MYOSITIS UK

Winter 2023

# Myositis News


## FUNDRAISING • RESEARCH
## AGM & CONFERENCE REPORT

Dear Member,

This magazine has taken some weeks to compile because there has been much activity around the issues of myositis and the medical developments and activity taking place, plus work and time by supporters trying to help us in many ways.
I trust this issue will enlighten you on all this recent activity, particularly if you are having to live with myositis, and it will give you some comfort in knowing how people are aware and do care to see improvement in your lives.

Les Oakley MBE
Chairman





# AGM & Conference Report

The annual general meeting and conference at the Woodland Grange, Leamington Spa, held on Sunday 23 July, was a highly successful occasion. This was a new, untried venue for the charity, so there is always a little reticence when the booking was made. However, it was an established conference centre and I must write that the staff were geared up and could not have been more accommodating. The Saturday meet and greet in the afternoon was well received by the members staying overnight. There were several new faces and this was an enjoyable time to have a general chat and to get to know each other. For me it was amusingly a bit like speed dating. If there were any issues with the accommodation it was due to the lack of air conditioning in the bedrooms. My room had some dodgy plumbing that could have been an issue, but a young lady came to the room with some tools informing me the maintenance man was off duty, but she was there to try to fix it. She was a deft hand with the plyers enough to get the problem temporarily sorted out. Amazingly, she was helping in the restaurant next day. Indeed, all the staff appeared to be able to multitask and were always pleasant and polite. Such a rare treat these days.


The annual general meeting went well considering we had two sets of accounts to be presented. This was the result of the pandemic causing all sorts of havoc some months ago. However, treasurer, Jo Goode, with the help of auditor Bridget Kalloushi made what could have been an onerous task an opportunity of explaining and presenting a charity being well managed and in compliance with the guidance of the charity commission. The delegates voted and the accounts were adopted. The trustees were retuned on bloc.

The conference was held in a large airy room with views across the grounds of the complex that were pleasing on the eye. The programme was busy with Dr James Lilleker from Manchester university talking about the evolving diagnostic criteria for IBM. This was followed by Professor Neil McHugh of the university of Bath presenting the role of autoantibodies in diagnosis and management of myositis and anti-synthetase without myositis. Dr Xia Lyu from China who presently is based in Manchester discussed anti-MDA5 positive dermatomyositis – stories from the Orient. Professor Lucy Wedderburn from the Institute for Child Health in London spoke about new and exciting updates on Juvenile Dermatomyositis. Dr Latika Gupta from India who is based at the Royal Wolverhampton hospitals NHS Trust and the University of Manchester talked about the pandemic, myositis and what is known so far.

The two grants provided by the charity this year for research into IBM were presented, first by Professor Pedro Machedo from Queens Square, London, talking about disease pathways for IBM and then Dr Stefen Brady from Oxford university discussing optimism in IBM.

After a hearty lunch it was back at the coal face with Professor Hector Chinoy of Manchester university

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speaking of myositis trials update.

The final session was a presentation by Jennifer Hall and Joe Conyers who are employed by a company called Adelphi. The bases of their talk were understanding the patient and caregiver experience. This created much interest in the room and the members were asked to participate by writing down their experiences, etc. This information is collected by Adelphi and processed to offer advice and guidance to pharmaceutical companies and medical institutions.

The closing session of the conference is always keenly anticipated with a medical panel sat together to answer questions from the members. As in previous years the panel answered every question as fairly as possible and those that were written questions and submitted by members were also answered with a similar honesty.

It takes months of organising to arrange for the speakers and it is usually in the last few weeks that the programme is put together. Busy schedules, particularly in the medical profession can change rapidly. However, I am grateful to everyone who participated in the programme for making it an interesting and helpful day. These people have very busy lives, but they still take time out to make the conference a worthwhile event at little cost to the charity. It had an international presence this year demonstrating because of the rareness of myositis it must be part of a worldwide collaboration when treating, managing and understanding this disease.

I am grateful to all the members who made the effort to attend, particularly those who had rail strikes to cope with. A conference needs people and I know there is much debate for hybrid meetings with an online presence for people who have a physical disability and unable to travel to be able to participate.

These options and costs are being constantly reviewed. However, we still have the problem of unpublished work and intellectual property rights that need to be protected from inadvertently being put on the worldwide web.

Irene has again pulled the rabbit out of the hat and magically brought together all the facets of not only the scientific programme, but the food, dietary needs and hotel accommodation needed during the weekend.

It is always a worry with so much happening in a short but intense space of time. Dear friends, Margaret and Bruce Cross for some years now have managed the registration desk and name tags, moving on to the charity information and merchandising desk once the conference has started. It sounds an easy task and you can bet something can go wrong and it normally does!

We were back into the one large room and we appear to have gone in a circle. This is how we started years ago, moved into break out rooms for disease type and because there are several myositis variations crossing the disease definitions and back again. We also had no children with JDM present although we had prepared for them to be there with their parents or guardians with a separate room if it was required. However, there were adults with JDM in attendance. The two things that have emerged from feed back forms amongst many comments was one member saying, “we do not know what the agenda is until the last minute and I questioned will it be important for me to attend and having done so, realising that the whole programme is relevant and helpful.” Another member said, “So I must sit through a talk that doesn’t really concern me, but it is only for ten or fifteen minutes, so it’s not a problem. Still quite interesting really.” There is also a feeling that although the key issues of Covid are behind us we still need to practice good health measures and be in a spacious and airy room because of the medication some members are still vulnerable.

At the closing of the conference there is an audible sigh of relief from Irene and me. It appears to us to have gone well and we are overly impressed with the advancements being made and I feel sure for those members attending for the first time this must have been very assuring. Developments in all the disease types are making satisfactory progress and no form of myositis is being left behind. However, there is still the issue of acute facial and scalp rash, skin itch and calcinosis in JDM and DM that are still of great concern, causing much misery. There is still much to be done, particularly if we had the money to invest in these issues but we can all be pleased of the progress that has been made.

