MYOSITIS UK

Autumn 2019

Myositis News

Inside:

3RD GLOBAL CONFERENCE ON MYOSITIS
FUNDRAISING • RESEARCH
2019 AGM & CONFERENCE

Autumn 2019

Dear Member

The year is scampering by and getting this magazine out has been the opposite and dragging its feet. Fortunately, with the use of the internet now a part of everyday life, it has not been a major issue. However, it is still a very important format to report about a host of activities associated with the charity and other relevant news.

Les Oakley MBE
Chairman

Trustees

3rd Global Conference on Myositis

27-30 March, Berlin

The Global conferences have been the driving force behind much of the progress made in Myositis research and it was important that Myositis UK should be in attendance to report on developments and new initiatives.

For Irene, our national myositis co-ordinator, this means a lot of work and hours in the office preparing our charity stand and booking all the transport and hotel accommodation.

We needed to transport a lot of material and managed to stow it away in four heavy wheeled cases plus having to carry lap tops and other media equipment. We are both not getting any younger and after loading the car and driving to Heathrow airport we had to get it onto the plane. The task we managed well considering the hustle and bustle of the place and retiring to the airport lounge before the flight for a cup of coffee was very welcome.

The conference was held in the European School of Management and Technology in Berlin, right next to the newly re-built City Castle and cultural heritage Museum Island.

More than 360 participants from all over the world attended to review and listen to the latest updates on clinical and scientific achievements in the field of myositis.

Fortunately for me the language and text was in English. The programme led to lively and fruitful discussions and intense networking on scientific and social levels. The conference is constantly growing, developing and attracting many young clinicians and researchers made possible by all the keynote speakers who gave state-of-the-art interviews and their personal insights into specific research topics relevant to myology and immune mechanisms.

The organising committee deserve to be congratulated. They consisted of Werner Stenzel for Germany, Olivier Benveniste from France and Ichinzo Nishino from Japan among others, plus a remarkable scientific committee.

We were joined at the conference by trustees Jo Goode and Laura Oakley, and charity member Chris Jensen. Laura needed to attend because Myositis UK became the only Gold Sponsor and it was necessary for us to display a stand to represent the input the charity had made. Laura's employers kindly

GCOM 2019

gave her time to attend because we could not have managed without her. Teddy-Bo came with us and we managed to find time in a busy schedule to photograph the bear visiting a few famous sights.

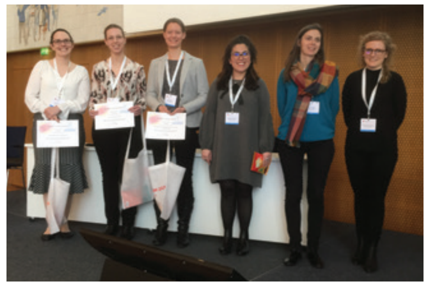
Our stand was in the foyer of the auditorium where we met up with other charities who are based in Germany, Holland, France and the United States. It was a pleasure to meet with what we now consider our old friends and catch up on news. It was also a pleasure to meet with the new chief executive officer for the Myositis Association (TMA) charity, Mary McGowan.

There were a 152 posters about myositis on display and they were visited and debated by the scientific community with three receiving a prize.

The GCOM Committee had introduced the idea of "speed funding" a young research doctor or scientist with an initial request for 15000 euros to support it. The trustees considered this a marvellous initiative and we offered to increase this to 45000 euros enabling three grants to be made. There were initially seventeen applications which were narrowed down to an invited six. The meeting for this was held in a separate room from the main conference. There was an international panel of judges who point scored on the presentations and the marks were totalled to give the results and the funding for these projects will take effect immediately. This proved a very popular part of the conference and unfortunately many delegates could not get into the room to witness this new concept. The winners were not announced until the next day.

At this juncture of the conference, before Irene and I were invited on to the conference main stage, Myositis UK member, Chris Jenner, was invited to give a personal account of the death of his dear wife and the missed opportunities that, if taken earlier, may have given a different outcome. However, myositis is a very complex disease in all its forms and at present, even with treatment, there is always a risk that disease progression does not take a predictable route.

After Chris's talk, and because of its content, I was able to express how important the following presentations were for future outcomes and Irene and I had the pleasure of congratulating the winners when their names were announced with much applause from the hall. They were Kyla Britson and E Wilfong from the USA and S Lassche from the Netherlands who will give a follow-up on their research in two years' time. Kyla Britson also received an award for the winning presentation which she had presented in the main conference hall.



The standard of application was amazing with impressive content and the three candidates who did not receive an award and whose work was also highly valued were invited by the organising committee to attend the next conference at their expense which will be held in Prague in the Czech Republic.

The winning subjects were: The Pathogenis and Treatment of Inclusion Body Myositis in a Xenograft Model – K Britson (USA)
Inclusion Body Myositis on a Chip – S Lassche (The Netherlands)
CD27-CXCR4hiCD21lo cells in Jo1-positive IIM E Wilfong (USA)

The GCOM conference was an amazing success and Professor Ingrid Lundberg rounded up the conference to say how pleased she was to have initiated the first conference.

Q&A Session At GCOM 2019

Silke Schlüter writes:

Finally, I am sending you the answers to your patients' questions for the GCOM patient workshop.

As you know, I made a summary from all submitted questions for the workshop, because there were many overlaps. So I just gave this summary to the experts from the MYOSITIS NETZ. I got many answers and added them to the questions.

But please consider:
The answers are only individual expert opinions from different persons and they are not guaranteed!

You all know that the diagnostic and treatment in myositis is sometimes very difficult and special and sometimes there are also different opinions about it.

We all make an effort for more consistent standards, but it will take time.

So I hope you and the patients are pleased about the answers on the following pages and they will be helpful.

Silke Schlüter, Chair of the German Myositis Diagnosis Group

Correlation Between Myositis & Other Diseases

Q. Is there any correlation between myositis and sleep apnea?
A. Yes, possibly.
Q. Is there any research around IBM as it relates to HIV and could the HIV meds be causing the muscle weakness?
A1. There are only a few case reports showing this combination, so it's unlikely, but possible.
A2. Some (older) meds can cause mitochondrial damage. HIV and sIBM is a rather rare but well established coincidence. Viral diseases can cause sIBM (Hepatitis B and C, as well).
Q. Is restrictive lung disease seen as part of polymyositis or another type of myositis?
A1. No.
A2. Different subtypes of interstitial lung diseases can be associated with anti-Synthetases syndrome and this makes restriction!
Q. Please comment on the link between IBM and LGL Leukemia.
A1. Very rare combination, both linked to pathogenic cytotoxic CD8+ T cells.
A2. LGL lymphocytes are associated with sIBM in variable quantity but this does not mean that all sIBM patients have LGL leukaemia. Conversely not all LGL leukaemia patients will get sIBM but some have been described and at younger age than 'normally' possible.
Q. Have any of the experts heard of a patient with dermatomyositis (with ILD) who is also being treated for a thoracic aortic aneurysm, and POTs? Do they have any thoughts on whether these conditions are somehow related?
A. No, this combination is by chance.
Q. 26 years old, diagnosed with polymyositis in addition to interstitial lung disease (ILD). What do I need to expect in future?
A. Intensive check-ups, try to ameliorate the manifestations with adequate medication.
Q. Will I keep feeling this continuous pain?
A. With therapy, it should become better.
Q. Will my joints be affected?
A. That could happen in an overlap situation.
Q. Will I have the chance to live like any other lady without difficulties, like having kids, for instance?
A. Yes, but first a remission has to be achieved.
Q. My doctor says he is 80% sure I have IBM. I was simultaneously diagnosed with breast cancer, which has since been treated. Is there any treatment?
A. There are clinical trials running but, most likely, tumors will be an exclusion.
Q. Also, will any of these treatments interact with my Tamoxifen?
A. Not known.
Q. Has there been any evidence of myositis affecting either heart or bowel muscles?
A. Yes

DM Research & Treatment

Q. I was diagnosed with Dermatomyositis with a muscle biopsy several years ago. I have been taking 5 to 7-and-a-half mg of Prednisone. Can you tell me if there are certain things that trigger an episode?

