NIAMS.

He will be remembered as a loving husband, father, mentor, and friend, as well as an accomplished scientist with a lifelong commitment to and passion for human rights and volunteerism. NIAMS extends sincere condolences to Dr. Plotz's wife of 60 years, Judith, his sons John and David, and his extended family, and to all who had the privilege to know him and were fortunate to have worked with him.

Learn more about Dr Plotz's accomplishments and work, and read a tribute to his service in the NIH Record.

The Zoom meeting we mentioned in the last magazine took place in late March. The charity along with Taryn Smith of the pharmaceutical company, Priovant, met up with members living with myositis. It was a pleasure to have these face-to-face talks and discuss the proposed trial using the drug brepcitinib. The drug, which is taken orally, is not a cure, but it may help improve symptoms of DM in adults. Many helpful and constructive questions were discussed of how people would qualify for the trial, the duration and side effects if any of the drug. There will be three medical centres participating in the trial based in Bath, Birmingham and Manchester. If you are eligible for the trial the age band being for enrolment is from 18 to 74. Your expenses will be covered including travel, meals and if necessary, an overnight stay. All study treatment and care costs will be included as well as the expenses of a travel partner.

The benefits will be to receive study related treatments and care at no cost to you. You will be monitored by study doctors who specialise in dermatomyositis, and you will be joining others in helping to advance research into dermatomyositis.

Talk to your doctor about how you would like to help in this trial so that there is a liaison with your doctor and the specialist centre. To learn more, visit www.ValorStudy.com

Abcuro Completes Enrollment of Registrational Phase 2/3 MUSCLE Clinical Trial of Ulviprubart for the Treatment of Inclusion Body Myositis

"We continue to focus on advancing our product candidate ulviprubart to treat patients with IBM who currently have no treatment options and are therefore delighted to achieve another important milestone for this clinical program," said H. Jeffery Wilkins, M.D., Chief Medical Officer of Abcuro. "Ulviprubart is a first-in-class therapy targeting KLRG1 and has great potential to transform the treatment paradigm for IBM where there is currently a significant unmet need. We look forward to sharing initial data from the Phase 2/3 MUSCLE trial in the first half of 2026."

"IBM is a tremendously debilitating disease which drastically and irreversibly reduces quality of life. Families are deeply affected as they witness their loved one's decline, while troubleshooting each facet of daily life to accommodate the condition. Living with IBM can make basic daily activities difficult and can negatively impact larger goals like maintaining hobbies and travel," said Paula J. Eichenbrenner, MBA, CAE, Executive Director of The Myositis Association. "IBM patients have no recourse in the current therapeutic landscape. Exercise and physical therapy can preserve muscle and stave off disease progression, but only to a degree. The lack of disease-modifying treatment options places more burden on IBM families as they must help their loved ones to manage anxiety about the inevitable muscle loss they will endure and feelings of being trapped with this rare, catastrophic disease."

The Phase 2/3 MUSCLE clinical trial (NCT05721573) is a global, randomized, double-blind, placebo-controlled, parallel multicenter registrational trial evaluating ulviprubart in patients with IBM. The objectives of the trial are to evaluate efficacy, safety, and tolerability of two dose levels of ulviprubart (0.5 mg/kg and 2.0 mg/kg) compared with placebo at 76 weeks in subjects with IBM followed by a 4-week safety follow-up period.

The charity is also in discussion with other pharmaceutical companies in research opportunities with newly developed drugs. So, even if you do not qualify for one study there are others where you may be able to participate in the months ahead.

Fundraising & JustGiving

Legacies

The funding for the trophies for the "Speed Funding" was made possible by a most generous bequeathment by the late Albert Geoffrey Howson. I had known Geoffrey for many years and he often asked if we had sufficient funds to cover costs of the charity outside of the funds allocated for specific medical research projects. This has always been an issue for the charity and I am particularly grateful that Geoffrey kept this in mind when he gifted the charity £8000.00 of unrestricted money to help cover charity costs.