# Research Update

Dr Meredyth Wilkinson has presented her work at this year’s Paediatric Rheumatology European Society (PReS) 2023 conference, and at the Young Investigator Meeting (YIM) in Rotterdam.

Her work was the first one to be highlighted as a top paper at PReS 2023.

The PReS society organize annual prestigious European meetings on Paediatric Rheumatology, with the aim of spreading knowledge regarding paediatric rheumatologic conditions worldwide.

This great achievement is a testament to Dr Meredyth’s work on the insight into the pathogenesis of Juvenile Dermatomyositis (JDM).

# Chairman's Reflections

The Charity has been running for thirty seven years and I would like to take this opportunity to take you back in time when I was a young man with a very sick child and why I have been driven to make research the heart of the charity function. I know as a group we have at times appeared, although this is not the case, to focus less on some issues, particularly on disability, mental health and welfare rights and the many other topics that impound on the lives of people suffering from neuromuscular disease. I have been rebuked in years gone by because I appear to be inactive or consider these not to be important. I am driven by the hope that it you can treat myositis, and dare I say cure it, then these other important issues may not be so relevant.

Nearly forty years ago myositis was a sentence for disability, pain and no hope. I have reached that time of life when I can now let it be known how I have witnessed the misery of myositis and the neglect of myositis because the disease is so rare.
My initial involvement was when my daughter was diagnosed with Juvenile Dermatomyositis in my local modern hospital by a very likeable and respected paediatrician. He was honest enough to tell me he had never treated it before but had taken the advice from notes sent via a fax machine from Professor Victor Dubowitz in London.

My daughter took a turn for the worse and she was desperately ill and to get her to the Hammersmith hospital in London for Professor Dubowitz to see if he could help and intervene in her decline. We did not have time for hospital transport, so in the car she went, no mobile phones, no sat nav to help us and just an old map to get us through the streets of London. My very young son being taken in by family.

On arrival at the children's department at the hospital we were faced with a Victorian building that was formerly a workhouse and thankfully that part has now been demolished. The shock of leaving a modern hospital to enter this dreadful place was enough to bring you to tears. However, we were soon to learn that the staff and medical teams were a revelation and just got on with their work in this grim building. The conditions were cramped. The main corridor was the width of a hospital trolley and one person to pass by. There were cubicles of wood and glass construction that were about six foot high with no privacy other then short curtains that could be pulled around a child's bed. In these small, square rooms there were three beds and a babies cot head to toe with just about room for a sink. My wife stayed in these conditions on and off for months. Parents had to sleep in the children's "games" room and over time, if you were fortunate, could progress from a plastic chair to a mattress on the floor to a much prized camp bed. There was no peace or quiet and if you did sleep it was from shear exhaustion. Children sadly died in those wards and staff and visitors tried extremely hard to collectively project a humane understanding of the misery going on in their presence. To add to this misery the hospital kitchen was condemned and permanently closed because it was infested with cockroaches. Food was brought in by outside caterers.

We got to know well other children with JDM and parents that were there. One was a young girl from Portugal whose mother received a small amount of funding from her country. She had to work as a hotel chambermaid to help fund her stay. The money ran out and they had to go back to their country. Regrettably, I do not know what happened to her. Another girl was unconscious on a life support system and was flown all the way from Australia who remarkably survived against all the odds. Another lad was from Ireland who had such severe contractures that made him wheelchair bound. My own daughter spent her childhood and early teens in a wheelchair too. These and many other children were in these conditions and schooling would have been a memory for them. However, within all this misery and heartache there were nurses and doctors doing their absolute best to help these children. One of the team was a young doctor called Christine Saunders. With Professor Dubowitz backing she wanted to form a group for JDM parents so that we could meet up and support each other. She wished to hold a meeting to explain what was going on in JDM and new medication that was becoming available that might help JDM. Irene and I took on the task along with Mike and Sue Clarke from Portsmouth to form the group. In fact, it was Mike who provided a microwave for the parents to use in the hospital.

We held our first meeting in the nurse's refectory and was well attended. Unfortunately, Christine was unwell and could not attend but a research scientist called Dr Jo Cambridge stepped in and chaired it. Tragically, Christine had been diagnosed with cancer and she passed away not many months later. It was now left to us parents and thankfully along with Jo to take on the excellent work that had been started.

Treatment, as I expect you know, was initially steroids, but there were new immunosuppressant drugs proving to be helpful. The future was looking brighter but these were experimental days and very unpredictable. My daughter had another severe relapse and the young male doctor in the clinic was upset and he cried more through frustration at trying to get the medication right. He was also not happy about the cockroaches on his surgery floor either! There were so many issues to be resolved.
We were determined to keep the contact group going and these were the days before the internet, so everything was written long-hand until we had a secondhand typewriter relying on the good old post and landline telephone. Connections were eventually made with adults with myositis who came under our wing because they were not well enough to take on the responsibility themselves. I became aware of how isolated they were in coping with their illness and even perhaps attending a hospital appointment would come away with no positive outcomes and little being done for them in medical research. The biggest shock for me was when I realised IBM was a down and out subject and was told it is exceedingly rare and there is nothing we can do about it anyway. It was this knowledge that made me angry to think, that was your lot, that was your destiny.

These are just a few of the reasons why I am still motivated about supporting medical research into myositis. It is a big challenge, but it is a moving picture and progress is being made in this country and around the world. I recall vividly the horror stories of years ago and they have made an impression on me and why I stay focussed on beating the misery of myositis and applauding the progress.

From this very brief resume or perhaps even a rant on my part I trust I may be excused from where perhaps I could have attempted to do more with other issues involving and affecting people with myositis. For me life can be a battle and through all these years I have had my sight set on the presently unobtainable but achievable goal a head. If I had been distracted by looking to my left or to my right I would have inevitably faltered, distracted perhaps by the misery of this illness or aware of the frustration of not having the skills sets to have made much of a difference to the inevitable outcomes.