A. Yes, any infection can trigger it.

Q. Could I avoid the swelling and rash?

A1. Immunosuppressants may be better than steroids.

A2. Heat or sunshine might worsen the symptoms.

A3. Please avoid sun, as it triggers the rash.

Q. Is there is any news on insights or treatment options of calcinosis?

A1. Currently sufficient immunosuppressive therapy is the best option.

A2. It depends on size. For small (1-2mm) deposits, there are reports on successful use of a prescription containing sodium thiosulfate.

Q. Based on my case history, with eventual lung cancer being diagnosed, should cancer screening be routinely part of the protocol for treatment?

A1. Yes

A2. Especially when certain antibodies are found in the blood (NXP-2 and TIF-1).

IBM: Research & Treatment

Q. In 2018, researchers achieved success in Alzheimer's disease: the antibody BAN2401 slows down the course of the disease. Can this research step (antibody) be applied to the clinical picture sIBM "sporadic inclusion body myositis" or further researched?

A1. Not known, but an interesting idea.

A2. For Alzheimer's disease there is so far no convincing data for the efficacy of amyloid-targeted therapies, maybe due to late induction of therapy. For sIBM effects are not known, but might mechanistically be justified and subject of further studies.

A3. ß-amyloid is a completely different mechanism in Alzheimer's disease. There is no or very scarce beta amyloid in sIBM! The fibrils are beta pleated tau.

Q. With possible good results from the arimoclomol trial at the moment, what help and at what progression of IBM will it prove beneficial to later stage ibmers. Will it stop the progression or even help to regain what I've already lost with strength and mobility?

A. That's what the trial needs to prove.

Q. Does IBM affect my heart, because it is also a muscle?

A1. Yes, possibly, but not proven.

A2. In literature, no affection of heart has been described, but I have 5 IBM patients, of whom all of elevated troponin t (a heart-specific muscle enzyme), but further diagnostics are without pathologic (MRI, echocardiographia). However, since IBM patients are older, the risk for heart problems is already increased. From my point of view, there is no need to concern for the heart of IBM patients. There is only a laboratory hint, but no clinical evidence.

Q. Is there any treatment or medication for IBM disease?

A1. Yes, please see the IBM trials at clinicaltrials.gov

A2. (https://clinicaltrials.gov/ct2/results?cond=IBM&term=&cntry=&state=&city=&dist=)

A3. Sometimes, intravenous immunoglobulins slower disease course. Until now, physiotherapy is the most helpful therapy. Another medical treatment that has fulfilled criteria of effectiveness in school medicin are not available.

Q. New cancer treatments now include targeting specific genes and cells (immunotherapy) with some amazing results. Is that research applicable to addressing s-IBM?

A1. Potentially, yes, but unlikely.

A2. Potentially, yes, but unlikely at present. Targeted therapies are a major goal in myositis research.

A3. Since the cause and mechanisms of the disease are less known and studied, we cannot answer whether immunotherapy will bring relief. Immunosuppression with Prednisolone and more does not help.

Q. Does anyone have any experience with the influence of procaine infusions on sIBM? I was alright after the biopsy of a muscle on the left lower leg with this preparation an already dramatically to name increasing strength and especially mobility of the leg muscles to notice, however, only about a day. I was able to reproduce the effect later. A Hamburg doctor injected me with 5 mL procaine 1%, i.v. The effect was repeated.

A1. That was discussed years ago but never followed up.

A2. I have no experience of this.

PM Research & Treatment

Q. Are there any new treatments for polymyositis both newly diagnosed and resistive to treatment cases?

A. Not licensed, but all immunosuppressants used for rheumatic diseases are being examined.

Q. Is there any new list of symptoms to diagnose polymyositis?

A1. No.

A2. A diagnosis of PM should be avoided; we can be more precise.

Q. Are there new diagnostic criteria for polymyositis with subtypes?

A. No.

Q. Are there natural treatment methods (alternative treatments)? How close are they to a cure?

A. So far, no natural treatment has proven any substantial effect on autoimmune diseases.

Q. I understand exercise is very good for polymyositis patients. I also can feel the benefits of exercise sometimes. I am in pain most of the time especially around my shoulders and neck area. Should I continue to exercise, or I am making more damage to the muscles and joints in this area? Or, is there hope that the muscles/joints will improve with exercise hence lead to reduction or no pain in the future?

A1. If pain is persisting, activity should be checked and therapy adapted.

A2. The recommended intensity and the form of exercise depend on the activity of PM in your case. If there is more disease inflammation activity and you need a higher dose of corticoids you have to be more careful und exercise with less effort should be done, using an aerobic exercise. If the course of the disease is more stable and you need a low dose of corticoids, you can be more active, perhaps even with a resistance training.

Q. My diagnosis is polymyositis. I have been taking Prednisone for over 17 years now. Can you tell me if there is a specific treatment or medication for PM yet?

A. Yes, immunosuppressants such as MTX.

Genetics

Q. I was wondering if there has been any research into possible genetic predispositions to myositis. I know that there is some talk about certain genetic mutations can lead to inflammation, which may cause autoimmunity problems. These then can manifest in various autoimmune diseases such as Lupus, MS, psoriasis and, perhaps, myositis diseases. Could there be any possibility of this?

A1. Yes, but different in most of the individuals.

A2. In autoimmune disorders there are always genetic and environmental factors contributing to the pathogenesis, genes might be risk factors but are not sufficient to initiate disease alone.

NM Research & Treatment

Q. How is the remission of HMA Co reductase autoantigen necrotizing autoimmune myopathy defined? Where do my CK levels and other inflammatory markers need to be at to say I am in remission?

A1. It's thought to be autoantibody mediated, remission is normal CK levels and no symptoms

A2. Remission should be measured clinically. Biomarkers can be helpful such as CK or auto AB titers. In anti-HMGCR-myositis CK levels stay elevated often and titers can correlate with clinical amelioration.

Q. With necrotizing myopathy, how many grams of protein, carbs and fats should I shoot for daily?

A. Not known, but should not make any difference, as the process is autoimmune

Q. What about bone building formulas for osteopenia?

A. Treatment according to osteoporosis guidelines.

Q. What is a realistic bone building program for someone with osteoporosis and NM?

A. Standard physical therapy.

hIBM

Q. Is there a difference between treatment options being considered for those with genetic IBM vs those with sporadic IBM? If so, why are the options different?
A1. At present, no specific options.
A2. For hIBM, can try sialic acid.
Q. What is the newest information on Familial Inclusion Body Myositis? I have IBM, my mother had IBM and I had one sister diagnosed with Polymyositis. I also have an older brother who is not affected at all. Has any connection been found?
A. There should be a genetic but family-specific link.
Q. Why is there not much interest with patients who are suffering with hIBM. We are of a more rare condition yet need help as well. I feel we are the forgotten ones.
A1. It's not forgotten, just too many similar problems for the few experts.
A2. My suggestion is to go and see an expert for hIBM. Depending on your country we can help and give names.