The late Mrs Ivy Carr who sadly died last year kindly bequeathed £140,726.26 to the charity in her will. She wrote to me in 2011 sending a donation for £50.00 adding that she was going to remember the charity in her will. I replied to her thanking her for her donation mentioning how kind her intended action was going to be for the charity, but I trusted it would be many happy and healthy years before her will could be activated. Just before last Christmas Irene and I were invited to an acclaimed annual carol concert at the chapel in King's College University, London. It was a remarkable candle lit evening and the choir and music was such a joy to listen to. We arrived home about one thirty in the morning and on opening the days post was a letter from Ivy's solicitors informing us that this money had been paid directly into the charity bank account. We stood and looked at each other completely stunned by this gift delivered at Christmas time. However, it has enabled the charity to further its plans with medical research in accordance with Ivy's wishes.

The family of the late Mrs Mildred Naylor honoured her wishes by donation part of her estate to charity.

Her daughter writes, "My father predeceased my mother and in a letter of wishes with their Wills they expressed a wish that we make a donation to charity on their behalf. Donations were sent following my father's death and from the post funeral collection for my mother to Myositis UK. My mother suffered from breast cancer and myositis hence these two charities. Towards the end of his life my father suffered from dementia, as does my mother's surviving sister, hence this chosen charity. Each charity received £23,574.00." Mildred had been a supportive member for many years.

The late Mrs Rosemary Boney graciously left the charity £1,099.99 in her will with the gift to be spent for research purposes.

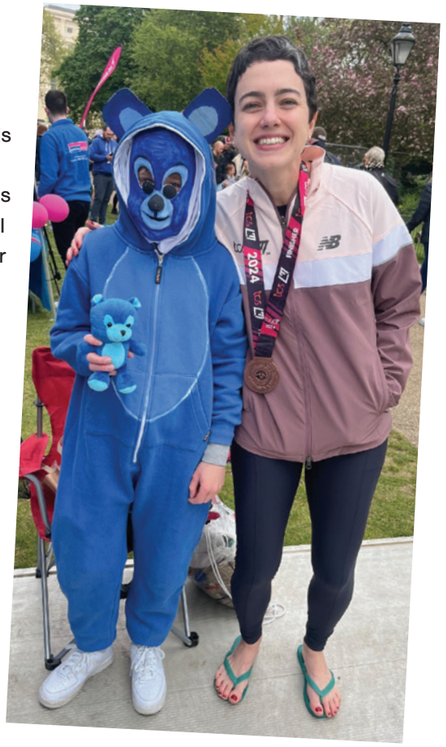
Mrs J Pearks mother left £3,000.00 in her will to the charity. She did not have the disease but she was aware of how it affected a member of her family who had dermatomyositis. She hoped the money will go into research into this disease.

I was very saddened by their passing but also humbled by the way they have helped the charity. It is just a shame I am not able to show my gratitude to them for the kindness they have shown.

We have also received many donations in memory of loved ones and in lieu of birthday, anniversary and Christmas presents, as well as private donations. We would not be able to make the commitments to research projects if it were not for these donations. We are very appreciative of these donations that are often sent we a simple message, 'please put towards funds'.

Thank you.

London Marathon 2024



Every year I have the privilege of reporting on the London Marathon and how we have had a succession of amazing runners joining Team Muscle.

This year has been no different and this year's international team has again proved to be quite remarkable. For the first time ever, all the team members plus their family and friends at some time during the afternoon visited the Myositis gazebo. I had the privilege of being able to talk to the team members as they finished and with the help of a glass of champagne the comments that they made were quite astonishing and very thought provoking.

One runner had overwhelming feelings of emotion and sheer joy at being able to run the race and know that their efforts would also help people living with myositis.

One runner who had competed in several marathons had never experienced the raw emotion that was almost overwhelming, particularly on one section of the race. The runner was feeling tired but was driven on by the crowds lining the route describing them as not just spectators and was aware something incredibly special was happening. They were all part of this effort and the need to not just high five people on the side of the road but to give them a hug as you would family. Complete strangers but for those few seconds of contact. Tear filled eyes and why this behaviour? Who were these people from what appeared all backgrounds and races that made our runner feel so special. That question will forever remain unanswered, but it was declared truly life changing.

