

Myositis News



FUNDRAISING • RESEARCH
AGM & CONFERENCE

AGM & Conference 2021-22

Dear Member,

Welcome to our first Myositis News magazine of the year. Easy words to write but getting here has been difficult with the trustees, at some time or another in the last six months, having prolonged sickness to cope with. However, we are up and running again and looking forward to a year of progression and success.

Perhaps because of our inactivity it has occurred to me how lacking the communication has been to the charity office and yet interaction on social media and similar formats has continued to be vibrant. For me, it has meant a change in how I perceive my role and where I need to be focussed in the coming months. As I am not an enthusiast of social media and have never enjoyed participating, my focus is now, as in the past, to continue to find a cure for these miserable diseases and channel my energies to this end. This is one area where good fortune has been with me and there is an exciting era ahead for the charity and medical research is

making progress.

As chairman (and even this word is open to debate) it has been a long haul. It is considered that a chairman or chair should not hold office more than a suggested seven years so that a charity can build on the input from many people to achieve a common goal. However, myositis is a rare disease and to me aspects of charity work that are considered by some are invaluable to its membership have to take second place to getting the disease researched with an outcome that is a benefit to its members. I have mentioned in the past that this is a club that no one wants to be a member of, but the illness brings us together and together we will overcome it, I am sure.

Having past my sell-by date as chairman by some considerable years and now having to admit to getting on a bit, I do worry about my future. Nevertheless, my drive and ambition have not diminished and I have never opted for the easy way out.

Les Oakley MBE
Chairman

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

The week or two before our conference were extremely busy because Irene had to make sure the membership was up to date and correct (for our recent members, Irene is the Group Co-ordinator). We then needed to let everyone know the venue and the conference programme. Before we could do this, Irene needed to arrange with the medical world who could attend and speak, and who was prepared to sit on the panel for the question-and-answer session at the end of the conference. She managed to get all the disease types represented and other interesting talks that would be beneficial and helpful to all of us.

It takes much time, and nothing is ever straightforward. In fact, two important speakers had to withdraw because one had gone down with Covid and the other was still recovering. It was also not helped by the postal strikes where we could not get the information sent out in a timely fashion, particularly the final programme.

While all this is going on, the venue had already been booked but Irene had discussed with the hotel conference manager the table lay-out, the audio systems needed, the catering and specific dietary needs, plus the accommodation and special needs in some of the rooms for some of our members.

During this period there is a need



for much printing in the office and everything that is required to produce our literature, along with name badges and lanyards. The continual daily check on members that are coming and members for many reasons who were coming but had cancelled, and the late requests to come, had to be accommodated. This had to be well monitored because getting the numbers wrong would be expensive for the charity. Appropriate banners for display in the hotel were acquired after the artwork was agreed with the manufacturers. All the charity merchandise needed to be checked and packed. The charity display stands and racks had to be made ready for the day. The agenda for the Annual General Meeting preceding the conference had to be compiled and that also had its issues because of Covid. A Zoom meeting with members would be required to get the audited accounts approved at a later date. It did not help, after all the checks and box

ticking, that when I announced I was going to give the chairman's report, I did not have a paper copy! After a long embarrassing pause and paper shuffling by me, Irene found a copy on the laptop. Phew!

On the day before the conference, we had to load the car with everything we needed. This took time because of the rain and the chance for a break in the weather to stagger and haul the hand truck from the office to the car. Nothing is ever easy!

We decided that the format for the conference room needed to be reverted to how we held our conferences some years ago. We had to do this because the number of members attending was low. Regrettably, we had no parents or guardians of children with Juvenile Dermatomyositis attending, so break-out rooms were not so critical, although we had two members

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with JDM who are now adults present. Perhaps a member can tell us why there was this non-attendance? Maybe it is because of the success of the treatment and management that children receive these days, making the need to attend unnecessary. We therefore put everybody in one big room, socially distancing. This system was criticised in the past by reasoning that members had to sit through talks other than of their illness.

However, the way our speakers delivered their talks to an audience such as ours has changed and are made very interesting using, where possible, words that can be readily understood. There was banter and humour between the speakers that made a very serious subject still understandable and amusing. Because we were not in break-out rooms, we left the question-and-answer session to the end of the conference with delegates writing them down on a question form and distributed among the appropriate medical panellist. When these were

covered, a roaming microphone was used for delegates to ask questions directly.

Every question was answered fairly and reasonably. Our panel – who are leaders in the understanding, treatments and management of the diseases – did not fail to provide an answer. It also must be mentioned that they gave their time up freely to help us. One of the questions which created a lot of humour and eyebrow raising was when the complaint was made that they could not get to see a specialist in recent times to discuss their myositis. Well, most chuckled and the panel expressed the fact that, “now’s your chance”, make use of it and they did.



There has been talk on the issue of using the internet and live-streaming the conference to those who cannot attend. During lockdown we tried this out with one doctor kindly issuing advice, while the Covid pandemic was at its height. This was a marvellous connection and proved to be well received by the members at a time particularly when isolation was a big issue while coping with a rare disease. We have been talking to doctors about Zoom meetings for this year and they are keen to make it a regular feature. However, it is considered a big expensive technical step to live-stream our national conference for two main reasons. One, it will reduce the number of members



physically attending. Even without live-streaming, the conference costs much charity money to put on and we need to have people in the room to justify the expense. Two, much of the scientific content is unpublished and this work needs to be protected. Also, you would miss the interaction in a physical attendance between the members, doctors and scientists. The Global Conference in Prague needed to use an online attendance and it was at times stilted and difficult to follow and this was with people used to using this procedure. The trustees are also aware that some members cannot travel but the proposed Zoom meetings, particularly if they are aimed at disease types, will to a degree compensate for no online streaming. It would be great to hear your views.

At our conference in Oxford our dear friends, Margaret and Bruce Cross, attended to help us with registration on the day and manning the charity merchandise tables. This year we had space at the back of the main room for the inclusion of



the tables and for them to join us, resulted in them taking over £230 for the charity which is a fantastic result considering the number there. They have undertaken this role for several years, but it was the first time they had been able to be in the conference room and listen to the speakers. They were really impressed and did not realise how well the charity had covered so many issues to help people with myositis.

This is perhaps an indication of why it is essential to maintain a physical attendance regardless of any other decisions that may be made in the future. The conference was a great success, made particularly so because we had very good speakers.

As well as the questions for the panel to answer I am grateful for the feedback comments from the members present. This information is very helpful when making future plans. All the comments were positive and it is very rewarding when we read of how members had



benefited from the day. Even the odd words of where we could improve were welcome and to be considered for future meetings. It was summed up by members writing:

“Very informative, something for everyone, a good variety of talks and a very friendly group!”

“Very good location, good road access. Thank you for a brilliant conference.”

“I made excellent medical contacts which was great.”

“See you all next year. It has been great seeing everyone in person.”

“Excellent and approachable speakers. I liked the format in one room.”

“Thank you for organising this day. I have learnt so much.”