Physical Therapy/Ergotherapy

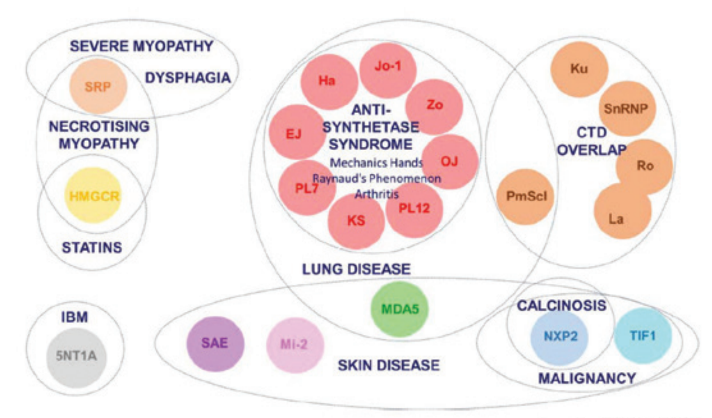
Q. I go to occupational therapy twice a week, physiotherapy twice a week and speech therapy once a week. Since the muscle reduction continues to progress, are there special therapies that can be applied?
A1. No, but the immunosuppressive therapy needs to be adapted.
A2. Physiotherapy should be adapted to your symptoms as well, however additional physical training at home might be even more important.
A3. The recommended intensity and the form of exercise depend on the activity of myositis in your case. If there is more disease inflammation activity and you need a higher dose of corticoids you have to be more careful und exercise with less effort, using a mild to moderate aerobic exercise. If the course of the disease is more stable and you need a low dose of corticoids, you can be more active, perhaps with a resistance training. And the intensity of the resistance training, as well, depends on the body conditions. As you describe muscle loss especially in arms and legs and stiffening of fingers there seems to be a high disease activity. So passive movements of your hand and finger joints should be done with your therapists and on your own. Active movements of the whole body muscles and joint should be done in your everyday exercise with low effort. The intensity and time of exercise should be discussed with your physician and your therapists.
Q. IBM is very rare: Are there any new findings for a possible therapy, physiotherapy and speech therapy and lots of exercise, for example infusion with immunoglobulins? (GE)
A1. IVIGs have not proven efficiency in IBM; but check clinicaltrials.gov for trials.
A2. (https://clinicaltrials.gov/ct2/results?cond=IBM&term=&cntry=&state=&city=&dist=)
A3. H. Alexanderson summarizes in a recent review (Exercise in Myositis; Current Treatment Options in Rheum (2018) 4:289-298) according to sIBM: "As of today, we do not know what exercise regimen is most effective in IBM; however, evidence supports safety of individually adapted exercise and that regular exercise can maintain function while inactivity leads to reduced muscle function." She further stated that blood-restricted resistance training (BRF) could be an effective exercise form for sIBM patients. Larger randomized controlled studies are needed to decide whether this kind of exercise should be used regularly in sIBM patients. Further studies have to be performed to clear whether intensive exercise should be combined with medications, for example Bimagrumab.
Q. What exercises do you recommend for IBM?
A1. Standard physiotherapy.
A2. I recommend for IBM patients a combination of aerobic exercise and resistance training individually adapted. Overstrain should be avoided.
Q. Can you gain back muscle lost thorough physical therapy?
A1. Yes
A2. Getting back muscles lost cannot be expected. The aim must be to improve strength and functional capacity, stabilization of preserved muscles and to slow down process of muscle wasting and loss of strength.

General Questions

Q. I was diagnosed with autoimmune hemolytic anemia in 2016. My hematologist gave me Sandimmune Neoral, methylprednisolone, antacid, and braxidin. Recently, my doctor suggested he check my blood with ANA Test. The result is I am positive for polymyositis. What is the difference between myositis and polymyositis?
A1. Poly just means "more than one muscle affected".
A2. There is no blood test saying you are positive for polymyositis, this is a diagnosis made by biopsy. I would recommend to consult a myositis centre.
Q. I have been told I will need prednisone for one year. Does myositis go away in one year?
A1. No.
A2. There are acute and chronic forms of myositis, therefore there is no clear answer to your question.
Q. If you had IBM, how would you treat yourself?
A1. Try to get into a clinical trial, see above.
Q. I was diagnosed with IBM about two years ago. I have noticed increased muscle burn when exercising, which I do regularly. If I push through the muscle pain, am I making my condition worse?
A.: No, but don't push it to the limit.
Q. Are there any type of myositis that presents with a drop head?
A1. No, but neck muscles can be affected.
A2. If Myositis is axial all the others can develop drop head during disease course – but rarely. Drop head is typical for SLONM which is not myositis.

Standards On Myositis

Q. When a patient is pursuing a diagnosis of myositis, is there a recommended list of blood tests including antibody tests to be undertaken?
A. We normally do CRP, CK, TSH, Na+, K+, Ca2+, ANA, anti-dsDNA (with typical symptoms for SLE), (pANCA, cANCA), myositis-associated antibodies and myositis-specific antibodies (see below).



Betteridge & McHugh 2015

Other Possible Medications for Myositis

Q. Can the myositis doctor community find better solutions than high dose, long term Prednisone? Prednisone has been around for over 100 years. Seems like we should be able to find a better treatment plan, especially for those of us who have Osteoporosis or other steroid sensitive co-morbidities.
A. Yes, there are multiple immunosuppressive options and IVIGs.

Windsor Castle

A couple of days after returning home from the GCOM meeting in Berlin, Irene was invited by her Majesty the Queen to a two-hour reception at Windsor Castle to celebrate the centenary of the National Council for Voluntary Organisations (NCVO) of which Myositis UK is a member.

Irene was very pleased to have been invited to this reception on 2nd April and thought that they were there to witness the occasion, as you would do at a garden party. However, she did not expect to be presented to the Queen and was taken back when she realised this was the case. She had to quickly learn to curtsy, which was amusingly demonstrated by a chap wearing a kilt.

When she met her Majesty she could not believe what a delightful and well informed lady she is. In that few brief moments Irene was able to say a few words about the charity. Irene also met Princess Anne and had a much longer talk about the charity when she was introduced to the Duke of Gloucester. He was very interested in her role and the work of the charity.

Irene then proceeded to the Great Hall where she was treated to as much champagne and canopies that temptation would allow her to accept!

While Irene was enjoying this wonderful occasion I was holed up in Weatherspoon's public house across the road, in the knowledge that I was driving home and had to forego the lovely ales on tap.

Irene said it was a wonderful experience for her, particularly as she works alone in the office without the opportunity of meeting many people. She was amazed at how many people also give up their time to work voluntarily for charities in so many special ways.

The following day we packed our cases again and drove to Southampton airport to fly to Newcastle to attend the twelfth UK Neuromuscular Translational Research Conference fully aware of the carbon footprint we were making that to us was concerning.

We have only missed one conference during this time and were able to meet up again with this scientific community and other support groups and charities.

Myositis UK AGM & Conference

Sunday 23 June 2019

This was held at the Oxford Belfry Hotel near Oxford.

The traditional "greet and meet" on the Saturday afternoon is always a pleasant occasion. It gives us all a chance to catch up with old friends and welcome new members.
It is a time to talk with folk who have to live with the disease in an informal way that paves the way to make the following day a better experience for everyone.
Irene, as usual, had programmed a day that was informative and helpful and from the comments online and from the feedback forms it has again shown to be a great success. Considering the amount of activity that is generated from the contents of the conference, plus the hotel accommodation and dining for members, there is always the possibility of an oversight or error somewhere.
After a welcome from me at the start of the day, the reading of the minutes of the previous year, my chairman's report and Treasurer's report by Jo Goode were accepted by the membership.

The officers were re-elected en bloc.

Chairman: Mr Les Oakley MBE
Honorary Treasurer: Mrs Jo Goode
General Secretary: Mrs Paula Jordan
Trustees: Mrs Nikki Baron and Miss Laura Oakley

After the AGM a report was given by our group co-ordinator, Irene, on the 3rd Global Myositis Conference in Berlin including visual images.

Laura Oakley presented and explained the new website to the audience. Both were well received and many remarks were made to how much work and effort must have been put in over a relatively short period of time.

We then broke out into our different disease-type rooms.

In room 1 - Dr Pedro Machedo and Dr James Lilleker chaired and talked about Inclusion Body Myositis.

In room 2 - Professor Hector Chinoy, Dr Dan Sado and Dr Luke Dancy (cardiology) spoke about Dermatomyositis and Polymyositis.

In room 3 – Polly Livermoor from Great Ormond Street held an informal meeting with play for the children that included discussions on research, treatment and trial updates.

Annual General Meeting and Conference

After lunch back in our respective rooms it was time for informal question and answer sessions. I sat in with the IBM members and every question was answered with honesty and compassion. There was no stone left unturned and all of us in that room spoke from the heart and must have left that room thinking there were no more questions they could ask and the doctors did not fail to attempt the most difficult questioning. All in that room were a credit in making it so very worthwhile in attending the conference. You cannot get these moments from interaction by letter or online. Even though you may have a miserable illness you could not have felt other than happy and encouraged when you left the room and I'm informed that this was the same in the DM and PM room and having cardiologists attend for the first time was well received. In the JDM there was "Brainstorming" for a booklet for schools to help schools understand JDM.

At half past three in the afternoon all the partitions were pulled back for a final discussion. This part of the afternoon I enjoy very much. Everyone is relaxed, the day appears to have gone well and the majority have a smile on their face.