This was not just a marathon run but a chance to reflect at the end of the event on what life and the joy of friendship is all about. Another runner had never heard of myositis but by accident had logged into the Myositis UK website, saw the situation of young children affected by the disease and just had to help in the only way he could and that was by running and raising money in the event.

A life-size Teddy-Bo costume was worn by my grandson, Noah. The costume was made by him with help from his mum, Sasha. He drew much attention to the Myositis UK gazebo. The gazebo is a new acquisition for the charity. My garden gazebo was getting a bit tired and the time had come to purchase a new one for the charity. I normally will always make do and not spend charity money on such items when research funding is important. With the trustees' agreement it was purchased with help from Geoffrey Howton's legacy. I was told by several runners you could see the Myositis gazebo from across the park. Perhaps this is the reason why everybody found us this year!

The London marathon has been a record breaker for the charity and over £27,000 has been raised and is still rising! I thank all in Team Muscle for raising sponsors and to our members for sending into the office donations in support of the runners and for donating on the team's fund raising pages. For us it was a brilliant but a very long day. It is hard work and tiring but also very rewarding.

Just being part of these runners' lives for one day and seeing the joy and sense of achievement is a privilege.

Guernsey family in London Marathon wheelchair-push

David Rowlinson, Jenny Rowlinson and Jonny Meardon raised more than £17,000 of the £27,000 for the charity. Mr Rowlinson has myositis, a rare progressive muscle wasting disease which primarily affects the external muscles in the legs and arms. He said: “The support we had all the way round was truly incredible from fellow runners.”

Mr Rowlinson sat in a specialist racing wheelchair guided by Miss Rowlinson and Mr Meardon, who trained extremely hard to be able to push his bodyweight as they ran. He said, “The crowd, the noise of the crowd was just amazing”. He added that crossing the line was a “euphoric feeling”, and the whole experience “will live alone in [his] memory”. He was first diagnosed with the condition in 2012, and it has since gotten progressively worse, meaning now cannot walk for long distances.

Mr Rowlinson and his team are also set to take on the Guernsey half-marathon in September. After completing the race in September, Mr Rowlinson said he would be donating his specialist racing chair to the Guernsey Sports Commission to be used by anyone for a running event. What an effort from David and his family in not only raising substantial funds but for the publicity he created from his participation.

Masonic Charitable Foundation

The Foundation charity payments co-ordinator, Karon Chatterton, sent a donation of £535 at the specific request from funds provided by the members of the Lodge of Perfect Light, London.

Netley Abbey Lodge

At the recent "Ladies Night" dinner and dance organised by Netley Abbey lodge, Southampton, £305 was donated to Myositis UK from the raffle held on the night.

Kira McIntosh

Edinburgh Half Marathon, 26 May 2024

Kira writes, "Last year my grandpa passed away after a late diagnosis of myositis. He was a wonderful person and an amazing painter who loved all things animals and wildlife. Grandpa always had a camera in his hand recording us all and making DVDs for us to watch back. We all love and miss him so much every day.

On the 26th May 2024 I ran the Edinburgh half marathon in his memory and was able to raise £625 for Myositis UK. I also used this as a chance to raise awareness of this disease, especially working and knowing a lot of people who also work in healthcare. I was able to have conversations and share a little bit of the knowledge I now have. Myositis was something I had never known about before my grandpa had it and being able to make people slightly more aware might, in the future, help someone reach a diagnosis earlier.

I was so proud of myself for completing the race (on a very wet, typical Scottish day!) and that I was able to raise so much to help fund more awareness and research into myositis."

Eastleigh Masonic Lodge, Hampshire

President of the Lodge, Ray Winkworth and the members made a generous donation to the charity for £650.00. This money was raised from their Christmas dinner and Carol evening last December.

It is quite remarkable how Eastleigh Lodge has continued to consider the charity worthy of their support over many years. I trust they are pleased to have contributed to the success of the charity and have seen it develop as the funds became available into a leading role in investigating and treating this group of miserable neuromuscular diseases not only in the United Kingdom but globally as well.