However, having written these words there have been during these years people who have made remarkable contributions to the charity, helping in many and varied ways covering the gaps where I have not focussed on to enable the charity to be appreciated and respected in its role in representing and helping the cause of people living with myositis.

# Clinical Trials

This is a very exciting time with various clinical trials about to take place in the UK and we have been sent the following request:

“We are seeking your help to recruit people with myositis to a number of clinical trials that are running in various sites throughout the UK (including Salford, Kings College London, UCL, Bath, Liverpool). Broadly speaking, patients with dermatomyositis, anti-synthetase syndrome or immune-mediated necrotising myopathy can be recruited. Patients have to be >18 years old (can be juvenile onset), moderately weak, on a stable dose of steroids if taking (<20mg), on stable immunosuppression, >6 months after receiving rituximab, or >12 weeks after IVIg. If you have anyone in mind, or if you think you might be eligible, then please contact Myositis UK by email only please msg@myositis.org.uk with your contact details – they can then contact the closest centre.”

Merck is currently recruiting adults with Dermatomyositis (DM) and Polymyositis (PM) to a clinical trial. Participants must be aged 18 to 75.

For more information follow the link below: https://clinicaltrials.merckgroup.com/en/trial-details/?id=MS200569_0041

Are you satisfied with your current dermatomyositis treatment? If you are still experiencing symptoms of dermatomyositis with your current treatment, you may be interested in learning about a clinical study sponsored by Priovant Therapeutics.

The VALOR Study is evaluating an investigational medicine called brepocitinib to see if it may improve symptoms of dermatomyositis in adults 18 to 74 years old. To learn more visit www.ValorStudy.com.

*If you are interested, please email Irene at msg@myositis.org.uk with your contact details – she will then forward your details to the closest centre.*

## Zoom Meeting On Clinical Trials

On Wednesday 1st November at 1pm a Zoom meeting was held for Myositis UK members. Dr Thomas Khoo gave a 15-minute presentation on recent clinical trials in myositis. Dr Thomas Khoo is a Rheumatologist visiting from Adelaide, Australia, and presently working with Professor Hector Chinoy in Manchester.

A question-and-answer session followed with questions being answered by Dr Khoo and Professor Hector Chinoy, Professor Neil McHugh, Professor Lucy Wedderburn, Professor Pedro Machado, Dr Alex Oldroyd, Dr Patrick Gordon and Dr Desmond Chua. This was a very informative and interesting session. We recorded the meeting and hope to have it available online soon. The next Zoom meeting will be in the New Year.



# Inclusion Body Myositis Workshop – The Netherlands

**A workshop entitled: Inclusion Body Myositis : 10 years of progress - revision of the “ENMC 2013 diagnostic criteria for IBM “and trial readiness was held in Hoofddorp, The Netherlands on June 16-18, 2023.**

The workshop was a follow-up of the ENMC workshop held in 2011 on IBM (https://www.enmc.org/download/inclusion-body-myositis/), which Myositis UK co-sponsored.

The ENMC (European Neuromuscular Centre) is a foundation, funded by eight European Patient Organisations (full partners) and four associated partners. From this budget they can organise eight to ten ENMC workshops each year and are able to cover hotel and travel expenses of the participants travelling from the European partner countries. Participants from other countries are generally kindly requested to cover their own travel expenses.

The workshop on IBM was very important, resulting in a high number of participants (29 instead of normally 20 participants). There were 29 participants travelling from: Great Britain (3), USA, Germany, Netherlands, Sweden, Australia, France, Japan, Belgium, and Denmark. Helping to fund this meeting enabled the organisers to accommodate the high number of participants attending thus securing the participation of the leading experts from the IBM field.
Wilma Hinloopen, Operations Manager at the European Neuromuscular Centre (ENMC) writes, “We had a very good workshop. All patient representatives, clinicians and researchers were very engaged. The first part of the workshop addressed clinical and pathologic features of IBM. The second part focused on potential applications of new diagnostic tools and during the third part of the workshop clinical outcome measures were addressed. The scientific report will follow and will be published in the medical journal Neuromuscular Disorders.”

**Lay Report on ENMC Workshop 272**
**Inclusion Body Myositis: Ten years of progress – revision of the “ENMC 2013 diagnostic criteria for IBM” and trial readiness.**

Organisers: Chris Weihl (USA), Marianne de Visser (The Netherlands), Jens Schmidt (Germany)
Participants: Helene Alexandersson (Sweden), Lindsay Alfano (USA), Yves Allenbach (France), Umesh Badrising (The Netherlands), Olivier Benveniste (France), Salman Bhai (USA), Jan De Bleecker (Belgium), Marie Christine Breeveld (patient representative), Hector Chinoy (UK), Louise Diederichsen (Denmark), Mazen Dimachkie (USA), Steven Greenberg (USA), Mridul Johari (Australia), James Lilleker (UK), Ulrika Lindgren (Sweden), Tom Lloyd (USA), Pedro Machado (UK), Tahseen Mozaffar (USA), Roland Mischke (patient representative), Elie Nadaff (USA), Merrilee Needham (Australia), Ichizo Nishino (Japan), Anders Oldfors (Sweden), Christiaan Saris (The Netherlands), Werner Stenzel (Germany), Giorgio Tasca (UK).

The 272nd ENMC workshop on Inclusion Body Myositis (IBM): Ten years of progress – revision of the ‘ENMC 2013 diagnostic criteria for IBM’ and trial readiness was held on June 16-18, 2023.
Twentynine participants from all over the world, including two patient representatives were brought together to revisit diagnostic criteria. It has been more than ten years since the 2011 ENMC workshop on IBM. Lessons from current natural history and previous treatment trials were shared to

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develop consensus guidelines on trial design and outcome measures. Two recently conducted trials in IBM with the drugs Bimagrumab and Arimocolomol failed to meet trial endpoints and this gave rise to discussions on appropriate outcome measures. Identification of promising biomarkers for IBM diagnosis and monitoring of disease progression were the goals of the workshop. It was recommended that currently, in the absence of a disease modifying therapy, management of people with IBM should follow existing standards of care.