It is worth noting that all the doctors and medical professionals gave up their Sunday free of charge to be with us. Without these gifted and benevolent people we would not have a conference worthy of merit and I will always be grateful for what they do for us. Dr Patrick Gordon was due to have attended but was unwell on the day. I feel sure he would have attended but he has a loving and caring family who quite rightly said: "No."

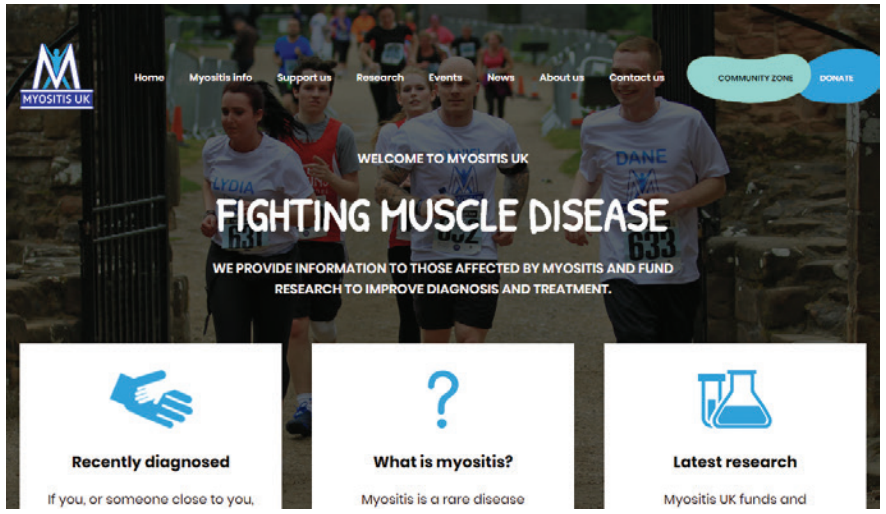
From the comments on line and from the feedback forms it has again shown to be a great success. Member, Jan Evans, made the following comments which were very heartening for the trustees. She writes: "Another successful conference! We found this year's DM session particularly interesting. Professor Chinoy was as interesting and approachable as ever and the introduction of the cardiologist to the event was a great idea. They were extremely interesting and made the subject very accessible. They delivered their talk with humour which made it easy for everyone to understand. The effect of DM on our cardiac system was something, I am sure, many of us had given little thought to. This discussion gave us awareness without the 'scare' factor, so thank you everyone for making it available. The hotel was comfortable and had benefited from the recent makeover. A lovely room and impressive bathroom! The staff friendly and helpful and lovely food. Well done to all of you. You are appreciated for what you do for us!"

Bob Cooper

Professor Bob Cooper has been very unwell and is unlikely to return to full-time work. His absence at medical meetings this year and his contribution for the welfare of myositis patients is well documented and appreciated. However, it is our time to think of him and trust the coming months will be kinder to him and allow him to enjoy a life away from the pressure of work that must have rested heavily on his shoulders.

New Website

Back in May we launched a new website for Myositis UK to help us more effectively meet our charity aims. The process was overseen by one of our trustees, Laura Oakley, who has a background in charity communications specifically regarding website content design.



WELCOME TO MYOSITIS UK

FIGHTING MUSCLE DISEASE

WE PROVIDE INFORMATION TO THOSE AFFECTED BY MYOSITIS AND FUND RESEARCH TO IMPROVE DIAGNOSIS AND TREATMENT.

Recently diagnosed

If you, or someone close to you,

What is myositis?

Myositis is a rare disease

Latest research

Myositis UK funds and

Website design is constantly evolving, and the pre-existing site was simply not fit for purpose. It offered poor user experience, was difficult to navigate, didn't load well on a mobile phone or tablet, looked dated, and was not easy for Myositis UK to keep up to date.

The new website, designed and built by freelance web developer Rob Fenech, based on a brief by Laura, has addressed these issues, creating a site that is fresh, optimised and relevant.

The process of creating a new website was carried out thoroughly and informed by analytics and research, including a six-month period of data gathering to identify how people used and interacted with the site, as well as research into what other charities of a similar size to Myositis UK were doing.

Once the right web developer was identified and brought on board through a procurement process, these analytics helped inform the design and structure. Laura also spent a considerable amount of time liaising with doctors and researchers to create new web pages that are up to date and clinically sound.

The 'myositis info' section is the most transformed. Previously, a lot of information was available in PDF files, often hidden away on the site and not kept up to date. This new section houses information on the types of myositis, medication, complications, and some specific pages for those needing more support such as those recently diagnosed.

As well as being brought up to date through content and design, there are lots of other benefits to the new website. It is now hosted on a platform that is easier to access and allows for greater control from an admin perspective, such as the ability to build contact forms. For example, it is now much easier to request a membership pack or sign up to our mailing list.

In addition, the design is more on brand and the site has been optimised to ensure it works across multiple devices. We have used a more accessible font so that is easier for people to read. And we've improved the navigation so that different users can more easily find relevant information, from someone who is newly diagnosed looking for information on myositis, to a researcher looking to apply for a grant. And the site is GDPR compliant.

The internet is increasingly people's first port of call to find answers and as a charity committed to sharing information about myositis, we needed a website that responded to those needs. We are confident our new site can now better serve our members and is an important tool in helping us achieve our main charity aims.

The website project continues behind the scenes as Laura seeks opportunities to improve it further, such as by populating the website with content of real people with myositis, and improving the ease in which people can donate to Myositis UK online.

We encourage you to take a look around the new website and get in touch if you would be interested in sharing your myositis story.

London Marathon 2019

It was an early start for Irene and me on the Sunday morning, 5.30am to be exact!

We had loaded the car the evening before with all the charity bumf ready for the morning. Irene had already wished our runners all the very best and to enjoy and savour this fantastic run.

We arrived in good time at Admiralty Arch to park the car and sought out a nearby café for breakfast before returning to unload so that we could set up our charity gazebo in St James's Park.

We had only two runners this year and the dropout rate was the worst I've known. I am sure many people with the best intentions do not really appreciate the time and effort you have to put in during the winter months to train for this event.

However, we knew we had two good, determined and well prepared runners – Zoe Betteridge and Richard Kirton – who would prove this by very commendable times that I can only envy.

London Marathon 2020 & 2021

All our Gold Bond places have been allocated for 2020. We had over 30 applications. We have 5 places each year plus any we have not used in previous years. In 2020 we will have 13 runners!

If anyone is interest in running in the 2021 marathon details are as follows:

- Represent Myositis UK at our key fundraising event of the year.
- Achievable minimum fundraising target of £1,000.
- Free Myositis UK running vest.
- Post-marathon reception in St James's Park.
- Lots of encouragement and support!
- Knowing you are raising funds for a worthy cause.

How to Apply

To run for Myositis UK, you will need to complete an application form and commit to raising a minimum of £1,000.

Places are awarded by the Trustees and successful applicants are required to pay a non-refundable deposit to accept and secure their place.
As this is a key fundraising and awareness-raising moment for a small charity like us, we ask our runners to wear either a Myositis UK running vest or shirt which the charity will provide with the runner's name printed on.

To request an application form, please email the office.

My London Marathon Experience

Zoe Betteridge

Towards the end of April, I had the privilege of running the London Marathon for the first time and am pleased to say that I manged to combine the opportunity with being able to raise money for a charity very close to my heart; Myositis UK.

The London marathon wasn't my first marathon, I had run Taunton in April 2018 where I had an amazing day managing to come home as the 3rd female overall, securing a 'Good for Age' automatic place for the London. However, whilst both races were 26.2 miles, Taunton was a much smaller affair with only 500 runners (compared to 41000), and a two-lap course where you hardly saw anyone on the second lap – I certainly can't say that for the streets of London!

I was lucky enough to be running the London marathon with my best friend Kathryn, who had been through the experience for the last two years and managed to navigate us to the start with the minimum of stress. After a nervous and very chilly wait in the starting pen we were shuffling towards the start line for what would turn out to be one of the most incredible experiences of my life. I had set myself a very ambitious target time of 3 hours and 20 minutes, however was well aware that whilst it was possible, all the stars would need to align for that to happen. As it was, it turned out it wasn't to be my day, having been reduced to nearly a walk with a stitch half a mile from the start.