Richard Kirkman Trust

The Trust and its administrators have been amazing supporters of the charity. Their help and kindness during this period has enabled the charity to achieve the progress it is making today.

Their latest gift for £2,000 was presented to the charity in December 2023.

Sally & Richard Hughes

The amateur theatrical company staged a production of Chitty Chitty Bang Bang in Eastleigh, Hampshire. Richard and Sally Hughes help the company enormously in the production and front of house during its production run. They organised a raffle and collection to benefit the charity which raised £209.20. The theatre also let us display our charity banners to create awareness about myositis to people attending. As you know my role in the charity is to help people with serious illness so going along and being entertained particularly by young, enthusiastic cast of performers, was a joy and a form of escapism on my part!

Katie & Dan Mullings

Great Manchester Run

Katie and Dan write, "Earlier this year, our Dad was diagnosed with Inclusion Body Myositis, a rare autoimmune disease which sadly has no cure or treatment. We will be taking part in the Great Manchester Run to raise as much money as possible for this small charity to help fund research and find some answers about this rare muscle disease.

Myositis UK relies solely on donations and fundraising to sustain the charity and fund vital research, so your donation means the world and will have a significant impact on the lives of individuals living with this disease. Thank you for your support."

https://ajbellgreat manchesterrun2024.enthuse.com/pf/katie-mullings

Katie and Dan have raised £710

JustGiving

Lacie Gibbons - Finding My Feet Again

100km Cycle ,
22 June 2024

"Hi guys and thank you for returning to my JustGiving Page! I will be cycling 100km on Saturday 22nd June 2024 to raise money for Myositis UK. If you are new here, hello! My name is Lacie Gibbons and I was diagnosed back in 2020 with a life limiting muscle disease JO1+ Polymyositis, a rare muscle disease called the inflammatory myopathies that involve chronic long-standing muscle inflammation and pain. This is an uncommon disease that causes muscle weakness affecting all aspects of physical movement with CK's of 33,800. CK is a type of protein that the muscle cells need to function. The higher the CK number the more sever the inflammation. I spent nearly six months in hospital unable to walk or do anything independently. I was told to accept that I would have to find a slower pace of life. I have been incredibly lucky to have the best rheumatology team who support my crazy ideas, and who have found the right treatment that works for me, knowing some people aren't as lucky! I have yearly Rituximab infusions (a type of chemotherapy) and take immunosuppressants every day to keep my immune disease at bay!

I have witnessed firsthand how devastating this disease can be for so many people with minimal funding. For as long as I am able, I am going to do as much as I can to raise awareness and hopefully money for Myositis UK. I am incredibly grateful that I am able to push myself and participate in these challenges, knowing others aren't as fortunate! No matter how big or small the donation every little helps! If you are unable to donate then please help me by sharing my page to raise as much awareness as possible.

So, with all that being said I am going to cycle 100km on Saturday 22nd June starting from Newark showground cycling across Nottinghamshire and Lincolnshire all in aid to raise as much awareness and money for Myositis UK.

Lacie completed her ride and sent the following update:

"103km cycled on a non electric, non assist, manual push bike in 5hrs all in aid of Myositis UK – thank you from the bottom of my heart to every single person who has donated and shared awareness, you will never know how much it means to me!

I'm forever in debt to everyone who has supported me back to full health, those who never stopped believing. I'm so proud of what I have achieved and will keep achieving with a life limiting muscle disease! I will never stop helping others who live with this awful disease, with minimal funding."

Lacie has raised £884 to date of her £500 target

In Memory Of Rose

Raeeza's fundraiser for Myositis UK
The Cancer Research UK London Winter Run,
25 February 2024

Raeeza writes, "I'm raising money for Myositis UK in memory of our wonderful mum, an otherwise fit and healthy woman, who was taken far too soon by one of the auto immune conditions they support research into.

The charity is very small and could do with your assistance. No amount is too small and all contributions are gratefully received.