“First time and would definitely come next year.”

Irene is always aware that things can go wrong. However, the important issues that were the essence of the conference appeared to run smoothly and any hitches did not interfere with proceedings; it ran on time and, from the feedback, everyone was happy with the day.

Lifestyle Medicine

By Dr Maria J. Goddard
BSc MBChB JCPTGP IBLM/BSLM
- Urgent Care Doctor - Certified Lifestyle Physician - Physical Activity Clinical Champion North London - Active Hospital Lead Royal Free NHS Foundation Trust

Dr Maria Goddard presented the following at our conference and has kindly agreed to share here. Lifestyle Medicine is evidence based therapeutic lifestyle interventions to optimise health, prevent, mitigate and even reverse chronic disease delivered by trained physicians and their teams alongside and as an adjunct to traditional medicine.

It is based around six pillars (see the graphic on the right).

Each pillar, if not optimised, can add to an individual's burden of disease and ticking all the boxes promotes health and healthy lifespan.

Those living with or caring for someone with a chronic disease, such as myositis, can be particularly vulnerable and thinking more about lifestyle can go a long way to helping them to achieve better overall health and perhaps new goals in what matters to them.

A sense of belonging and purpose and keeping active in society and family life is also imperative.

There are some very simple rules:- Eat wholefoods, avoid processed foods, don't eat too much and, mainly but not exclusively, plants.

Keep active and move more – follow the Chief Medical Officer's guidelines when possible. Aerobic activity and muscle strengthening exercises are equally important. Living with myositis will require creative and personalised solutions to managing these goals.

Sleep well – 7/8 hours a night, 7 nights a week.

Avoid toxins such as tobacco, too much alcohol (no more than 14 units per week), illegal drugs, environmental hazards and unnecessary pharmaceuticals and supplements.

Keep stress in check, remember anxiety and low mood should make us think about addressing or changing the problems that make us feel that way if we can.

Relationships are rarely straightforward, communication is key to keeping them healthy.

The Pillars of Lifestyle Medicine

- Healthy Eating**: Lifestyle Medicine supports people to reduce consumption of ultra-processed foods by teaching the knowledge and skills required to follow healthier eating patterns of people's own choosing.
- Mental Wellbeing**: Lifestyle medicine teaches proven techniques to reduce stress and help people with relaxation. Practitioners support people to find purpose in life and improve health through connection with nature.
- Healthy Relationships**: Lifestyle medicine supports people to develop and sustain healthy and meaningful relationships and increase social connection to reduce stress and promote both physical and mental health.
- Physical Activity**: Lifestyle Medicine supports people to choose ways they could incorporate more physical activity in their lives, as well as reducing time spent sitting down.
- Minimising Harmful Substances**: Lifestyle Medicine supports people to stop smoking, reduce excessive alcohol consumption, avoid addictive substances and behaviours such as gambling or harmfully excessive internet or social media use.
- Sleep**: Lifestyle Medicine supports people to achieve good quality sleep and avoid behaviours which can impair sleep quality.

Chief Medical Officer's Guidance for Physical Activity in Adults 2019

Physical Activity for Disabled Adults
 Make it a daily habit

- Improves mental health and quality of life
- Makes maintaining a healthy weight easier
- Makes daily tasks easier and increases independence
- Strengthens muscles and bones
- Improves fitness
- Improves mobility and balance
- Helps to prevent chronic disease
- Creates opportunities to meet new people and feel part of the community

Physical activity for adults and older adults

- Benefits health
- Improves sleep
- Maintains healthy weight
- Manages stress
- Improves quality of life
- Type II Diabetes -40%
- Cardiovascular disease -35%
- Falls, depression etc. -30%
- Joint and back pain -25%
- Cancers (colon and breast) -20%

Be active

at least 150 minutes moderate intensity per week OR at least 75 minutes vigorous intensity per week

Build strength
 on at least 2 days a week

Minimise sedentary time
 Break up periods of inactivity

Improve balance
 For older adults, to reduce the chance of frailty and falls 2 days a week

UK Chief Medical Officers' Physical Activity Guidelines, 2019

As we age or develop health issues, we tend to slow down and do less but this only makes matters worse and our risk of other diseases rises. We must maintain healthy activity levels at all ages. But remember – it's never too late to

start and something is always better than nothing!

Many of the chronic diseases that we are faced with at this point in time originate in poor lifestyle and inequalities in society and the medical

profession now recognises this. Many different aspects of our lives impact our health and education and knowledge are key to self-awareness. Knowledge is power that can help motivate and enable us to make changes that will reward us.

AGM & Conference 2023

We have booked the Woodland Grange, Old Milverton Lane, Leamington Spa, Warwickshire, CV32 6RN. The date of the conference is Sunday 23rd July. The main feature is that it is a bright and airy venue. It is still important that you are kept in a roomy and safe environment.

The venue and hotel is set in sixteen acres of beautiful gardens. It is run by an award-winning team and is known for the quality and provenance of its food, light, contemporary and modern facilities. For members staying, it offers guests an on-site games room, gym, two bars and a fine dining restaurant.

The accessible, yet secluded, venue is located just outside Leamington Spa, in the heart of the UK and easily accessible between Birmingham, Warwick and Coventry. However, while offering a quiet retreat-style setting, the venue is easily accessible by both road and rail and has plenty of car parking spaces.

For those members wishing to stay on the Saturday night, we will be holding a "Meet and Greet" at the hotel on the Saturday afternoon. This is an informal get-together for a cup of tea or coffee with biscuits and a chat!

We have secured accommodation with walk-in showers or accessible rooms for those members wishing to stay at the hotel on the Saturday



night. The conference is free to members and their partner/carer, parents or guardians along with a child living with myositis. Siblings are welcome to attend at no charge. If we have a number of JDMS attending, a separate room will be provided and there will be a play area for the children.

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 during lunch. To date, the following medical professionals have confirmed their attendance at the conference: Professor Hector Chinoy, Professor Hugh McNeil, Professor Pedro Machado, Dr Stefen Brady, Dr Saadia Ali and a paediatric



representative from Great Ormond Street, Xia Lyu, a Rheumatologist from Shanghai, and Francisca Bozan from Santiago, Chile. Xia and Francisca are currently working with Professor Chinoy at Manchester. Others to confirm.

Further details and booking information have been included with this magazine.

Clinical Study

Evaluating Dysphagia in Inclusion Body Myositis (IBM): IBM Swallow

Swallowing is frequently affected in inclusion body myositis (IBM). Dysphagia (swallowing problems) can be linked to life threatening medical complications including malnutrition and pneumonia. However, little attention has been given to swallowing in IBM. There is limited understanding of what specific structural changes and mechanisms contribute to abnormal swallowing in IBM.

We are conducting this study to further our knowledge of swallowing difficulties in IBM. We seek to follow swallowing function in twenty IBM patients with two study visits over the course of a year. Patients will be asked to attend the National Hospital for Neurology and Neurosurgery in London for the study visits. This study is forming a major focus of Dr

Salam's PhD project.