At the beginning of the workshop, the two patient representatives set the scene and shared their diagnostic journey with the other participants. They also expressed their wishes about clinical and research priorities: to increase awareness of the disease amongst the general practitioner and other medical specialists who are faced with people with myositis, focus research on unmet patient's needs and note the urgent need for the most suitable treatment option of swallowing impairment (dysphagia), which is very bothersome and socially limiting.

The first part of the workshop extensively addressed clinical and pathologic features, both common and uncommon, which was very helpful in drawing up diagnostic criteria. Establishing a diagnosis of IBM as early as possible is paramount and the need for a simple and broad-ranging diagnostic guideline was noted. Such a guideline will not only rule out diseases which may present as mimics of IBM, but also allow for enrollment in future trials. Patients may present with uncommon features, but eventually the typical picture may evolve. Given the serious impact of an IBM diagnosis, discussion regarding muscle biopsy led to the recommendation that a biopsy should be performed with a minimum set of studies on the biopsy.

Epidemiological studies showed great variability of the frequency of IBM in different parts of the world. Recent studies showed that it is important to recognise that there may be sex and ethnic related differences in clinical manifestations, particularly affecting the severity of weakness of the legs and swallowing difficulty. It was convincingly shown that survival is somewhat shortened in IBM patients. In this part of the workshop, the mechanisms of the disease were shown particularly the role of inflammation as a driving factor.

The second part of the workshop focused on potential applications of new diagnostic tools. Various imaging tools were presented including muscle MRI (Magnetic Resonance Imaging), ultrasound, and PET (positron Emission Tomography), of which MRI seemed to be the most suitable for advancing the diagnostic approach. Muscle ultrasound appeared to be promising because it is patient-friendly, applicable as a point-of-care tool, and cost effective. It was noted that expertise in performing and interpreting such studies is variable across the world.
Biomarkers in serum and muscle tissue may be used for diagnostic purposes. Serum biomarkers could possibly help in the future to support a diagnosis when a biopsy is not possible.

A major part of the workshop was dedicated to revising the 2011 diagnostic criteria. This aimed to make them as inclusive as possible for enrollment of patients in clinical trials, and, on the other hand, to avoid misdiagnosis of patients. It was emphasized repeatedly that there is an important difference between recommendations for other clinicians on how to diagnose IBM in general healthcare settings compared to recommendations that are required for research studies.

During the third part of the workshop clinical outcome measures were addressed, which outcomes are currently available and what are their limitations? For future trial design, it is of utmost importance to know the natural history of the disease, though caution should be taken when extrapolating from these studies. It was clear that, in people with IBM, research must be done on outcome measures that assess swallowing difficulties, which is often an unrecognized symptom. Swallowing difficulties are a major determinant of morbidity as the disease advances.

There was consensus on using the IBM-FRS (Functional Rating Scale, a questionnaire assessing the function of arms and legs and swallowing) as an outcome measure for a trial in which a drug is tested for effectiveness and safety. The participants also agreed that, in early trials, quantitative MRI as a biomarker could be used to assess whether a drug works.
Finally, a research agenda was created since many presenters concluded that further research is needed for various outcome measures and biomarkers.
A full report will be published in the medical journal Neuromuscular Disorders.

Myositis UK were delighted to donate £5000 as a co-funder of the meeting.

# British Association of Dermatologists 103rd Annual Meeting


Irene and I attended the meeting on 27th -29th June. We set up our stand and we were very busy and it still amazes me how many people present were not aware of the association of Dermatomyositis with skin issues, particularly as the name is a give away. The organisers were pleased with the effort we made to contribute to this very busy and essential occasion. In fact, we have been invited to attend their future meetings.

One of the benefits for being there was that some of the companies represented gave us free trial samples of their non prescription products that may be of benefit to our members. We had some of these products on display at our conference with samples to take away. Through these columns, I would like to thank Loreal and Aveeno for their free samples and other companies who provided us with individual products to try.

# UK Myonet Autumn Meeting

This scientific meeting was held on Friday 6th October 2023 at the Albany meeting room, St. Giles, London. It was the first meeting since Covid and Irene and I along with our treasurer, Jo Goode attended. Everybody from the medical community present were pleased to be there and meet up face to face to discuss and participate in the busy agenda.

Professor David Isenburg gave an introduction followed by Professor hector Chinoy giving an update on Myoprosp.  Dr Meredyth Wilkinson talked about, “Insights into the pathogenises of JDM” and Dr Gautam Sen talked about “detecting myocarditis in the idiopathic inflammatory myopathies (IIM). The latest findings.” Dr Jennifer Hannah spoke of the “outcomes in myositis interstitial lung disease.” Dr Thomas Chong Khoo talked about “Anti-HMGCR: Past, present and future”.

After lunch, Dr Latika Gupta subject was, “Coming of age-optimising digital approaches for holistic care in myositis.” This was followed by Dr Hennah speaking again about the incidence, prevalence and mortality in IIM and myositis ILD using HES data. “Myositis screening – why, when and how,” was presented By Dr Alex Oldroyd. Dr Saadia Ali presented a talk on developments with MYOACT (Myositis disease activity assessment tool).

Dr Aveen Connolly presented cases of severe dermatomyositis particularly with a rash on the whole of the face and scalp of adults. Treatment with a drug she has been using is showing to improve the condition although further data and controlled trials are needed before its general introduction as a prescribed treatment. However, her work is very promising.

The afternoon rounding off with an enthusiastic debate covering the days agenda. Covid had severely interrupted the research of myositis particularly with this group of research doctors and scientists. There was a sense of great optimism in the room with how research was back on track and how pleased they all were to be able to meet up to discuss and debate the future of myositis. As an observer sat at the back of the room it was a pleasure to witness this event and to see how hard these people work behind the scenes in attempting to improve the quality of life for all myositis patients.