The run is held by Cancer Research but I would like to also raise funds for this smaller charity." - Thank you

Raeeza has raised £8,577

Raeeza posted the following update:

"I only went and completed my first 10km run!! Mum definitely got me through this one and nearly £8k raised!!!! Thank you to everyone who has helped me get to this incredible amount! X"

Anya Armitage – Lyra's Fundraiser for Myositis UK

Anya writes, "Lyra is a happy, funny and brave two-year-old. On her second birthday she caught glandular fever and this triggered an auto immune disease called Juvenile Dermatomyositis (JDM).

Lyra's treatment involves MRI's, weekly blood tests, chemotherapy injections, high-dose corticosteroids and many other things that no kiddo should have to endure. The treatment causes harsh side effects including nausea, stomach pains and can damage the eyes. These medications also make her immunosuppressant meaning a simple cold can turn into infections and hospital stays.

Having your child diagnosed with an autoimmune disease is scary, but when that disease is so rare and there is no cure, it is even scarier. Luckily, Myositis UK are a charity improving the diagnosis, treatment and prognosis of myositis.

We would be so grateful if you would consider donating to Myositis UK, helping us keep up the fight against rare muscle disease, finding better treatment options with less side effects and finding a CURE.

You can help children get back to being kids again. Thank you, thank you, thank you!"

Lyra has raised £1570

Simon Donhou

Cycling Alpe D'Huez,
1st June 2024

Simon writes, "Thanks for taking the time to visit my JustGiving page. As an avid cyclist, I am thrilled to announce that I will be conquering the epic Alpe D'Huez route in June 2024 with a couple of my closest friends. This personal cycling challenge is not only a test of my physical endurance but also an opportunity to raise funds and awareness for Myositis UK.

Alpe d'Huez is a climb in the region Bourg d'Oisans. It is 13.9km long and bridges 1118 vertical meters with an average gradient of 8%. The top of the ascent is located at 1840 meters above sea level.

Myositis is a rare autoimmune disease that affects the muscles and can have a profound impact on individuals' lives. I hope to be able to advocate for those living with myositis and contribute towards research, support services, and improved treatments.

Approximately three in every million children are diagnosed with Juvenile Dermatomyositis each year. As many of you are aware, my youngest, Matilda, was diagnosed in mid-2023, under the age of two.

This was picked up initially with skin signs but further investigations revealed that it had already started to affect her muscles. She has undertaken numerous investigations, scans, blood tests and currently has a daily and weekly medication regime which lowers her immune system.

She is a warrior, a force of nature and an absolute champion and has taken all of this in her stride. She has the most amazing older sister and family surrounding her. The future is not certain but we are hopeful that this condition should not be something she will need to contend with in her adult life.

I am setting a target of £1,000 for this fundraising campaign. Every donation will make a difference in the lives of those affected by myositis. Your support will not only help me reach my fundraising goal but also provide much-needed resources to Myositis UK. Join me in making a positive impact by donating today, no matter how big or small. Together, we can bring hope and support to individuals battling myositis."

Simon completed the ride and sent the following update:

"As I have said before, my youngest, Matilda, was diagnosed in mid-2023, under the age of two with Juvenile Dermatomyositis.

She is a warrior, a force of nature and an absolute champion and has taken all of this in her stride. She has the most amazing older sister and family surrounding her. We call her weekly methotrexate injection her 'stamper' and she helps us with this, as does her older sister. The daily hydroxychloroquine has an awful taste but again, she is now accepting of this and has her chewable vitamin afterwards to try to correct the taste. The future is not certain but we are hopeful that this condition should not be something she will need to contend with in her adult life.

I set a fundraising challenge around nine months ago in with a target of £1,000. The challenge was to cycle up Alpe d'Huez. I wanted to try and help make a difference in the lives of those affected by myositis, to widen awareness of the condition and provide much-needed resources to Myositis UK.

We have this week, completed our goal of climbing Alpe d'Huez, without using electric motors, e-bikes or opting to use the ski-lifts that were readily available throughout the local town.