Magnetic resonance imaging (MRI) has recently emerged in IBM and myositis in general as a non-invasive tool to sensitively monitor disease activity and muscle damage. We plan to use MRI to evaluate the structure of muscles within the head and neck that are important in eating and swallowing. In addition, patients will have their swallowing examined by experienced speech & language therapists. Their assessments will include an x-ray of swallowing known as a videofluoroscopic swallowing study.

IBM can have a major impact on hand function, especially the ability to bend the fingers. Professor Machado has collaborated with other researchers to show that MRI scans

of the leg muscles in IBM patients may be useful in monitoring disease activity. Patients recruited to IBM Swallow will also undergo an MRI of the forearm muscles, to investigate the ability of MRI to monitor forearm involvement and hand function.

Study Doctor: Dr Sharfaraz Salam, Neurology SpR and Clinical Research Fellow

Principal Investigator: Professor Pedro M Machado, Professor of Neuromuscular disease and Rheumatology

Please contact Dr Salam on zchaf7d@ucl.ac.uk if you are interested in participating in IBM Swallow or being involved in other research related to IBM.

Working With Pharmaceutical Companies

In our last magazine I mentioned that the charity had been talking to pharma companies in how we could benefit each other in the interest of myositis patients. The charity is presently talking to a company located in the USA who have a medication that they consider if used in a controlled study trial will hopefully be of benefit

to Dermatomyositis sufferers. This is exciting news and although over the years we have had some false dawns, this trial appears to have ticked a few boxes already. The company will be recruiting dermatomyositis patients who wish to participate through appropriate centres in this country. I will keep you updated.

Research

My name is Dario Cancemi and I am the Study Coordinator for the Juvenile Dermatomyositis Cohort Biomarker Study and Repository Database. I would like to bring to your attention this very interesting paper led by our JDCBS Basic Sci Deputy, Dr Meredyth Wilkinson.

Lay summary

In this paper, we have examined genes (the human code) and the pattern of expression of these genes in immune cells called monocytes from JDM patients. We

discovered that genes that code for mitochondria (the 'powerhouse' energy producers of the cell) were less active in JDM patients (even those already on strong treatment compared to healthy children of the same age). We also found that markers of inflammation were more switched on in these same JDM patients. Looking at the mitochondria in more detail we discovered that the mitochondria were more varied in size and there was more release of mitochondrial DNA in JDM compared to controls.

We showed that this mitochondrial DNA was oxidised and could switch on gene markers of inflammation. These genes could be switched off by blocking pathways that lead to inflammation and by using an anti-oxidant drug (already used in clinic) called N-acetyl cysteine (NAC). We believe that these discoveries now allow us to look for new and very specific drugs to improve the treatment of JDM.

Full paper - <https://ard.bmj.com/content/82/5/658>

A brand new REDCap-based database

We are very proud to announce that the Juvenile Dermatomyositis Cohort Biomarker Study and Repository (JDCBS) database has recently moved to a REDCap-based digital platform. Data are now stored on the GOSH DRE (Digital Research Environment),

a secure, cloud-based, data analysis platform for biomedical research, precision medicine and healthcare. This new setup provides much improved security, functionality, future proofing, and better management of the database.

Myositis UK Grants



The trustees of Myositis UK have agreed to provide £5000 to help fund a follow-up workshop entitled: "Inclusion Body Myositis : 10 years of progress - revision of the ENMC" in the Netherlands on June 16-18, 2023. The charity also helped fund the initial workshop in 2011.

The workshop will be organised by Professor M. de Visser - Department of Neurology, Amsterdam University Medical Centre, The Netherlands, Professor Jens Schmidt - Department of Neurology and Pain Treatment, Immanuel Klinik Rüdersdorf - University Hospital of the Brandenburg Medical School Theodor Fontane,

Rüdersdorf bei Berlin, Germany and Professor Conrad Weihl - Neuromuscular Division, Washington University School of Medicine, Saint Louis, MO, USA.

The ENMC (European Neuromuscular Centre) is a foundation, funded by 8 European Patient Organisations (full partners) and 4 associated partners. From the foundation's budget, they organise 8 to 10 ENMC workshops each year and are able to cover expenses of the participants from the European partner countries.

The workshop on IBM is important, resulting in a high number of participants (29 instead of 20). Professor Hector Chinoy will be one of the UK participants.

Funding Research

Myositis UK has recently adopted a new process for reviewing grant applications to decide on which research projects to support. Funding opportunities are now advertised on our website and researchers working in the field of myositis are invited to apply. Applications are then sent for independent review before a consensus decision is reached by our 'Scientific Advisory Committee' and 'Medical Advisory Board'. Once the outcome has been agreed by our

'Board of Trustees', the successful candidates are notified, and an award is made. The aim of this process is to ensure that funding is awarded to high quality research projects that deliver patient benefits, in an open, fair, and transparent manner.

The outcome of the March 2023 funding call has just been announced with four research projects being supported. These include two large 'Inclusion body myositis' grants -

totalling £240,000 – and two smaller 'general myositis' grants – totalling £20,000. Funding for the inclusion body myositis grants was made possibly due to a legacy totalling £260,000 from Joyce Winifred Norman. Funding for the smaller grants was made possible due to the fundraising efforts of Myositis UK members and supporters. Below is a summary of the four research projects (provided by each of the Principal Investigators) that will benefit.

Project 1

Dr Stefen Brady (John Radcliffe Hospital – Oxford): Optimism – Rapamycin for Inclusion Body Myositis
Inclusion body myositis (IBM) causes progressive disability and a seven-fold increased risk of dying early. Unlike other forms of myositis, no treatment has been shown to affect the progression of IBM. In 2017, a small pilot study of an anti-transplant rejection medication, Rapamycin, was the first to show benefit. We have been invited to join Optimism, an international

collaborative study whose goal is to ascertain the benefit of Rapamycin. We expect Rapamycin treatment to produce similar benefits as previously observed in the pilot study including slowing disease progression and weakness. Rapamycin is cheap, widely used in the UK, and licensed for treatment of autoimmune disease. In the event of a positive outcome, it can easily be made available to people living with IBM, improving their quality of life.

Project 2

Professor Pedro Machado (University College London – UCL): Disease pathways for IBM stratification and therapy

Inclusion Body Myositis (IBM) is a disease that causes progressive muscle wasting and disability. There is currently no known treatment, and the cause of IBM is unknown. It is believed that genetic and environmental factors may trigger inflammatory and degenerative pathways in the body, particularly as someone ages. We are part of the IBM genetics collaboration and have completed a genetic study that found new genetic associations. Moving forward, we plan to expand

our study by collecting genetic data from more IBM patients and comparing it with data from people with polymyositis or dermatomyositis. We will investigate specific genetic regions in IBM using advanced techniques such as exome and genome sequencing to identify exact genetic variations associated with the disease. We will investigate altered and/or reduced protein production by sequencing IBM muscle samples. Pathological studies and tissue culture investigation of muscle tissue and patient cells will be used to gain insight into disease mechanisms and potential drug targets.