Myositis UK sponsored the cost of the room for this UK Myonet meeting.



# Consensus Meeting – Rotterdam

**Clinical Trial with IFNi in JDM (JAK inhibitors)**

This meeting was to look at the prospect of a clinical trial in JDM within Europe and the UK.

The charity group coordinator, Irene Oakley, was invited to attend this meeting in Rotterdam, Netherlands, on the 26th-27th September. This was a scientific meeting but Irene was invited to give a talk as a parent of a child with JDM. The title of her talk was ‘Patient’s perspective on a clinical trial in JDM’ and what should be taken in consideration when discussing new developments in treatment.

Irene writes, “My talk started with the following statement: ‘Who am I?’  I am a founder of Myositis UK that supports patients with myositis, but most importantly I am the mother of Paula, who was diagnosed with JDM at the age of 5 in 1983. In 1985, with the support of her doctors, a group for parents with JDM was formed. We became a registered charity in 1988 and since that time have included adult forms of myositis. Paula is now 46 and a mother of a healthy 7-year-old boy.”

My presentation consisted of 12 slides of questions and statements that parents of children may ask

before allowing their child to be part of a clinical trial. I concluded with the following statement: “The rights, safety, and well-being of the children in any trial are the most important considerations and should prevail over interests of science and society.”

Other presentations were:
Background on Interferon type I/II in JDM – Saskia Veldkamp
Update on JAK inhibitors in JDM – Meredyth Wilkinson
The French experience – Brigitte Bader-Meunier
Agents: registration, EMA, paediatric labels and patents – Tjitske van der Zanden
Trial design: statistics and N – Peter van de Ven
Trial design: methods and statistics – Nicola Ruperto
European Reference Network – Nico Wulffraat

Marc Jansen writes, “Thank you for attending the JDM IFNi trial consensus meeting. Most importantly, as a consortium, we have a clear shared goal to perform a JAK/STAT study in newly diagnosed patients with JDM. We are already getting towards consensus on how this trial should broadly look like and what next steps are necessary to take.”

The next meeting will be online in January 2024.

# Fundraising & JustGiving

## Minster Lions Club, York

Shaun McDonagh writes, “I recently lost my wife Linda to cancer and dermatomyositis. On the 28th May a celebration of her life was held at the Station Club in Stamford Bridge. At the event a collection was organised by the Lions Club, the proceeds of which were shared between Cancer Research UK and Myositis UK.” *£139.23 was kindly donated to the charity.*

## Linedance Club, Lancashire

Mrs Clifford writes, “Please find enclosed a cheque for £298, a donation to your charity, Myositis UK in appreciation of the work you do. This amount was raised by our Linedance Club at a social dance in memory of one of our dancers who had suffered from Inclusion Body Myositis for some years.”

## Holmeswood Fun Day

Holmeswood is a small village in North East Derbyshire, historically a mining village with a population of around three thousand people.

The fun day was arranged in memory of Christine Cummings (pictured right), a much loved and dearly missed resident who died in May this year aged fifty four. Christine was an award winning sculpturer. Although coming from a farming background she had been an artist all her life and her creations featured in many of the UK’s most prestigious galleries. Christine was a well known, talented ceramic artist who was an advocate to the village. Her ceramic work is instantly recognisable through the style of Raku firing. She had the ability of creating life-like creatures from clay.

Jill Cubbin writes, “The fun-day had lots to see and do including stalls of local crafts people selling fantastic pieces of art. A display of vehicles including vintage tractors, ex military vehicles, wagons old and new, including a “Mercedes-Benz Actros edition 2” which has recently appeared on BBC’s Top Gear from W&M Thompson transport.

There were competitions including colouring, photography and also a pet show that our local vets (Rufford vet group) sponsored and judged. The show was well supported and included some super entries including, cats, dogs, Guinea pigs, chickens, ducks, millipedes and stick insects. First place went to “Howel” the dog.

The funday also had a crown green bowling competition and lots of other competitions with great prizes to be won. There was also a fantastic raffle supported by our generous local businesses. There was a busy refreshments counter with cakes galore. Every imaginable flavour of cake was available and served up with a fresh brew from the fantastic refreshments team.

A local educational farm attended and were a huge asset to the day, teaching visitors about different animals and husbandry. The field nurse, who supports health care In the local community, came along and offered health advise in their ‘pop-in clinic.’ Importantly, there was a bouncy castle and face painting to keep the kiddies entertained.

There really was all sorts to do and see. The Atkinson well-being choir providing a soundtrack to the day with their up-beat singing. There was a quick turnaround in the hall at night where a dance was also arranged to raise more funds by Christine’s sister, Sue.”

“Thanks to our amazing visitors and volunteers, it really was a fun day.”

The fund day raised a remarkable £4,570 and has been recorded in memory of Christine. If you wish to learn more about Christine there is a piece about her being interviewed on YouTube two years ago and will give you an insight into this much missed and acclaimed villager.

# Lacie Gibbons – Charity Walk

**Lacie's fundraiser for Myositis UK, a 22-mile trek around the Peak District on 5th August 2023.**

Lacie's story taken from her JustGiving site: "My name is Lacie and as many of you are aware I was diagnosed in January 2020 with JO1+ Polymyositis. 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 became very poorly in November 2019. 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 who have fought for my yearly course of rituximab treatment which is a form of chemotherapy, alongside immunosuppressants every day to keep my immune disease at bay.

On 5th August 2023 I will be taking on the 22mile hike around the Peak district with 4600ft of ascent to raise money for Myositis UK. This should take around 10 hours. Any donation no matter how small would be greatly appreciated."

"Twenty-two miles hiked around the peak district in torrential rain, wind and just getting over shingles, what an incredible achievement and all in aid for Myositis UK, a charity that's so, so close to my heart. Being told I'd never hike a mountain again three years ago, to tackling six in one day. Reaching all six summits in 10hrs 7mins, 32k, 3322kcals burnt. Win hill-1515ft, Lose hill-1561ft, Hollins cross-1286ft, Mam tor-1696ft, Brown Knoll-1866ft, Kinder Scout-2076ft.