(It turns out that sipping on water whilst waiting in the starting pen is not helpful – lesson learnt!)

After the bad start I was back up and running and managed to catch my friend up and run with her for the majority of the course, both of us supporting each other through the bad patches and steering each other through the crowds of runners. The atmosphere was electric and at times pretty deafening; there were supporters lining the barriers throughout the entire course and a real camaraderie between the runners. I had passed the Cutty Sark in what seemed like minutes and got to experience the fantastic ambience of Tower Bridge whilst still feeling reasonably good. On the two-way stretch immediately afterwards, we missed seeing Mo Farah coming back the other way, but got to see a few of the Elites making it look all too easy. Next up was Canary Wharf where the fatigue started to hit. The marathon course seems to weave its way around the buildings for what seems like forever and coming around the corner to spy the O2 Arena when I thought I was already heading back towards the centre was probably the least motivating point of my race.

Once I was back on the two-way section, I had the boost of seeing all the runners coming the other way and knew I was finally heading towards the finish. Unfortunately, by mile 20 my legs were getting very heavy and sore and my pace was starting to drop. Knowing that I was below my target pace it was time to switch to plan B – to ease back and start soaking in the atmosphere.

The last mile seemed to stretch on forever, but eventually I crossed the finish line in 3 hours and 32 minutes with a big smile on my face. It was not the time I was hoping for, but it was right at the top of the list of life's amazing experiences. Having collected my medal and kit bag, it was time to shuffle to St James' Park to meet up with Les and Irene and some much-needed seats, refreshments and bubbly!

Overall, I had an incredible experience; the last few miles of the marathon were extremely tough, but knowing that every step I took was raising money for Myositis UK was more than enough motivation for me to make it to the line – so a big thank you to everyone who sponsored and supported me and to Les and Irene for all their help on the day. I can't wait to do it all again!

The event raised over £3,000 for the charity.

Fundraising

Christmas Cards

We reintroduced our Christmas cards in 2018, however, the take-up was lower than we expected. We will be selling the cards again this year at a reduced price and we look forward to your support.

Donations In Memorium

The charity has received many donations in memory of loved ones as well as being a beneficiary of several bequests. Thank you to all who have given in this way.

Co-op's Community Fund

Irene and I attended a cheque presentation as a result of our name being put forward to benefit from this fund and we received a fantastic sum of £2,845.

This money was raised by customers who shopped at their stores in the Sholing area of Southampton. When they shopped at the Co-op, 1% of what they spent on selected own-brand products and services went to the Co-op Local Community Fund. The funding period was for eleven months to 27th October 2018.

The event was organised by Sheila Elsey who is a member pioneer at the Spring Road Sholing shop where Dan the store manager assisted in the cheque presentation.

With Sheila, we then visited the Co-op store in South East Road to join store manager Kev and Portsmouth Road store manager Geoff. A total of £8,391 was presented.

It is amazing how much unheralded work goes on, supported by the Co-op, where £19m has been raised. I must add, too, that the enthusiasm shown by Sheila was remarkable and everybody appreciated the effort she made.

Local Donations

For some years, Ahmad Tea have helped us and this year they have again, with a donation of £500. The company follows our progress with much concern and we are greatly indebted to them.

For several years I have received a cheque from Mr John Herod for £100 as he, also, follows what the charity is achieving. He has no other connection to the charity which makes this gesture very much appreciated.

Another local company which is aware of Myositis UK is Secretarial Law who presented a cheque on behalf of the trustees of The Richard Kirkman Trust for £1,500. They have annually been pleased to help along with several trusts for many years.

Masonic Donation

I attended a presentation evening in Southampton organised by local Masonic lodges and was presented with a cheque for £300 from Netley Abbey Lodge. The presentations were to various local charities from different masonic lodges. It was an enjoyable evening with a buffet and the mayor of Southampton presenting the cheques. I then had my photo taken with the cheque with Adrian Mori, Netley Abbey Lodge, V.W. Bro. Jon Whitaker, Deputy Provincial Grand Master of Hampshire and Isle of Wight and Cllr. Peter Baillie, Mayor of Southampton.

Cholmeley Park Masonic Lodge

The President of the Lodge, David Greenhalf, and his wife, Beverly, kindly named Myositis UK as one of his charities that they were supporting through his year of office. They donated £2,500 to Myositis UK as a result of their activities. Irene and I had the pleasure of attending one of their weekend dinner and dance events in the Cotswolds. It was a wonderful occasion and we had a lovely time. I was invited to London where Dave's Lodge meets to receive the cheque and I had the opportunity of saying a few words of grateful thanks.

West Linton Bowling Club, Scotland

Treasurer Archie Mears sent a donation for £619. The money was raised by the Club Charity Bowling Day in appreciation of assistance to Andrew Macnab at the request of the Macnab family, West Linton.

Haskins Garden Centre

Southampton Magna Rotary organised a fundraising event at Haskins Garden Centre, Southampton. It was a ticket only event after the store had closed. There were various local craft stalls, a raffle and a silent auction. The price of the ticket included a 2-course meal and Haskins gave a 10% discount in the garden centre. There were two charities being supported by this event and Myositis UK received £1000 from the event. Our thanks to Terry Pugh and all of the Magna Rotary team for organising a great evening.

Letitia Jane Rawson

Pat and John Rawson, whose daughter Letitia sadly died a few years ago, write: "Another year round and once again just to say thank you for keeping us up-to-date with all the news from the charity. This is the time of the year when her birthday comes round, when we particularly remember Letitia, although she is never far from our thoughts. Please accept the enclosed small contribution (in her memory) to the myositis cause."

Margaret & Bruce Cross

Margaret and Bruce run the reception desk at our conferences. Having been shopping they noticed something "stuck" in one of their trolley wheels and found a man's wedding ring. They were able to return it to a grateful couple who insisted on giving them a "reward". Margaret and Bruce didn't want a reward but said a gift to Myositis UK would be very kind. They promptly gave a donation of £40.

Afternoon Tea

Head Office staff at Avante Care & Support in Faversham hosted an afternoon tea to raise awareness and funds for Myositis UK. We would like to thank everyone involved for their support.

They wrote on their website:
The event was held in memory of Avante colleague and friend Amanda Gibbs who had worked with Avante Care & Support for over 10 years in the payroll department and sadly passed away last September. The myositis charity was close to Amanda's heart.

The afternoon tea included an abundance of homemade cakes, scones and sausage rolls all kindly baked and donated by staff. Alongside the food was a range of entertainment including bingo, an egg and spoon race, a crossword puzzle, darts and a raffle where all prizes were kindly donated from generous staff across Avante Care & Support.

The afternoon was a great success, full of fun and laughter, with a generous £350 raised for Myositis UK.

Elaine Cox, Assistant Payroll Manager, said: "We are delighted with the success of the event. We wanted to host an afternoon tea in memory of our colleague and dear friend Amanda. It felt right that we should use the day to help raise much needed funds and raise awareness for Myositis UK. I am so grateful for all the help, donations and fun that everyone brought to the afternoon."

Eastleigh Masonic Lodge

John Ewbank, Lodge Charity Steward writes:
"It is my pleasure, once again, to enclose a cheque for £500 from Eastleigh Lodge. We know you have an ongoing challenge to raise funds and we hope this gives a moments respite. I have no doubt we will continue to support you as funds permit."

Eastleigh Lodge has been a supporter of Myositis UK for many years and this kindness is given discreetly without ceremony other than a sincere wish to help our cause. Their regular contribution has been of such a great help during this time and enable the charity to realise the progress it has made.

JustGiving Pages

The following news has been taken from JustGiving pages where fundraising for the charity has taken place.

Susan Kemp

Moonlight Colourthon, 6 July 2019

£1,490 raised + £275.25 Gift Aid

Susan's story:

My husband Ian was diagnosed with dermatomyositis in October 2018. There is no cure for this disease at present so Ashleigh and I are taking part in the Colourthon Half Marathon on 6 July to try to raise some much needed funding for Myositis UK, which is a small national charity providing information to those affected by myositis and funding research to improve diagnosis and treatment.