Project 3

Dr Saadia Ali (King's College Hospital – KCH): Improving clinician utilisation and data quality on the MYOACT patient register

The idiopathic inflammatory myopathies (IIMs) are rare group of autoimmune conditions affecting 10,000 patients in the U.K. There are two advanced treatments available for this condition in the U.K. Rituximab and Abatacept. However, large clinical trials have failed to confirm a benefit from these drugs in the IIMs. Further analysis of these studies suggested that some types of IIMs may benefit from these drugs. This represents a significant unmet clinical need and there is an urgent demand for further data to confirm these findings and elucidate which patients benefit from these drugs. Real-life patient registries can be complementary to clinical trial data as they pool together patient information from across the country, increasing the amount of information available to analyse, making it an asset in rare diseases like IIMs. The MYOACT patient audit was set up with

the aim of monitoring the safety of these drugs in the myositis population and confirming which patients are likely to benefit. As more drugs become available the registry will help us better select right drug for the right patient. However, despite the audit being a requirement for NHS funding for these drugs, the audit has not been widely used by clinicians. A survey and focus group of myositis experts established that many clinicians found the MYOACT website too complicated and there was too much data to be completed in our busy clinical environments as the main reasons for underuse. The aim of my research is to re-engage clinicians with the MYOACT audit by making it more user friendly and designing a smart phone application to input data quickly into the register ultimately improving data quantity and quality. This would make it easier to monitor the safety and clinical use of these important treatments in myositis ensuring their appropriate use in patients.

Project 4

Dr Sokratis Varakliotis (Great Ormond Street Hospital – GOSH): MyGRATE - Supporting the migration of JDCBS to a Trusted Research Environment with dataset Quality Control

The Juvenile Dermatomyositis Cohort Biomarker Study and Repository (JDCBS) is the largest cohort study with linked patient biological samples for JDM and related inflammatory myositis conditions that begin in childhood. Since 2000, 16 UK centres have been contributing data and samples, supporting multiple national and international studies on genes, immune cells, and muscle in childhood myositis. The study has recently undergone two vital changes:

a. migrated to using the internationally agreed set of data collected, called the JDM Consensus Dataset, designed for clinical use, to improve collaborative research and allow easier sharing of data between

different researchers, and

b. migrated its data collection away from a standalone system to a secure research environment, called the GOSH Digital Research Environment or DRE, which will be maintained long into the future.

This proposal focuses on the crucial process of data migration from the old standalone database to the DRE, while providing continuous operation of the study, to make sure this happens smoothly. The aim is to apply quality control, e.g., data cleaning, checking and recovery methods, using specialised software techniques. This will ensure more accurate migration and will maintain 20 years of high-quality data continuity between the historic and the modernised version of the dataset, to the benefit of patients through all the current and future research projects which use this unique dataset.

The following are two articles printed in newspapers recently:

An interesting letter written by Andy White of Sheffield to a national newspaper to explain the question, “Do muscle fibres increase or become stronger after exercise?”

He writes, “The number of muscle fibres does not increase, but prolonged exercise can cause components within them to increase via muscular hypertrophy. This results in an increase in strength. Skeletal muscles are composed of long tubular cells known as myocytes – or muscle fibres. These cells contain layered chains of proteins called myofibrils suspended in sarcoplasmic fluid. This fluid contains adenosine triphosphate (ATP), glycogen, creatine phosphate and water, chemicals

that provide energy to working muscles. It is the number and density of myofibrils within the cell that cause an increase in muscular strength. Research shows a baby is born with the full complement of muscle fibres. Lifting heavy weights causes trauma and micro-tears to the myofibrils. Your body treats this as an injury, so it overcompensates and, in an attempt to recover, increases the volume and density of then ‘injured’ chains. Exercise can result in an increase in muscle size, strength and power. When the volume of sarcoplasmic fluid in your muscle cells increases, this increases muscle volume. It can improve the aesthetic of the muscle, but not improve the strength or performance.”

Good Health Page

It was very interesting to read in a good health page of a national newspaper that the doctor advising mentioned the issues of Raynaud’s and suffering from cold. He mentioned that the illness can lead to dramatic and very different episodes in reaction to the cold. He mentioned people with certain autoimmune diseases – rheumatoid arthritis, scleroderma and DERMATOMYOSITIS are more likely to develop Raynaud’s, but it can affect anyone. At last dermatomyositis is appearing in the popular press!

Invitation



The charity has been offered a free stand at the 103rd Annual Meeting of the British Association of Dermatologists (BAD). It is organised by the British Association of Dermatologists (BAD) and will be held from June 27 - 29, 2023 at the ACC (Arena and Convention Centre) in Liverpool.

It is the first time for the charity to attend and it will be interesting to hear of latest developments in treating and understanding skin conditions particularly in dermatomyositis as well as scleroderma, psoriasis and eczema. These conditions often have an overlap with myositis. It will also be useful to let the delegates know what we do as a charity through our stand.

Fundraising & Events

For the first time in our history I am reporting on two London marathons. The reason for this is because they have been held six months apart. However, the support for them, as usual, has been fantastic, not only by our runners but their families, friends and you, our membership.

London Marathon October 2022



This event is always a worrying time because the coordination of the organisation is centred on one day and the weather is the determining factor that controls the outcome.

Irene and I loaded the car on the Saturday evening aware that there could be rain in the morning. We needed to load the gazebo, picnic table, chairs and charity banners along with trolley, bungy straps, wire, tape, hammer knowing that as always, we will forget something that is much needed. First thing on Sunday morning, at 6am, we loaded the food, drinks, etc, that would be needed for a team of eleven runners and their supporting families. Wet weather clothing had to be taken as well, just in case.

After joining the M3 motor way in light rain the sky blackened and within a few minutes the deluge began. Certainly not the best driving conditions with spray affecting visibility. We remained very quiet, realising it could be a long miserable day ahead if the weather did not improve. However, as we neared London there was a hint of blue sky.

This lifted our mood and as we drove into London the rain stopped and perhaps all would be well.

It has been some years since we have needed to take all our bumb because Covid put a stop to almost everything as I expect you can recall. We headed for a car park where we have always parked up near the Admiralty Arch. We were relieved as it was just around the corner and underground beneath a huge office block and other city facilities. However, our mood certainly changed when we realised that we had just arrived at a building site and everything was demolished, and the car park no longer existed. As you can imagine what do we do now! Panic did not set in for Irene as she is always optimistic and already processing our next move. For me, if there had been a can in the road, I would really have given it a good kick most possibly bruising my foot in the process turning the air blue in exasperation.

We found some parking in Leicester Square but because of the road closures due to the marathon took

some negotiating to find it. Eventually, we were parked up again beneath buildings but much farther away from St James's Park. This would not normally have been a problem but with advancing years and a few old injury problems for both Irene and me, shifting all our kit was going to be an issue. Thankfully, our daughter Laura met us at the car park and the three of us loaded up all the equipment determined to convey it in one hit in the knowledge that the food and drink would be gone making it a lighter load for the return journey.