What an absolutely crazy ride this past three years have been. Emotionally and physically draining at times, and only getting through the hardest days because I have the most incredible support system. This is the toughest walk I've done yet. Thank you from the bottom of my heart to all my family and friends for always being there for me and getting me through the hardest three years of my life and to everyone who has shared my page and donated."
*Lacie raised £893*

## Fair Oak Masonic Lodge, Hampshire

The members of the Lodge are always busy raising funds to help charities and their community. The Lodge have been keen supporters of Myositis UK for over twenty years and they have helped us again with a donation for £360.

I was invited along to their recent meeting and their president, Geoff Ford, kindly presented me with a cheque. This continued support from Fair Oak Lodge and help from other Masonic Lodges is very much appreciated. There is always little publicity surrounding these donations, but I am aware that Masonic Lodges and masonry in general are one of the largest financial givers to charity in the country. Quite amazing.


## Richard Greathead

**UK National Three Peaks Chjallenge, 17th June 2023**

Richards's story. "On the 17th of June, Steven Dunne and I will be attempting to climb the three highest mountains in England, Scotland and Wales in less than 24 hours. I'm raising money for Myositis UK, a charity which helps fund research for the diagnosis and treatment of muscle disease, an illness close to my heart as my Mum suffered for 25 years. It's a terrible, debilitating disease which needs better treatment and prognosis. I would be very grateful and it would help spur us along if my good friends and colleagues could dig deep and help with a donation. Wish us luck!"
*Richard raised: £1905*

## Adam Sheppard

Adam Sheppard has sent in this update since his fundraising 40 Before 40 Walk for Myositis, mentioned in our last magazine. He writes, "Thank you all for your generous donations, I am thrilled to have smashed my target. On advice from my wiser half, I split the walk across two days and added some extra miles. I am happy to share with you that I walked/staggered/stumbled over 50 miles."
*Adam raised £605*

## Sophie Kavanagh

**Pretty Mudder (Race For Life), 1st July 2023**


Sophies's story, "Thanks for taking the time to visit my JustGiving page. This year, on the 1st July 2023, me and Lillie will be running the Pretty Mudder 5k (Race for Life) for Myositis UK. This will be at Heaton Park if you would like to come and cheer us on. Any donation will be much appreciated and we would both like to thank you in advance for all your support.
*Sophie raised £40*

## Stephanie Alder

**Beachy Head Ultra Marathon, 21st October 2023**

Stephanie's story, "I am raising money for a little known neurological condition called Inclusion Body Myositis. My mother has suffered from this chronic disease for several years and it has severely affected not only her physical health but her mental and emotional wellbeing. As a keen walker, she regularly completed the Beachy Head Marathon. Please support me as I run the Beachy Head Ultra Marathon to raise funds towards research for this rare but incredibly debilitating disease."
*Stephanie raised £410*

# Future Events

## Yograj To Shave Off His Beloved Beard

He says, “I am doing a ‘Great Shave Off’ because we need to fund research to find a cure. I am shaving my beard which has been living on my face for just under six years to raise money for Myositis UK.

It may not seem like a big deal, but to me, my beard has been one of my most defining features. Those around me will know how reluctant I am to shave it off, but I feel it is important that I raise awareness as well as funds. I will be posting a picture of the results and my transformation on the 26th of January 2024 on this JustGiving page! Save the date!

A few years ago, my mum was diagnosed with Autoimmune Polymyositis. This brought into my world this relatively rare and unknown condition. Myositis required us to make a number of lifestyle changes and brought to my attention just how much an impact this condition can have on lives.


Myositis UK seeks to improve the diagnosis, treatment, understanding and prognosis of myositis. They do this by providing information, relieving isolation, raising funds, and funding research. We found Myositis UK very useful when my mum was first diagnosed as they have a wealth of information about the condition on their website. I am raising money for the charity to help to find a definitive cause and treatments for the condition.

Myositis can affect people of any age. There is no good way to predict who will be affected by it and there is currently no cure. With all of this in mind, I hope that you can join me in my efforts to raise awareness and help me to fundraise for Myositis UK!”

*Yograj has raised £1,407 to date.*

ttps://www.justgiving.com/fundraising/Yograj-Deorukhkar

## Harley French

**UWCB London, 16th March 2024**

Harley writes, “I’m boxing for charity on the 16th of March 2024 to raise money for the charity Myositis UK, for my mum and her tough ongoing battle with polymyositis.”
https://www.justgiving.com/fundraising/Harley-F


## London Marathon 2024

The charity’s Team Muscle has been selected and we have an international group of runners who are going to do their very best for the charity. Our team is very special for next year because we have a wheelchair assisted place. David Rowlinson has Inclusion Body Myositis and is braving himself in the chair while being pushed by his daughter, Jennifer and her boyfriend, Jonny Merdon. It will be their first marathon and they are doing it for Myositis UK. David is flying from Guernsey to take part with a special wheelchair to get around the course. This has taken a lot of effort and organising by them to take part in the event and are presently training and raising sponsorship. My son, David Oakley, will be taking part. He has run the event on two previous occasions raising substantial funds when, would you believe, we could not get runners to make up the team. Scott Jones from the States, who is director of clinical operations at Priovant Therapeutics who are running the Valor Trial in Dermatomyositis is a team member and accomplished marathon runner.

We are also delighted to have in the team, Nick Mapes, Geraldine Owens, Lais Fraga Alegretti.

Geraldine writes, “My Dad William had been struggling with reoccurring bladder cancer in the past few years and before Christmas 2020 this triggered a rare autoimmune disease called Paraneoplastic Dermatomyositis. Over a few months his condition worsened and Dad passed away quite suddenly in April 2021. Myositis UK provided great advice and information to our family and I am very pleased to be running for them.”