David Jordan

Vale Velo Sportive, 6 April 2019

£1,431.78 raised + £312.50 Gift Aid

David's story:

Over the last 18 months our lives have been altered by my wife's diagnosis with polymyositis.

We are dealing with this disease head on. Nicola is still working full time, delivering 3 fitness classes a week as well as attending the gym 3 mornings a week. I though the least I could do was a 117k cycle ride and try to raise a bit of cash for the ongoing fight with myositis.

Update:
Thank you so much for all the donations and kind messages of support, it certainly helped keep me going and got me over the line! We have been overwhelmed by the generosity, we cannot thank you enough - the target has been smashed out of sight.

Rachel McMurray
Hackney Half Marathon, 19 May 2019

£728.84 raised + £101.25 Gift Aid

Rachel's story:

Harry's dad was diagnosed with polymyositis last year and is currently undergoing treatment. I have decided to challenge myself and run the Hackney Half Marathon in May, while taking the opportunity to raise some money for Myositis UK.

Milan Udani

£50.00 + £12.50 Gift Aid

For my sister's 36th birthday on 11 January 2019, she has asked everyone who is planning on gifting her to instead donate money to Myositis UK as her late father suffered from it.

Five Go Mad In Surrey

£2,477.55 raised + £529 Gift Aid

Julia Corkey's story:

"You need to make the best of a bad lot". In a triumph of British understatement, that was how the neurologist broke the news to my mother that she had been diagnosed with the disease Inclusion Body Myositis (or IBM).

My mum Betty had spent her working life as a doctor, mainly in public health, baby clinics, school health and Blood Transfusion. She endured this cruel diagnosis of relentless decline with stoicism.

We, her family, had the difficult task of watching mum's inevitable decline and seeing this lively, sociable woman become entirely dependent on the support of fabulous carers.

That struggle came to an end on 28th May 2016, when mum died at the age of 79.

It's entirely fitting that on 25th May this year, I and four work colleagues – Tony, Lizzie, Robin and Fergus – are going to walk a 25 kilometre stretch of the London to Brighton challenge for Myositis UK. It's a fun outing with a serious purpose. On the day when we set off for Surrey, mum would have turned 82. IBM never overcame her spirit; she did indeed "make the best of a bad lot". With any small amount you can spare, we will do the best job we can to raise money for Myositis UK on May 25th.

Update:
A massive thank you for supporting our Famous Five sponsored walk yesterday. Knowing so many generous people had supported us in raising money in memory of dearest Mum kept me going despite my painful knee. It was a leisurely 7 hour stroll with much merriment and the occasional break fuelled by Lizzie and Robin's copious snacks.

My brother Jonathan joins the Famous Five, Lizzie, Tony, Robin, Fergus and me in saying thank you so very much for your support.

Georgia and Gabriella Basiuk
Great Manchester Run 10k, 19 May 2019

In memory of Roman Basiuk

£595 raised + £110.25 Gift Aid

Their story:

I, along with my sister Gabriella and brother Tomas, are raising money for Myositis UK in memory of our amazing Dad, Roman.

I am hoping that this is the start of my fundraising journey for a brilliant charity. I wish to channel the negative energy I have from the difficult past year into a fantastic cause.

I want to try to find hope in all that has happened over the last 18 months and work towards preventing other people from experiencing what we all went through. Me and Gabriella are therefore beginning our fundraising journey by running the Great Manchester Run 10k on 19th May 2019. Me and Gaby are not the best at running so this is going to be a challenge for us! My Dad was always there when I was younger, racing at the side of me and spurring me on when I was struggling at cross country and so I'm hoping he's going to do the same for us during this 10k!

In Memory of Tricia

£700 raised + £128.75 Gift Aid

Russell Owen's story:

Mum had a condition called inclusion body myositis. It was the main contributing factor to her physical challenges in life which she lived with for many years. It was also a factor in why she died on 11th May.

She would be very proud to know that we were supporting this charity that supports research into this condition and may go to help or prevent someone else from having to deal with the same battles that mum endured.

Russ, Robin & Don. Xxx

Tomas Basiuk
Snowman Legend, 27-28 July 2019

£1,175 raised + £213.75 Gift Aid

Tomas's story:
In October 2018 I lost my best mate, my Dad Roman Basiuk. He wouldn't want me to feel sorry for myself, instead he would want me to channel my emotions into something positive. That is why I have decided to compete in The Snowman Legend, the toughest triathlon in the UK, fundraising for Myositis UK.

Update:
My admission to the event was driven by my sheer desire to do something huge for my Dad, and reluctantly I may have been a bit naïve. My plan, now, is to compete in this event next year, and prior to that compete in plenty of other events so I can ensure I am fully prepared.

Lung Buster Challenge

£660 raised + £95 Gift Aid

Friends of Lisa at United Commercial Finance took part in this challenge, completing three half marathons for Myositis UK because we can... and they can't. This event included rowing, cycling and running.

Gillian Sellar

£20.00 + £5.00 Gift Aid

Hoping more treatments can be found for this cruel condition.

Jasminder Oberoi

Mount Kilimanjaro Trek

£1,172.98 + £191.25 Gift Aid

Jas's story:

I'm doing this trek to raise awareness of, and research funding for, myositis. My Dad was diagnosed with it a few years ago and it has been having a progressively degenerative impact on his quality of life. There's currently no cure for myositis and I'd love one day for there to be one. So I hope that by doing this 6-day trek, which goes to an altitude of almost 6,000 metres, I can raise money for research and make a difference!

Update:

I'm pleased to report that I managed to reach the summit of Uhuru Peak in Tanzania on 3rd August, so thanks to all of you for your generous donations, which will go straight to the charity.

Shana Emmerson

Asda Foundation Yorkshire Marathon, 20 October 2019

£564 raised + £98. 75 Gift Aid

Shana's Story:
About 18 months ago my sister was diagnosed with myositis. Running is something she can no longer do, so what better way to raise money than run my first marathon.

Su Wilson

Stephen & Nicky's Long Course Weekend, Wales, 5-7 July 2019

£665 raised + £61.25 Gift Aid

My lovely cousin Stephen Rogers and his friend Nicky Rees are competing in their 10th Long Course Weekend in Tenby and have asked to raise money for Myositis UK. Why? Well, I was diagnosed with Juvenile Dermatomyositis when I was six years old and I've been living with the effects of it for over 40 years. Back then they knew little about the autoimmune disease and today's treatments are slowly improving for newly diagnosed children but still there is more research needed to find out why this horrible disease happens and how to control it.

Although I think Stephen and Nicky are crazy to be swimming, running and cycling in a weekend event, I am proud and thankful for them to be taking on this challenge.

London Marathon 2020

In memory of Ian Tagg, Target: £1000

Tommy Tagg's story:
In December 2010 I lost my dad, it's been 8 years now and anyone who has lost someone so close to them will know it takes years before you can say "I'm ok".

In 2020 I will be running The London Marathon for Myositis UK. So, in the words of Den Dennis: "Give us all your money!"

https://www.justgiving.com/fundraising/tommy-tagg

Tommy is the first of our Gold Bond runners to set up his JustGiving page.

Abbie Marks

Weston Park 5k, 24 November

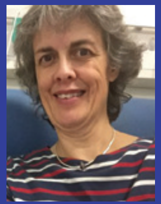
Abbie's story:

Heidi and I are going to do a 5k run for Myositis UK because our dad was diagnosed with the disease a few years ago. Any donations received would be very much appreciated from us both and we'd like to say a huge thank you! www.justgiving.com/fundraising/abbie-marks2

Helen Kurtz

Team Muscle

Helen's story:



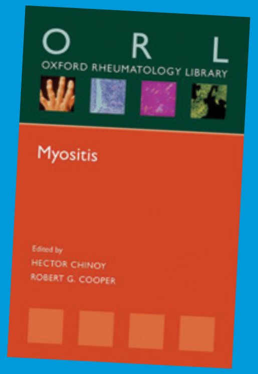
Last year I was diagnosed with myositis. It has had a huge impact on my life as I have been unable to work and it limits my daily activities significantly. I have had a lot of support from Myositis UK and would like to raise as much money as I can, through creative activities, to say thank you. https://www.justgiving.com/fundraising/helen-kurtz

Hector Chinoy

Congratulations to Hector on being made a professor earlier this year. Many of you will know Dr Chinoy either from attending our conferences, meet-ups or being one of his patients.