Eventually we got to the site to pitch the gazebo and the sun was now shining so the doom and gloom had been lifted and we could get on and enjoy this super occasion. We could now trace the progress on an app on our phones of the runners and it was great that many took the trouble to find us and for us to be able to thank them for the effort they had made. Even those that could not make a visit to our pitch were in touch and they all had a brilliant and memorable run. At the end of the run the area is crowded with runners and

spectators making it very difficult to move around so you can appreciate how difficult it is when you also have friends and family scattered around the London circuit to have time to find us. There is no doubt the London Marathon is the event to take part in for there is just nothing like it. The atmosphere, kindness and bonhomie shared by everyone during the day is quite remarkable.



We also did a head shave on runner James Collins. During lockdown, he grew a "man bun" and his boss was prepared to pay £200 to have it removed and that was doubled to £400! We placed James on a chair in front of our gazebo and with the help of his family and friends hacked away at his hair. This was being filmed on face time so that his mum who has myositis could witness the event! James said his mum has not been well and this would make her laugh. Well, the park was packed and was enjoyed and filmed by many people. James was anaesthetized by champagne so perhaps I expect he did not feel the chill around the back of his neck until next day.

The afternoon passed by so quickly with runners and families coming and

going. At the time of writing this item, Team Muscle has raised £14,000 and still rising. What a fantastic effort and brilliant day. Well, with all the chat still ringing in my ears and now everyone gone and day light fading it was time for the three of us to pack up and attempt to get a mini marathon of getting the loaded trolley back to Leicester Square. Buoyed on by such a memorable and delightful day it was a case of mission accomplished parting company with Laura we then left for home arriving at 9.30 in the evening ready for bed!

– Les Oakley



London Marathon April 2023



Well, here we go again: the car loaded up with all the charity gear we needed for the day plus making room for my son, David, and grandson, Noah, who had kindly made the time to help Irene and I to shift the gear to St James Park. We were well aware of the weather forecast and managed to get the gazebo erected in the park before the rain that was on and off during the day.

Team Muscle consisted of six runners: Tommy Tagg, Karen Crooks, Rory Murphy, Ricky Williams, Sam Blackholly and Molly Harington. They all made it round the course with no apparent injuries (I bet there were a few aches and pains next day).

The times were:
Rory finished in 2hours 54 minutes



Sam finished in 3hours 40 minutes
Ricky finished in 5hours 20 minutes
Molly finished in 5hours 37 minutes
Karen finished in 5 hours 37 minutes
Tommy finished in 6 hours 51 minutes

Rory has set a charity record for the fastest run. Unbelievable, particularly as it was his first marathon. The following article was taken from Rory's fundraising page.

Rory Murphy explains why he is running. "I'm running for Myositis to increase awareness of the condition and improve the research around treatment. This is so important to me, as being mobile and active is such a key part of my life. I'm a huge believer that physical activity improves your mood, makes you



feel more positive and engages you with the community. For me, barely a day goes by where I don't exercise - whether it be running, gym, tennis, or football - but when I don't workout I feel deflated and agitated. As a result, I can't imagine not being able to use my muscles as much as I'd like on a daily basis. I think this marathon presents an incredible opportunity to use my fortunate bill of health to raise money for research around Myositis and improve the lives of those currently living with it. Can't wait to see you at the finish line."

The team raised a magnificent sum through their sponsorship of £8017 with some gift aid to be added. If any member wishes to donate to the efforts of the marathon "Team Muscle" we have set up a "JustGiving" page where donations can be made.

<https://www.justgiving.com/fundraising/Irene-Oakley1>

Three of our runners and their families and friends found us in the park and it was great to meet them and to thank them for all the effort they have made to help us. These moments of friendship make all the work worthwhile. I just wish I could bottle it and use it as a remedy for



all our ails. It is the best tonic in the world! It was approaching seven o'clock and the sky was looking very dark and angry. Communications via mobile phones was poor and we reckoned as it was getting late the chance of a runner turning up now was remote. At the end of the day the crowds had cleared and the gazebo was only about three hundred yards from Horse Guards Parade. The sky

was getting darker and the decision was made to pack up and go. Dave did all the hard work getting the trolley back to the underground car park which is an all up-hill slog. As we left the car park, the skies opened up. April showers it certainly wasn't. The roads flooded and it was a tricky ride through a busy central London and eventually home by 11pm!

- Les Oakley



Secretarial Law Limited

Company secretary Alison Leggett, at the request of the Trustees of the Richard Kirkman Trust, enclosed a cheque for £2000 to help in our work. Many of you may recall the Trust has been very supportive of Myositis UK and as a charity we are also grateful for the kindness and concern shown to us by Secretarial Law.

Ahmad Tea

Rahim Afshar of the company kindly presented Myositis UK with a cheque for £500. This company has followed the charities progress and have been supportive for many years and are pleased with the progress and developments achieved by the charity.

Craft Evening

Mia Duddridge of Thrupp, Stroud, sent in a donation for £313 raised at a craft evening by her daughter, Harriet Beer.

The Larbey Family

The charity over the years has been fortunate to have people who have sadly lost loved ones turn their loss into a positive force by remembering them through raising money for research in the hope that others will not have to endure the sadness and misery that they have lived through.

One such family is the Larbey family who have raised funds in memory of their father, Charles, on Just Giving and through the motor racing skills of his son, Mathew Larby, on track days.

Mathew was determined to gain publicity and awareness for myositis and in particular Inclusion Body Myositis from his racing activities. To my knowledge this would be the first time that such a high-profile event or occasion has ever been given to promote IBM. This was such a kind offer for the charity and it was a pleasure to see the charity logo on his racing car and a wonderful development for publicity of the illness.

Mathew added a QR code to our logo on his Caterham Seven car, so that

people could scan with their phones in the paddock and be taken to our website. He also drew attention to the logo via his social media channels. He has been racing for nearly ten years.

Mathew writes, "I raced at Silverstone for last round of the 2022 Championship season. Three points separate me and two other fellow racers for the overall Championship, it has been an epic season. My Dad was able to watch most rounds as they are broadcast on YouTube but it will be an emotional final day without him. I'll carry his name on my car one more time, as I did at the start of the season.

We had our last races that same weekend - it was an emotional couple of days. Such is the nature of our close racing, I finished fourth in the race, less than half a second behind the leader which was only good enough for third overall in the championship. Only a few championship points separate the three of us and at one point with less than three laps to go, our

positions meant a three way-tie was in effect. I finished second place in the championship narrowly missed out on first place by 0.08 and was overtaken on the second to last corner!

The Sunday invitational end of season Trophy race went a little better and managed to get 3rd, so at least I take champagne on my boots into the winter testing months. Lots of people were using the phones with the QR code so that was nice to see."

The Larbey family raised £655 on Just Giving and this was their accompanying story. "Thank you for visiting our page for Charlie. Charlie was an amazing and much-loved husband, dad, grandad and friend. He is very much missed from all our lives and those who knew him. He added so much to all our lives.