Over the course of a few big days in the Alpes, we cycled 224km, climbing approximately 4,800m. We reached the peaks of Alpe d'Huez, Col de Sarenne, le Berarde, Col de le Croix de Fer and Col de Glandon.

In total the money raised currently stands at £1,827! This is a truly fantastic sum that will go to the charity Myositis UK, contributing towards research in diagnosis, potential treatments and supporting families affected like my own."

Simon has raised £2025

Derri Tattershall

Tough Mudder – 13 July 2024

Derri writes, "In April 2021 my mum became extremely unwell. She could barely stand up, she was struggling to breath and was sent to hospital by her GP.

It was initially thought that she had pneumonia, however after a week in hospital, numerous tests and unsuccessful antibiotic treatments she was diagnosed with a rare auto immune disease called Anti-synthetase syndrome. (This comes under the umbrella of myositis.) This disease is life changing and affects various parts of the body including the muscles and lung function. There is currently no cure for this condition, its managed by daily medication which my mum and many others will be on for life. Myositis UK raise funds for research to help improve the diagnosis, treatment, understanding and prognosis of myositis.

Myself, my sister Jorden and my partner Adam, will be taking part in the 10k Tough Mudder in Manchester on 13th July to raise money for this charity. Please help us do this as they do not receive any funds from the government. Any amount would really help, thank you xxx."

https://www.justgiving.com/page/derri-tattersall-1712347923011

Derri has raised £280 to date

Update on Yograj

We reported in the last edition of 'Myositis News' that Yograj was shaving off his beard to raise funds for the charity and that he had raised £1,407 to date. I am pleased to say the amount now raised is £1,980.

World Myositis Day

This year will be the second “World Myositis Day”

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

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

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

Prescription Charges Coalition

This is an update on the work of the Prescription Charges Coalition, of which Myositis UK is a member:

Election activity
“We’ve written to the Conservative and Labour party leaders to ask that they commit to review the prescription charge exemption list if they’re elected on 5 July.

Backlash at prescription charge rise
The Coalition has been quoted widely showing our disappointment at the government’s increase in prescription charges in England from 1 May.

We hand in open letter calling on government to Freeze The Charge
In February we handed an open letter into the Department of Health and Social Care calling on the UK government to freeze prescription charges in 2024 and 2025.

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

Christmas Cards

I know it is only just summer, but we now have the 2024 Christmas cards in stock. An order form is enclosed with this magazine, and it will also be available on the website.

Holiday Insurance

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

Support us through easyfundraising

Thank you to everyone for raising donations for Myositis UK with easyfundraising. You have raised £1,835.13 to date. If you haven’t signed up yet, it’s easy and FREE. 4,400 shops and sites will donate to us when you use easyfundraising to do your online shopping – at no extra cost to you! Every donation you raise makes a difference to us so please sign up. https://www.easyfundraising.org.uk/causes/myositisuk/

PayPal Giving Fund

We have received a further £198.14 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.

Literature Update

COVAD Study Group:

Listening to patients, for the patients: The COVAD Study-Vision, organizational structure, and challenges.
Joshi M and others, COVAD study group. Published in Int J Rheum Dis May 2024. PMID: 38720408.

Collating the voice of people with autoimmune diseases: Methodology for the Third Phase of the COVAD Studies.
Kadam E, and others, COVAD Study Group. Published in Rheumatol Int. July 2024. PMID: 38609655.

Impaired health-related quality of life in idiopathic inflammatory myopathies: a cross-sectional analysis from the COVAD-2 e-survey.
Yoshida A and others, COVAD Study Group. Published in Rheumatol Adv Pract. March 2024. PMID: 38524696.

Characteristics and risk factors of COVID-19 breakthrough infections in Idiopathic Inflammatory Myopathies: Results from the COVAD study.
Hoff LS and others, COVAD study group. Published in Rheumatology (Oxford). March 2024. PMID: 38430474.

Global disparities in the treatment of idiopathic inflammatory myopathies: results from an international online survey study.
Ziade N and others; COVAD Study Group. Published in Rheumatology (Oxford). March 2024. PMID: 37228012.