Myositis Book

Edited by Hector Chinoy and Robert G. Cooper
Oxford Rheumatology Library



A concise and practical guide aimed at improving the treatment of patients with idiopathic inflammatory myopathies. An essential and compact guide for both physicians and trainees in the fields of rheumatology, neurology, and dermatology.
Features key points at the start of each chapter to summarise content for accessible information.

This book is intended for the medical profession but we do have copies for sale at a special price if any member would like one. The cost is £22 including p&p. Please send a cheque made payable to Myositis UK to the office.

Dr Jo Parkes

Dear Myositis UK,

I wanted to write to thank you for your support of young investigators in myositis research. I was really impressed with the speed funding event at the most recent Global Conference On Myositis (GCOM) in Berlin. I have been attending GCOM since it began. When I went to the first GCOM in Stockholm in 2015 I was in the first year of my PhD at the University of Manchester and it was amazing to meet some of the scientists whose work I had spent the last few months reading. In 2017 I got a travel bursary from Myositis UK to attend the second GCOM in Potomac, Maryland. Here I had the opportunity to re-connect with some of the scientists I had met in Stockholm, including Prof Kanneboyina Nagaraju. One evening I asked him if it would be possible to come and work with him once I had completed my PhD. In my final year he helped me apply for funding and I am now working as a post-doctoral researcher in his lab in Binghamton, New York, with a two-year mentored research fellowship from The Myositis Association. I wouldn't be here without the Myositis UK travel bursary which allowed me to attend the second GCOM so I just wanted to say thank you for your amazing and continued support of young investigators in myositis research!

Best wishes, Dr Jo Parkes

Research

The third global myositis conference was held earlier in the year and this allowed for even stronger collaborations to be formed and opportunity for young myositis researchers to engage. Dissemination of ongoing projects (many in their infancy and unpublished) and ideas were enthusiastically shared by those attending the Berlin meeting. You would of read that Myositis UK was pleased to fund travel bursaries to young researchers for this conference and award funding to research projects of three young scientists (at the very start of their myositis career) via the conference's Speeding Funding initiative. With funding grass roots it's an area that we can really make improvements to the diagnosis, understanding, management and ultimately treatment of myositis. Hector Chinoy (now professor) and Zoe Betteridge were researchers who previously received prime funding from us. Their work and collaborations have seen them become highly respected world experts in their fields. A literature search on Pubmed emphasises this with further publications in journals this year. To note this search does not include the vast number of poster presentations and oral submissions at various medical conferences this year or ongoing work.

Below is a short list of published work by researchers who have received assistance from Myositis UK (funding of salary, research consumables, dissemination of information, miscellaneous support, etc.). If the full paper is available online to read for free this is stated. Visit www.pubmed.com and enter the given PMID number or perform your own search. There are over 600 articles to read for the term 'myositis' for this year alone to browse through.

Genetics of idiopathic inflammatory myopathies: insights into disease pathogenesis.

Rothwell S, Chinoy H, Lamb JA.
Published in Current Opinion in Rheumatology, August 2019. Abstract only. PMID: 31415030

Safety and efficacy of intravenous bimagrumab in inclusion body myositis (RESILIENT): a randomised, double-blind, placebo-controlled phase 2b trial.

Hanna MG plus 46 coauthors of the RESILIENT Study Group.
Published in The Lancet Neurology, September 2019. Abstract only. PMID: 31397289

Including myositis-specific autoantibodies improves performance of the idiopathic inflammatory myopathies classification criteria.

To F, Parker MJS, Ventín-Rodríguez C, Lilleker JB, Chinoy H.
Published in Rheumatology (Oxford), June 2019. Free access in full. PMID: 31382296

Genomewide Association Study of Statin-Induced Myopathy in Patients Recruited Using the UK Clinical Practice Research Datalink.

Carr DF, Francis B, Jorgensen AL, Zhang E, Chinoy H, Heckbert SR, Bis JC, Brody JA, Floyd JS, Psaty BM, Molokhia M, Lapeyre-Mestre, Conforti A, Alfirevic A, van Staa T, Pirmohamed M.
Published in Clinical Pharmacology and Therapeutics, June 2019. Free Access in full. PMID: 31220337

Focused HLA analysis in Caucasians with myositis identifies significant associations with autoantibody subgroups.

Rothwell S plus coauthors of the Myositis Genetics Consortium (MYOGEN).
Published in Annuals of the Rheumatic Diseases, July 2019. Free access in full. PMID: 31138531

Frequency, mutual exclusivity and clinical associations of myositis autoantibodies in a combined European cohort of idiopathic inflammatory myopathy patients.

Betteridge Z, Tansley S, Shaddick G, Chinoy H, Cooper RG, New RP, Lilleker JB, Vencovsky J, Chazarain L, Danko K, Nagy-Vincze M, Bodoki L, Dastmalchi M, Ekholm L, Lundberg IE, McHugh N; UKMyonet contributors.
Published in Journal of Autoimmunity, July 2019. Free access in full. PMID: 30992170

Comparison of Three Immunoassays for the Detection of Myositis Specific Antibodies.

Mahler M, Betteridge Z, Bentow C, Richards M, Seaman A, Chinoy H, McHugh N.
Published in Frontiers in Immunology, April 2019. Free access in full. PMID: 31114570

[18F]Florbetapir positron emission tomography: identification of muscle amyloid in inclusion body myositis and differentiation from polymyositis.

Lilleker JB, Hodgson R, Roberts M, Herholz K, Howard J, Hinz R, Chinoy H.
Published in Annuals of the Rheumatic Diseases, May 2019. Free access in full. PMID: 30760470

The temporal relationship between cancer and adult onset anti-transcriptional intermediary factor 1 antibody-positive dermatomyositis.

Oldroyd A, Sergeant JC, New P, McHugh NJ, Betteridge Z, Lamb JA, Ollier WE, Cooper RG, Chinoy H; UKMyoNet.
Published in Rheumatology (Oxford), April 2019. Free access in full. PMID: 30535395

The performance of the European League Against Rheumatism/American College of Rheumatology idiopathic inflammatory myopathies classification criteria in an expert-defined 10 year incident cohort.

Parker MJS, Oldroyd A, Roberts ME, Lilleker JB, Betteridge ZE, McHugh NJ, Herrick AL, Cooper RG, Chinoy H.
Published in Rheumatology (Oxford), March 2019. Free access in full. PMID: 30496561

Recent developments in classification criteria and diagnosis guidelines for idiopathic inflammatory myopathies.

Oldroyd A, Chinoy H.
Published in Current Opinion in Rheumatology, November 2018. Free access in full. PMID: 30138132

Rapamycin for inclusion body myositis: targeting non-inflammatory mechanisms.

Lilleker JB, Bukhari M, Chinoy H.
Published in Rheumatology (Oxford), March 2019. Free access in full. PMID: 29529264

Investigation of the psychometric properties of the inclusion body myositis functional rating scale with rasch analysis.

Ramdharry G, Morrow J, Hudgens S, Skorupinska I, Gwathmey K, Currence M, Herbelin L, Jawdat O, Pasnoor M, Mcvey A, Barohn RJ, Burns TM, Dimachkie MM, Amato AA, Hanna MG, Machado PM.
Published in Muscle Nerve, August 2019. PMID: 31107564

Genome-wide meta-analysis reveals shared new loci in systemic seropositive rheumatic diseases.

Acosta-Herrera M, Kerick M, González-Serna D; Myositis Genetics Consortium; Scleroderma Genetics Consortium, Wijmenga C, Franke A, Gregersen PK, Padyukov L, Worthington J, Vyse TJ, Alarcón-Riquelme ME, Mayes MD, Martin J.
Published in Annuals of the Rheumatic Diseases, March 2019. Free access in full. PMID: 30573655

Community exercise is feasible for neuromuscular diseases and can improve aerobic capacity.