As you may know, in his last few years of life, he put up an immense fight against a horrible wasting disease called Inclusion Body Myositis (IBM). IBM still remains a widely unknown disease and as a result does not receive the research and awareness



that is needed to further understand and improve the lives of those that have it and their families around them. Myositis UK (<https://www.myositis.org.uk/about-us/>) is a small national charity providing information to those affected by myositis and funding research to improve diagnosis and treatment.

We are hugely grateful for any donations that you would like to make in his memory, no matter how small. We would prefer this to any sending of flowers.

Thanks again, the family of Charles 'Charlie' Larbey."



Christmas Cards

Although proving popular again, we have only managed to break even this year. I have no doubt that the cost of postage plus postal strikes did not help but we will endeavour to maintain this traditional feature of the charity. Thank you to everyone for buying cards and for the donations made to the charity on the Christmas card order form.

Donations

The charity would like to offer our greatest thanks and appreciation to the many people who have donated to the charity. Also, to those who have sadly lost loved ones and donated in their memory and of course to those

that make a regular donation by a standing order to help our cause. It is so easy to skip these benefactors who have collectively made the work the charity is promoting possible today.



Tempest Dance Studio

Mandy of the Tempest Dance Studio Durham and Washington writes, "We raised £415 from a raffle at our Student Pole and Aerial Showcase. We raised it because my son Tyler Mills was diagnosed with Dermatomyositis by Professor Chinoy and we want to help support research and speed up diagnosis. I attach a photograph of me with two of our performers."

Netley Abbey Masonic Lodge, Southampton – Christmas Dinner

Irene and I attended the lunch time dinner accompanied by my daughter and charity trustee, Paula, along with her husband, Andy, and our grandson, Lawrence. It was a lovely occasion with a packed gathering and many dressed in festive attire to enjoy a traditional Christmas dinner with all the trimmings! A raffle was held and a visit from Father Christmas with a sack full of Christmas presents for the children followed by a cacophony of sound being created by everyone present through some well sung Christmas carols enhanced by Christmas cheer! However, there was another Christmas surprise to come when in the closing proceedings the Lodge president, Stuart Wigginton, presented me on behalf of the Lodge members and guests a cheque for £500 for the charity. I was absolutely astounded and amazed because there had been no hint of this most generous presentation.



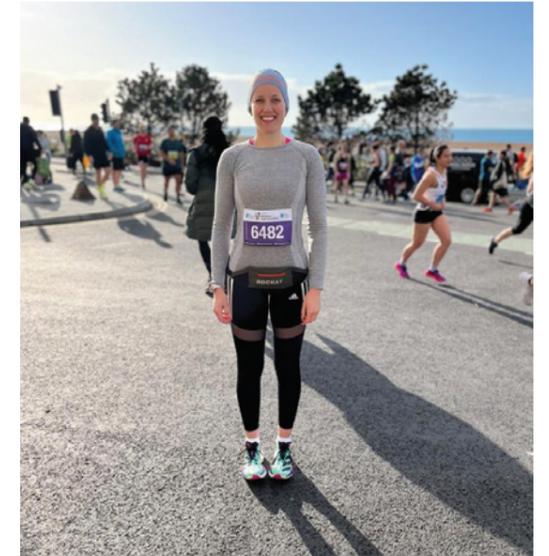
Jenny Rowlinson – Hastings Half Marathon

"Thanks for taking the time to visit my JustGiving page.

My dad has Body Inclusion Myositis and I'd give anything for there to be a cure for this horrible disease. I'm hoping together we can raise a little bit of money for this wonderful charity, so they can continue with their scientific discoveries and hopefully one day we will have a cure.

Thank you so much for visiting this page."

Jenny raised £1,595



Adam Sheppard's 40 before 40 Walk for Myositis

"Thanks for clicking on my page. I thought it was time for a new challenge and so I'm going to walk 40 miles from Milton Keynes to Oxford.

Why 40 miles you ask? Well, I figured it'd be good to walk 40 miles before I turn 39 and 13 months.

Who am I doing this for? I'm again looking to raise some money for Myositis UK. A charity that's very close to my heart and probably one you've never heard of. They help tackle rare conditions, specifically rare muscle



and autoimmune diseases which can be life threatening. And this amazing charity does great and important work supporting people diagnosed with this rare disease and funding research to improve diagnosis and treatment.

I believe that this is a very worthy cause and if my stumbling through 40 miles can help raise a little money for them - then awesome."

Adam has raised £160 to date

Janet Downes' Endure24

I am raising money for juvenile dermatomyositis for Myositis UK because my son was diagnosed in 2009.

Event: Endure24, 24-25 June 2023

"Thanks for taking the time to visit my JustGiving page.

I am doing Endure24 solo in 2023 to raise money for juvenile dermatomyositis. My son was diagnosed with it in 2009 at LGI (Leeds General Infirmary) 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. He had intravenous drips of steroid and plasma and then steroid tablets for six months along with methotrexate injections for two and a half years

after which he went into remission for just over a year. Then it flared back up again at end of 2012 and he had to start all the medication again. 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.

Just an update to let you know how my training for Endure24 solo is going. Unfortunately, since the end of March, not too good due to being diagnosed with osteoarthritis in my left knee. However, today I completed a nine-mile run with partner Graham and Freddie our dog, which I don't think I could have done if I hadn't started doing lots of yoga. My intention is to do 10 5-mile laps in 24hours, however if



I cannot complete that I will put £5 into my charity for every lap I cannot complete – feeling happy."

Janet has raised £120 to date

Lacie Gibbons' Peak District Trek

"My name is Lacie and as many of you are aware I was diagnosed in January 2020 with JO1+ Polymyositis, a rare muscle disease called the inflammatory myopathies that involve chronic long-standing muscle inflammation and pain. Before my diagnosis I was a fit and healthy 26-year-old who was training to cycle from London to Paris, spent many days riding horses and loved being in the gym. I spent many months in hospital after my diagnosis, learning how to do daily tasks again. I am extremely fortunate to have an incredible rheumatology team behind me.

On 5th August 2023 I will be taking on the



22mile hike around the peak district to raise money for Myositis UK, a charity that is so close to my heart. This should take around 10 hours. Any donation no matter how small would be greatly appreciated."

Lacie has raised £345 to date

Craig and Karen Hike Margate to Land's End

Every year we are fortunate to have people who are prepared to go that extra mile to help the charity in its search for a cure. This year is no exception and Craig and Karen Mosley are the latest couple fired up to help in any way they can. However, this effort on their part is special because Craig, unfortunately, is living and coping with Multiple Sclerosis which is another serious neuromuscular disease. This must be a first for any charity where someone with a life threatening illness is prepared to put this issue into the background to help an equally harrowing disease in the hope to improve the outcome for people when diagnosed with myositis.