Flares in IIMs and the timeline following COVID-19 vaccination: a combined analysis of the COVAD-1 and -2 surveys.
Sen P and others; COVAD Study Group. Published in Rheumatology (Oxford). January 2024. PMID: 37084267.

Other Literature updates:

272nd ENMC international workshop: 10 Years of progress - revision of the ENMC 2013 diagnostic criteria for inclusion body myositis and clinical trial readiness. 16-18 June 2023, Hoofddorp, The Netherlands.
Lilleker JB and others, 272nd ENMC workshop participants. Published in Neuromuscul Disord. April 2024. PMID: 38522330.

Collaborative research in myositis-related disorders: MIHRA, a global shared community model.
Saketkoo LA and others. Published in Clin Exp Rheumatol. February 2024. PMID: 38436382.

Patient global assessment and inflammatory markers in patients with idiopathic inflammatory myopathies - A longitudinal study.
Lodin K and others; MyoNet Registry Study Group. Published in Semin Arthritis Rheum. April 2024. PMID: 38241913.

International Guideline for Idiopathic Inflammatory Myopathy-Associated Cancer Screening: An International Myositis Assessment and Clinical Studies Group (IMACS) initiative.
Oldroyd AGS and others; International Myositis Assessment and Clinical Studies Group Cancer Screening Expert Group. Published in Nat Rev Rheumatol. December 2023. PMID: 37945774.

Moving forward together: collaborative landscapes of research in idiopathic inflammatory myopathies and calcinosis.
Saketkoo LA and others; International Myositis Assessment and Clinical Studies Group and The Myositis International Research and Health Collaborative Alliance (IMACS/MIHRA) Calcinosis Scientific Interest Group. Published in Rheumatology (Oxford). May 2024. PMID: 37449887.

Performance of the 2017 EULAR/ACR Classification Criteria for adult and juvenile idiopathic inflammatory myopathies and their major subgroups: a scoping review.
Saygin D and others. Published in Clin Exp Rheumatol. February 2024. PMID: 38436279.

Defining criteria for disease activity states in juvenile dermatomyositis based on the Juvenile Dermatomyositis Activity Index.
Rosina S and others; Paediatric Rheumatology International Trials Organisation (PRINTO).
Published in RMD Open. February 2024. PMID: 38307698.

Responsiveness and meaningful thresholds of PROMIS pain interference, fatigue, and physical function forms in adults with idiopathic inflammatory myopathies: Report from the OMERACT Myositis Working Group.
Saygin D and others; OMERACT Myositis Working Group. Published in Semin Arthritis Rheum. February 2024. PMID: 38141522.

Pain is Common in Myositis and Associated with Disease Activity.
Pillai AC and others. Published in Rheumatology (Oxford). February 2024. PMID: 38410059.

The impact of pain on daily activities in patients with idiopathic inflammatory myopathies: Report from the OMERACT myositis working group.
Saygin D and others. Published in Semin Arthritis Rheum. May 2024. PMID: 38851171.

Designing, Developing, and Testing a Chatbot for Parents and Caregivers of Children and Young People With Rheumatological Conditions (the IMPACT Study): Protocol for a Co-Designed Proof-of-Concept Study.
Livermore P and others; IMPACT Steering Group. Published in JMIR Res Protoc. April 2024. PMID: 38568725.

Remotely collected patient-reported data characterises the impact of idiopathic inflammatory myopathy flares upon work productivity.
Williams J and others. Published in Rheumatology (Oxford). May 2024. PMID: 38141204.

Mental health in paediatric and adult myositis-related diseases: current state of research, interventions, and future steps from the MIHRA Psychological Impact Scientific Working Group.
Lanis A and others. Published in Clin Exp Rheumatol. February 2024. PMID: 38488093.

Content analysis of patient support groups related to myositis on Facebook.
Afsar AP and others. Published in Clin Rheumatol. February 2024. PMID: 38212556.

Current myositis clinical trials and tribulations.
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Where are we now in biological drugs for myositis?
Neves A and others. Published in Rheumatology (Oxford). February 2024. PMID: 38321569.