Lais writes, “My mother has been living with myositis since 2005, and we have been experiencing the challenges of a condition that causes progressive muscle weakness. The physical and emotional demands are intensified by the lack of research and information. The definitive cause is still unknown and this is why I am running the London Marathon 2024 for Myositis UK, a charity that funds scientific research to improve the diagnosis and treatment of muscle disease. I am passionate about running as some of my friends and family know. However, the 42 km distance is a great new challenge.

Nick writes, “I came across Myositis UK when I was researching muscle wastage after experiencing complications following an Achilles operation, and sadly now live with an irreparable wasted calf muscle as a result of that ordeal. Although my personal condition is unrelated, it resonated with me when I discovered that there is a rare autoimmune disease called Myositis, which causes muscle weakness. And whilst there are different types of this disease, I want to shed light on one particular aspect: Juvenile Dermatomyositis (JDM), a heart-breaking condition that affects children. While many children recover from JDM, some may face difficulties with movement due to contractures and long-term disability. Others may endure chronic symptoms such as pain, muscle weakness, delayed growth, and potentially damage to bones and internal organs. I will be at the start line alongside the incredible Myositis team on April 21st!”

What a fantastic team we have!

You may wish to sponsor them so here are their fundraising pages.

https://2024tcslondonmarathon.enthuse.com/pf/lais-fraga-alegretti
https://2024tcslondonmarathon.enthuse.com/pf/david-oakley

https://2024tcslondonmarathon.enthuse.com/pf/geraldine-eardley

https://2024tcslondonmarathon.enthuse.com/pf/scott-jones

https://www.justgiving.com/page/david-jenny-jonny

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

# Land's End To John O' Groats Walk

Intrepid walkers Craig and Karen Mosley raised a fantastic £1260 from their Margate to Land's End walk. They are now attempting to walk from Land's End to John O' Groats on May 1st 2024.

They make this tremendous effort and commitment in memory of their daughter, Elise Amy, who passed away from myositis at the age of nineteen.

They would appreciate very much if you could raise sponsorship for them or meet up with them on the walk. They would also appreciate publicity, so if you really wish to make a difference, get some publicity for them from your local newspaper, radio station or television station. Perhaps, even a cup of tea and a chat on route to offer encouragement I expect would be most welcome.

Unfortunately, Craig also must cope and live with multiple sclerosis, so this is truly an effort for him.
The pair of them are helping to make awareness of myositis and raising funds. Let's, if possible, step up and cheer them on their way in appreciation and support.


No doubt, we will be hearing much more about this couple and how they are determined to raise money in memory of their daughter and the need for awareness of this miserable disease.

## 5K Run

Stewart Wright is taking part in a 5K run organised by Fylde Coast Runners in Blackpool on Saturday 20th April 2024 for Myositis UK. Stewart wanted to do something to help as his wife has just been diagnosed with Dermatomyositis.

## Christmas Cards

We have them for sale and if you can afford to post them are still a good way to make awareness of the charity at Christmas time. I'm old fashioned and I still like to receive and send these cards.


# NIHR Support

Myositis UK is now an NIHR non-commercial Partner. This means the studies that we fund may be eligible to access the NIHR Study Support Service which is provided by the NIHR Clinical Research Network within the NHS, and the wider public health and social care environment, across England.

In partnership with local R&D office, researchers are encouraged to involve their local NIHR Clinical Research Network team in discussions as early as possible when planning a study. This will enable them to fully benefit from the support available through the NIHR Study Support Service.

If the study involves NHS sites in England researchers will need to apply for Health Research Authority (HRA) Approval. Guidance on submitting an application for approvals is available on the HRA website.

## 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/

## Other Ways To Raise Donations

### amazonsmile

You shop. Amazon gives.

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

### easyfundraising

feel good shopping

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

### PayPal Giving Fund

To date we have received £1,355.52 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.

# 5th Global Conference on Myositis

The 5th Global Conference on Myositis is being held in Pittsburgh, Pennsylvania, from 13th-16th March 2024.

Since the first conference held in Stockholm in 2015, followed by further conferences in Potomac in 2017, Berlin in 2019, and Prague in 2022, this conference has firmly established its place in the field of myositis research. The GCOM conference is well attended, with an average of 300 to 400 delegates in the past including students, young researchers, clinicians, doctors, etc., from all over the world. Participation of researchers, clinicians, and health professionals from the fields of rheumatology, neurology, paediatrics, dermatology, pathology, immunology, pulmonology, physiotherapy and other specialities offers a unique opportunity to meet and discuss the topics from different perspectives. From the outset of these conferences, strong attention has been paid to stimulating the active participation of young physicians and scientists. Hopefully, 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.

Myositis UK has participated at all the four previous GCOM conferences. In particular the charity funded the “Speed Funding” in Berlin which was a great success. This has been well reported in previous editions of “Myositis News”. The trustees have agreed to fund the “Speed Funding” at GCOM 2024. Young scientist/ investigators will be encouraged to apply for a maximum of two years funding of $15,000 for a research project in the field of myositis. Eligible are all young scientists without a permanent position (e.g., Ph.D. student, junior post-doc, or medical trainee). The applications will be evaluated in a two-step process. They are invited to submit a short project summary developed together with an established researcher. A scientific panel will assess applications and will select the six best projects for oral presentations. These presentations will be given during the GCOM 2024 conference. After the talks, the panel will vote for three winning projects. The result will be announced, and the prizes awarded on the last day of the conference.



# Myositis UK AGM & National Conference 2024

The date next year is Sunday 14th July 2024 at the Woodland Grange, Old Milverton Lane, Leamington Spa. It is the same venue as this year. The staff of the Woodland Grange were very helpful and the venue and accommodation ticks most of the boxes for a successful conference. Please make a note in your diary.

# World Myositis Day Founded

Representatives of various international myositis groups and organizations from Australia, Canada, Czech Republic, Germany, Sweden, the Netherlands, United Kingdom and the United States of America have jointly decided to establish the World Myositis Day.