I cannot contemplate how Craig and Karen are driven but, for my own part, I have had very close family members with MS, renal failure and cancer over the years as well, of course, myositis. It was when this disease was



diagnosed in a member of my family thirty-five years ago that I realised there was no hope, no direction and no future making this a driving force for me to get these diseases addressed. And now thankfully they are. – Les Oakley

Craig writes: "So, on June 1st, 2023, me and my wife Karen, will be taking three months out of our day-to-day life to undertake a "Hike" for charity along the south coast (Margate to Land's End) following the coastline. The hike is about 650 miles and we estimate that it will take us around three months. We hope with your help to raise five thousand pounds.



A few years ago, I was diagnosed with Multiple Sclerosis, so I'm not expecting this to be an easy task for me. I suppose this is my way of saying, "F**K you M.S." I have decided to hike for Myositis UK in memory of my daughter, Elise Amy Mosley, who passed away aged nineteen due to the unpredictable nature of myositis. Please find the link below. It would be great if some of you wish to meet up with us along our journey to offer support."

<https://www.justgiving.com/Craig-Mosley>

Craig has raised £230 to date

Rachel Curley – Fundraiser for Myositis UK

"Thanks for taking the time to visit our JustGiving page. After 9.5 years, Rachel Curley will be leaving the Careers and Employability Service at the University of Nottingham in October. Rather than acknowledge Rachel's contribution to the Service by way of a leaving present, Rachel has requested that colleagues consider donating to her chosen charity, Myositis UK."

They raised £270



Teddy-Bo's Escapade

During the Global conference for Myositis in Prague I had the good fortune to meet up with a German patient, Roland Mischke, who has Inclusion Body Myositis. He was representing the German patient group. I was talking to him about Teddy-Bo and the benefits that he brings when promoting the charity. He then told me he needed the bear for a special purpose without giving any details or why.

True to his words some weeks later he has got back to me and Teddy-Bo became a glider pilot in his 4.3m wingspan model glider. The bear was towed into the air by a motor driven modal aeroplane. He wished that we should include Teddy-Bo's escapade in this magazine with the words, "Blue bear in the sky looking for myositis patients." I expect we have lost something in the translation but this does not matter because we



have a common universal cause to beat this disease and publicise it anyway we can.

There is no doubt the bear and his escapades that you create are such fun for all ages. If you would like a bear to take on holiday, photographing him during your travels or in any other situation, please get in touch with the office. Cost £5 plus £3.50 p&p.



Holiday Insurance

We have had a number of enquiries about travel insurance, particularly companies that cover medical conditions. 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/>

Offered Free – Lift Seat Toilet Raiser



Member Bill Love is offering this toilet raiser free to a good home where hopefully it can make a big difference to somebody's life. Full details of the seat can be found online at: <https://liftseat.co.uk/home-lift-seat-powered-toilet-lift/> It will need to be collected from Falmer, Brighton. For contact details, please email the office: msg@myositis.org.uk

Other Ways To Raise Donations

amazon smile
You shop. Amazon gives.

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

easyfundraising
feel good shopping

Thank you to everyone for raising donations for Myositis UK with easyfundraising. If you haven't signed up yet, it's easy and completely free. Some 4,400 shops and sites will donate to us when you use easyfundraising to do your everyday online shopping – at no extra cost to you! Every donation you raise makes a difference to us so please sign up and share today.
<https://www.easyfundraising.org.uk/causes/myositissupportgroup/>

PayPal
Giving Fund

To date we have received £1,145.59 since the beginning of 2023 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.

Published Research Update

Since the last magazine there have been many studies published in the medical literature. The titles from a selection is reprinted below and full details including full papers (for some) can be found on pubmed.com by typing in the PMID number. These include international collaborations including International Myositis Assessment

and Clinical Studies (IMACS) and Myositis Genetics Consortium (MGC). Interest in COVID-19 and the importance in autoimmune diseases like myositis has led to many papers by the COVAD study group. Furthermore, the surveys by the Global Rheumatology Alliance which you may have completed has started to publish findings.

Performance of the 2016 ACR-EULAR myositis response criteria in adult dermatomyositis/polymyositis therapeutic trials and consensus profiles

Saygin D and others; International Myositis Assessment and Clinical Studies Group (IMACS)
Published in *Rheumatology (Oxford)* March 2023. PMID: 36929923.

Investigating characteristics of idiopathic inflammatory myopathy flares using daily symptom data collected via a smartphone app.

Oldroyd AGS, Krogh NS, Dixon WG, Chinoy H.
Published in *Rheumatology (Oxford)* November 2022. PMID: 35274670 Free to read article.

Identification of Novel Associations and Localization of Signals in Idiopathic Inflammatory Myopathies Using Genome-Wide Imputation.

Rothwell S, and others; Myositis Genetics Consortium.
Published in *Arthritis Rheumatol* December 2022. PMID: 36580032 Free to read article.

Evidence of nerve hypertrophy in patients with inclusion body myositis on lower limb MRI.

Elmansy M, and others.
Published in *Muscle Nerve* December 2022. PMID: 36151728.

Two emerging phenotypes of atypical inclusion body myositis: illustrative cases.

Salam S and others.
Published in *Clin Exp Rheumatol* March 2023. PMID: 36861744 Free to read article.

Current status of clinical outcome measures in inclusion body myositis: a systematised review.

Roy B and others; International Myositis Assessment and Clinical Studies (IMACS) Inclusion Body Myositis Scientific Interest Group.
Published in *Clin Exp Rheumatol* March 2023. PMID: 36762744 Free to read article.

Inclusion body myositis: from genetics to clinical trials.

Nagy S, Khan A, Machado PM, Houlden H.
Published in *J Neurol* March 2023. PMID: 36399165 Free to read article.

Ro52, Myositis, and Interstitial Lung Disease.

McHugh NJ.
Published in *J Rheumatol* February 2023. PMID: 36379570.

Zilucoplan in immune-mediated necrotising myopathy: a phase 2, randomised, double-blind, placebo-controlled, multicentre trial

Mammen AL and others.
Published in *Lancet Rheumatol* February 2023. PMID: 36923454.

Rituximab in myositis: where are we now? A survey of current usage.

Oliveira T, Yildirim R, Deakin C, Isenberg D.
Published in *Rheumatology (Oxford)* January 2023. PMID: 36622027.

Adverse events of treatment with rituximab in patients with myositis.

Gilaberte S, Rua J, Isenberg D.
Published in *Rheumatology (Oxford)* February 2023. PMID: 35809059.

Rituximab-induced hypogammaglobulinaemia in patients affected by idiopathic inflammatory myopathies: a multicentre study

Conticini E and others.
Published in *Clin Exp Rheumatol* March 2023. PMID: 36861742 Free to read article.

Anti-transcription intermediary factor 1-gamma IgG2 isotype is associated with cancer in adult dermatomyositis: an ENMC multinational study.

Cordel N and others.
Published in *Rheumatology (Oxford)* April 2023. PMID: 36250907.

Low copy numbers of complement C4 and C4A deficiency are risk factors for myositis, its subgroups and autoantibodies.