Rituximab in the treatment of progressive interstitial lung disease associated with the antisynthetase syndrome.
Narváez J and others. Published in Arthritis Res Ther. June 2024. PMID: 38890654.

Therapeutic efficacy and safety of JAK inhibitors in treating polymyositis/dermatomyositis: a single-arm systemic meta-analysis.
Ma C and others. Published in Front Immunol. March 2024.PMID: 38576610.

Safety and tolerability of intravenous immunoglobulin in patients with active dermatomyositis: results from the randomised, placebo-controlled ProDERM study.
Aggarwal R and others; ProDERM investigators. Published in Arthritis Res Ther. January 2024. PMID: 38233885.

Chimeric antigen receptor T cell therapy: a new emerging landscape in autoimmune rheumatic diseases.
Lyu X and others. Published in Rheumatology (Oxford). May 2024. PMID: 37982747.

Idiopathic inflammatory myopathies: one year in review 2023.
Conticini E and others. Published in Clin Exp Rheumatol. February 2024. PMID: 38488099.

Idiopathic inflammatory myopathies: current insights and future frontiers.
Connolly CM and others. Published in Lancet Rheumatol. February 2024. PMID: 38267098.

Clinical features and prognosis of idiopathic inflammatory myopathies with coexistent multiple myositis-specific antibodies.
Liang X and others. Published in Clin Exp Rheumatol. May 2024.PMID: 38819961.

Autoantibody evaluation in idiopathic inflammatory myopathies.
Tebo AE. Published in Adv Clin Chem. April 2024. PMID: 38762242.

Assessing the sensitivity and specificity of myositis-specific and associated autoantibodies: a sub-study from the MyoCite cohort.
Loganathan A and others. Published in Rheumatology (Oxford). March 2024. PMID: 38479813.

Clinicopathological Reclassification of Idiopathic Inflammatory Myopathy to Match the Serological Results of Myositis-Specific Antibodies.
Park YE and others. Published in J Clin Neurol. January 2024. PMID: 38179634.

Exercise recommendations for patients with myositis: a narrative review of safety and efficacy.
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Does inspiratory muscle training improve lung function and quality of life in people with inclusion body myositis? A pilot study.
Williams E and others. Published in Neuromuscul Disord. April 2024. PMID: 38489862.

Imaging swallowing function and the mechanisms driving dysphagia in inclusion body myositis.
Salam S and others. Published in Clin Exp Rheumatol. February 2024. PMID: 38372730.

Sporadic Inclusion Body Myositis at the Crossroads between Muscle Degeneration, Inflammation, and Aging.
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Phenotypic spectrum of inclusion body myositis.
Roy B and others. Published in Clin Exp Rheumatol. February 2024. PMID: 38436356.

Treatment resistance in inclusion body myositis: the role of mast cells.
Acosta I and others. Published in Neuromuscul Disord. May 2024. PMID: 38865916.

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Warman-Chardon J and others. Published in CMAJ. April 2024. PMID: 38621777.

Disease activity trajectories in juvenile dermatomyositis from childhood to adulthood.
Nozawa T and others. Published in Rheumatology (Oxford). January 2024. PMID: 38216715.

Calcinosis in Juvenile Dermatomyositis-Epidemiology, Pathogenesis, Clinical Features, and Treatment: A Systematic Review.
Gonçalves Júnior J & Shinjo SK. Published in Curr Rheumatol Rep. February 2024. PMID: 38060107.
Published in Rheumatology (Oxford) June 2023. PMID: 36370070

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 an account on X, but we do not post often.

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

The traffic on our community forum is quiet as many prefer to use a forum that is inside one of their already open social medias. For this reason, Treasurer Jo Goode set up a Facebook myositis community forum group a few years ago. This Group is very active, self served by its users and Jo administers the page to welcome new people and ensure correct and safe discussion.

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. The Myositis UK Facebook Page acts as the hub for our other Facebook Pages and is administered by Paula Jordan (Trustee) and Jo Goode (Treasurer).

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

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

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

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

Postscript

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

– Les Oakley, Myositis UK

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