This special day will be celebrated every year on September 21st from now on. 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 to 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!

# Literature Update

A selection of published research from Pubmed.com since the last review in May 2023.

## Anti-HMGCR immune-mediated necrotising myopathy: Addressing the remaining issues.

Khoo T, Chinoy H. *Published in Autoimmun Rev October 2023. PMID: 37884200.*

## Epidemiology of the idiopathic inflammatory myopathies.

Khoo T and others. *Published in Nat Rev Rheumatol November 2023. PMID: 37803078.*

## Distinct HLA associations with autoantibody-defined subgroups in idiopathic inflammatory myopathies.

Leclair V and others; Dissect Consortium and The Immunoarray Development Consortium.
*Published in EBioMedicine October 2023. PMID: 37769433 Free PMC article.*

## Comparison of clinical features between patients with anti-synthetase syndrome and dermatomyositis: Results from the MYONET registry.

Hum RM and others; MYONET registry. *Published in Rheumatology (Oxford) September 2023. PMID: 37698987 Free article.*

## Healthcare utilization and unmet needs of patients with antisynthetase syndrome: An international patient survey.

Weiss M and others. *Published in Rheumatol Int October 2023. PMID: 37452880 Free PMC article.*

## 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) November 2023. PMID: 36929923 Free PMC article.*

## Safety and efficacy of arimoclomol for inclusion body myositis: a multicentre, randomised, double-blind, placebo-controlled trial.

Machado PM and others; Arimoclomol in IBM Investigator Team of the Neuromuscular Study Group.
*Published in Lancet Neurol October 2023. PMID: 37739573 Free article.*

## Efficacy of non-pharmacological interventions: a systematic review informing the 2023 EULAR recommendations for the management of fatigue in people with inflammatory rheumatic and musculoskeletal diseases.

Santos EJ and others; EULAR taskforce on recommendations for the management of fatigue in people with inflammatory rheumatic diseases.
*Published in RMD Open August 2023. PMID: 37604639 Free PMC article.*

## Moving forward together: collaborative landscapes of research in idiopathic inflammatory myopathies and calcinosis.

Saketkoo LA and others; International Myositis Assessment and Clinical Studies Group (IMACS)/XX Calcinosis Scientific Interest Group.
*Published in Rheumatology (Oxford) July 2023. PMID: 37449887.*

## Study to Assess Content Validity and Interrater and Intrarater Reliability of the Inclusion Body Myositis Functional Rating Scale.

Symonds T and others.
*Published in Neurol Clin Pract August 2023. PMID: 37324533.*

## Juvenile idiopathic inflammatory myositis: an update on pathophysiology and clinical care.

Papadopoulou C and others.
*Published in Nat Rev Rheumatol June 2023. PMID: 37188756 Free PMC article.*

## Gender differences in patient experience in idiopathic inflammatory myopathies: Sub analysis from the COVAD dataset.

Yoshida A and others.
*Published in Mod Rheumatol September 2023. PMID: 37769200.*

## Delayed adverse events following COVID-19 vaccination in patients with systemic sclerosis and other autoimmune diseases: a substudy of the COVAD-2 cohort.

Panchawagh S and others.
*Published in Rheumatol Int December 2023. PMID: 37712977.*

## Long-term safety of COVID vaccination in individuals with idiopathic inflammatory myopathies: results from the COVAD study.

Doskaliuk B and others; COVAD study group.
*Published in Rheumatol Int September 2023. PMID: 37351634 Free PMC article.*

## High fatigue scores in patients with idiopathic inflammatory myopathies: a multigroup comparative study from the COVAD e-survey.

Grignaschi S and others; COVAD study group.
*Published in Rheumatol Int September 2023. PMID: 37314497 Free PMC article.*

## 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) May 2023. PMID: 37228012.*

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

Ali SS and others; COVAD Study Group.
*Published in Rheumatology (Oxford) September 2023. PMID: 37004201.*

## Vaccine hesitancy decreases in rheumatic diseases, long-term concerns remain in myositis: a comparative analysis of the COVAD surveys.

Sen P and others; COVAD Study Group.
*Published in Rheumatology (Oxford) October 2023. PMID: 36734536.*

## COVID-19 vaccine safety during the antenatal period in women with idiopathic inflammatory myopathies.

Andreoli L and others; COVAD Study Group.
*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.

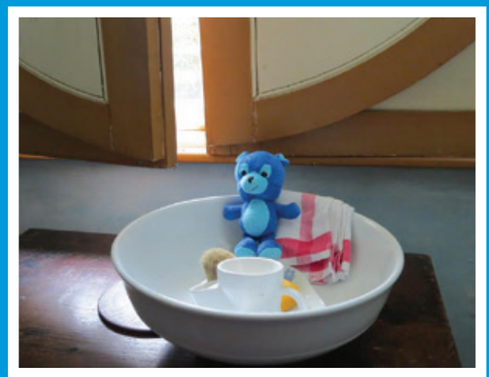
## Postscript

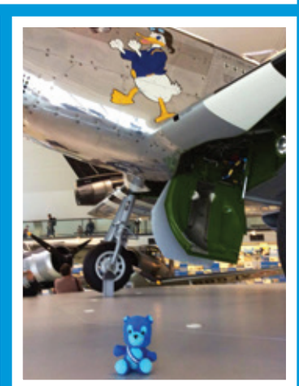
In conclusion, I need to thank many people who have not been named in this issue. However, Myositis UK are aware of how much support and time they have given to help people cope with their illness. There have been many generous financial donations as well as encouraging correspondence from people following the activity of the charity online and through this magazine. Myositis UK is and always will be a small charity because it represents a rare group of diseases. However, because of this help it is fondly respected and encouraged by people not only in this country but abroad as well. I thank you for making this possible.

***– Les Oakley, Myositis UK***



# Teddy-Bo Memory Lane



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