Zhou D and others; MYOGEN Investigators.
Published in *Ann Rheum Dis* February 2023. PMID: 36171069 Free to read article.

Long-term survival of patients with idiopathic inflammatory myopathies: anatomy of a single-centre cohort.

Guimarães F, Yildirim R, Isenberg DA.
Published in *Clin Exp Rheumatol* March 2023. PMID: 36861745 Free to read article.

Juvenile Dermatomyositis: what comes next? Long-term outcomes in childhood myositis from a patient perspective.

Boros C and others; JDM Cohort and Biomarker Study (JDCBS).
Published in *Pediatr Rheumatol Online* November 2022. PMID: 36384526 Free to read article.

Experience with the use of mycophenolate mofetil in juvenile idiopathic inflammatory myopathies.

Varnier GC and others.
Published in *Rheumatology (Oxford)* February 2023. PMID: 35929784.

Role of CD14+ monocyte-derived oxidised mitochondrial DNA in the inflammatory interferon type 1 signature in juvenile dermatomyositis.

Wilkinson MGL and others.
Published in *Ann Rheum Dis* May 2023. PMID: 36564154 Free to read article.

Pain in individuals with idiopathic inflammatory myopathies, other systemic autoimmune rheumatic diseases, and without rheumatic diseases: A report from the COVAD study

Shinjo SK and others; COVAD Study Group
Published in *Int J Rheum Dis* April 2023. PMID: 36872076 Free to read article.

COVID-19 Vaccination in Autoimmune Diseases (COVAD) study: Vaccine safety in idiopathic inflammatory myopathies.

Gil-Vila A and others; COVAD Study Group.

Published in *Muscle Nerve* October 2022. PMID: 35869701 Free to read article.

COVID-19 vaccination-related adverse events among autoimmune disease patients: results from the COVAD study.

Sen P and others; COVAD Study Group.

Published in *Rheumatology (Oxford)* December 2022. PMID: 35713499 Free to read article.

Factors associated with the severity of COVID-19 outcomes in people with neuromuscular diseases: Data from the International Neuromuscular COVID-19 Registry.

Pizzamiglio C and others; Neuromuscular Diseases and COVID-19 Study Group.

Published in *Eur J Neurol* February 2023. PMID: 36303290 Free to read article.

Factors associated with severe COVID-19 in people with idiopathic inflammatory myopathy: results from the COVID-19 Global Rheumatology Alliance physician-reported registry.

Yeoh SA and others; COVID-19 Global Rheumatology Alliance.

Published in *RMD Open* September 2022. PMID: 36100295 Free to read article.

Flares in IIMs and the timeline following COVID-19 vaccination: a combined analysis of the COVAD-1 and 2 surveys.

Naveen R and others.

Published in *Rheumatology (Oxford)* April 2023. PMID: 37084267.

Higher risk of short term COVID-19 vaccine adverse events in myositis patients with autoimmune comorbidities: results from the COVAD study.

Dey M and others; COVAD Study Group.

Published in *Rheumatology (Oxford)* May 2023. PMID: 36282492 Free to read article.

COVID-19 severity and vaccine breakthrough infections in idiopathic inflammatory myopathies, other systemic autoimmune and inflammatory diseases, and healthy controls: a multicenter cross-sectional study from the COVID-19 Vaccination in Autoimmune Diseases (COVAD) survey.

Hoff LS and others; COVAD Study Group.

Published in *Rheumatol Int* January 2023. PMID: 36271958 Free to read article.

Impaired physical function in patients with idiopathic inflammatory myopathies: results from the multicentre COVAD patient-reported e-survey.

Yoshida A and others; COVAD Study Group.

Published in *Rheumatology (Oxford)* March 2023. PMID: 35920795 Free to read article.

Flares after COVID-19 infection in patients with idiopathic inflammatory myopathies: results from the COVAD study

Saadia Ali S and others; COVAD study group.

Published in *Rheumatology (Oxford)* April 2023. PMID: 37004201.

Vaccine hesitancy decreases, long term concerns remain in myositis, rheumatic disease patients: A comparative analysis of the COVAD surveys

Sen P and others; COVAD study group.

Published in *Rheumatology (Oxford)* February 2023. PMID: 36734536. Free to read article.

Late News

We have received the following from Professor Graham

“Hello Myositis UK team,

I’m a clinical psychologist, with much of my research work dedicated to psychological interventions for people living with muscle diseases, including myositis.

I was looking at your website, which is great. Lots of useful information. I wanted to let you know that we have completed a randomised controlled trial of a psychological therapy for quality of life and mood that included a sample of people with IBM and published the paper on this recently. You can access the paper here:

<https://www.cambridge.org/core/services/aop-cambridge-core/content/view/E856E14AE5C9AC581D2C8477F5DAD1CB/S0033291722000083a.pdf/div-class-title-a-randomised-controlled-trial-of-acceptance-and-commitment-therapy-for-improving-quality-of-life-in-people-with-muscle-diseases-div.pdf>

The results were really encouraging, with a good effect on QoL and mood. Serves as evidence that psychological therapies can be helpful in helping people to live well even though muscle diseases are often challenging to live with.

Hope you are all well!”

*Christopher Graham PhD DClInPsychol
Professor of Clinical Psychology ,Glasgow*

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.

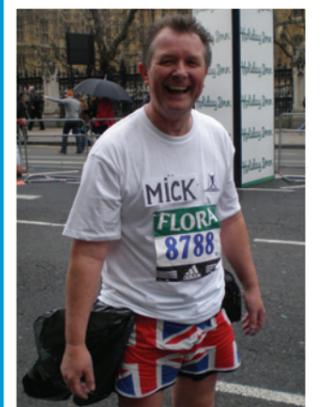
Memory Lane, Fundraising 2008



*Rachel and Kenton Sumner –
Bracknell Half Marathon*



Ocean Brass



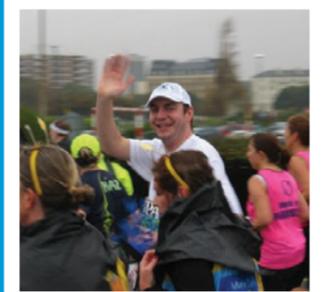
*Mike Clarke, former trustee,
London Marathon*



*James Borrett,
London Marathon*



In memory of Bobby



*Lee Hooper,
Great South Run*

Postscript

I trust you have found this magazine an enjoyable and informative read. Please can I have your news and views about anything related to myositis for our next publication. I am sure, if possible, we can rely on your attendance to the annual conference giving support to the medical profession who will be speaking and presenting. Myositis UK is a small charity in numbers and yet we are fortunate to have leading scientists and doctors prepared to give up their time freely to talk to us about our illness and listen to our hopes and fears and who will also respond in such a compassionate and understanding way. Many patient groups and medical charities would love to have the connection we have. We are very fortunate and I look forward to seeing you in Leamington Spa so that we can repeat the success of last year's conference.

– Les Oakley MBE, Chairman of Myositis UK



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