Wallace A, Pietrusz A, Dewar E, Dudziec M, Jones K, Hennis P, Sterr A, Baio G, Machado PM, Laurá M, Skorupinska I, Skorupinska M, Butcher K, Trenell M, Reilly MM, Hanna MG, Ramdharry GM.
Published in Neurology, April 2019. Free access in full. PMID: 30850441

The role of imaging in evaluating patients with idiopathic inflammatory myopathies.

Kubínová K, Dejthevaporn R, Mann H, Machado PM, Vencovský J.
Published in Clinical and Experimental Rheumatology Online, September-October 2018 Supplement. Free access in full. PMID: 30296982

Paraneoplastic Dermatomyositis: relevance of myositis specific autoantibodies in a small cohort.

Maier L, Betteridge Z, Udvardi A, Schmid-Simbeck M, Seeber A, Volc-Platzer B.
Published in Journal of the European Academy of Dermatology and Venereology, August 2019. Free access in full. PMID: 31429503

Investigation of myositis and scleroderma specific autoantibodies in patients with lung cancer.

Betteridge ZE, Priest L, Cooper RG, McHugh NJ, Blackhall F, Lamb JA.
Published in Arthritis Research and Therapy, August 2018. Free access in full. PMID: 30092841

Galectin-9 and CXCL10 as Biomarkers for Disease Activity in Juvenile Dermatomyositis: A Longitudinal Cohort Study and Multicohort Validation.

Wienke J, Bellutti Enders F, Lim J, Mertens JS, van den Hoogen LL, Wijngaarde CA, Yeo JG, Meyer A, Otten HG, Fritsch-Stork RDE, Kamphuis SSM, Hoppenreijs EPAH, Armbrust W, van den Berg JM, Hissink Muller PCE, Tekstra J, Hoogendijk JE, Deakin CT, de Jager W, van Roon JAG, van der Pol WL, Nistala K, Pilkington C, de Visser M, Arkachaisri T, Radstake TRDJ, van der Kooi AJ, Nierkens S, Wedderburn LR, van Royen-Kerkhof A, van Wijk F.
Published in Arthritis and Rheumatology, August 2019. Free access in full. PMID: 30861625

Systemic and Tissue Inflammation in Juvenile Dermatomyositis: From Pathogenesis to the Quest for Monitoring Tools.

Wienke J, Deakin CT, Wedderburn LR, van Wijk F, van Royen-Kerkhof.
Published in Frontiers in Immunology, December 2018. Free access in full PMID: 30619311

Being on the juvenile dermatomyositis rollercoaster: a qualitative study.

Livermore P, Gray S, Mulligan K, Stinson JN, Wedderburn LR, Gibson F.
Published in Pediatric Rheumatology Online J, June 2019. Free access in full. PMID: 31215480

Juvenile dermatomyositis: novel treatment approaches and outcomes.

Varnier GC, Pilkington CA, Wedderburn LR.
Published in Current Opinion in Rheumatology, November 2018. Abstract only. PMID: 30124602

Research Grants

The trustees have approved the following grant applications:

- £5,000 to University of Manchester to fund data base manager for IMACS coreset measures online training tool.
- 45,000 euros for the “speed funding” at GCOM.
- £12,800 to Dr Janine Lamb to fund the salary of an experimental officer for 6 months. This role is fundamental to supporting many of their ongoing myositis research activities. The person is currently responsible for receiving and co-ordinating patient samples from all of the participating UK Myositis Network (UKMYONET) and MYOPROSP centres. This role includes sample labelling, separation of plasma or serum e.g. for autoantibody testing in Bath, extraction and measurement of DNA, sample storage, data entry into our secure database and ensuing sample integrity and data quality. They also prepare samples for collaborative research activities, liaise with clinical and scientific collaborators and is the designated individual for our Myositis Research Tissue Bank.

Dr Simon Rothwell

Research Lay Summary

Focused HLA Analysis in Caucasians with Myositis Identifies Significant Associations with Autoantibody Subgroups. Annals Rhem Diseases. In Press 2019.
Rothwell, S., Chinoy, H., Lamb, J.A., Miller, F. W., Rider, L.G., Wedderburn, L.R., McHugh, N.J., Targoff, I.N., Mammen, A.L., Betteridge, Z. E., Tansley, S.L., Bowes, J., Vencovsky, J., Deakin, C. T., Danko, K., Limaye, V., Selva-O’Callaghan, A., Pachman, L. M., Reed, A. M., Molberg, O., Benveniste, O., Mathiesen, P., Radstake, T., Doria, A., De Bleecker, J. L., Lee, A. ., Hanna, M. G., Machado, P. M., Oliier, W. E., Gregersen, P. K., Padyukov, L., O’Hanlon, T. P., Cooper, R.G., Lundberg, I. E., Myositis Genetics Consortium (MYOGEN).

What was already known?

The idiopathic inflammatory myopathies, known collectively as myositis, are a rare group of autoimmune diseases. In these autoimmune diseases, the immune system, which normally protects the body against infections, attacks its own muscle tissue leading to muscle wastage and weakness. Other complications may also occur, such as characteristic skin rashes, interstitial lung disease, and cancer.

Currently, we do not know the exact causes of myositis, however they are thought to be ‘complex diseases’. This means that both genetic and environmental risk factors play a role in the disease. Previous studies have shown that a part of DNA known as the major histocompatibility complex (MHC) is involved. This is also the case in other autoimmune diseases such as rheumatoid arthritis or lupus.

The MHC contains many genes that are important in the immune system, especially those that allow the body to recognise the difference between self (our own body), and non-self (such as bacteria and viruses).

What was discovered?

Many myositis patients have specific proteins called antibodies in their blood. As these antibodies target our own body, they are known as ‘autoantibodies’. Patients with the same autoantibody may have similar features of disease, follow a similar disease course, or respond to treatment in a similar way. In this study, we investigated whether genes that contribute to disease risk are different in patients with different autoantibodies.

We have previously collected genetic data from myositis patients in 14 countries across the world as part of the Myositis Genetics Consortium (MYOGEN).

For this study we also collected information about which autoantibodies these patients had. We then grouped myositis patients together based on these autoantibodies, and compared their DNA to people without the disease to identify possible genetic differences.
We found that for some autoantibody groups, there were unique genetic differences that we previously did not know about. We knew that a region of DNA was involved with this disease, but our study identified specific genes within this region that we think are directly involved with disease. We are also beginning to understand what these changes in DNA actually do in our body, and why they are involved in disease.

One specific autoantibody is present in both adults and children with myositis.

This is of particular importance, as there is a strong risk of cancer in adults with this autoantibody. However, there is no increased risk of cancer in children with this autoantibody.

This study has shown for the first time that there are differences in the DNA between adults and juvenile patients.

This may explain why the disease in adults and children with this autoantibody looks different.

Why is this important/what is the benefit to patients?

Myositis is a rare disease. Because it is rare, not much is known about genetic risk factors. This is the largest genetic study to investigate differences between myositis patients with different autoantibodies.

This study has shown that grouping patients by autoantibody is important for conducting meaningful genetics research.

The clinical features of this disease can vary greatly between patients.

Understanding the genetics of myositis may help us to discover why certain patients have a specific form of disease. It may be that there are different environmental risks of which we are not yet aware, and this is an ongoing area of research.

Due to the continued efforts of MYOGEN collaborators across the world collecting patients’ DNA samples for research, this is the largest study of its kind in myositis.

This study paves the way for future studies that may lead to drug treatments or strategies for this debilitating and under-researched disease.

50 Word Lay Summary

Myositis patients with the same autoantibody seem to have similar features of disease. We investigated whether there are specific genes that are associated with different autoantibody subgroups in both adults and children with myositis. We found unique genetic differences with some autoantibody groups, and we identify specific genes that we think are directly involved with disease.

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 the office.

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. A twitter page and an online community forum. Treasurer, Jo Goode, has set up a facebook myositis forum page as well as the meet-up page. Links to all the pages are listed below.

Myositis UK is our main charity page. It allows us to post messages in real-time and re-post suitable messages from other organisations. It acts as the hub for our other Facebook Pages and is administered by Paula Jordan (Trustee) and Jo Goode (Treasurer).
http://www.myositis.org.uk

Team Muscle Facebook Page is for anyone fundraising or supporting fundraising for Myositis UK. It is a great way to promote your event, share your Just Giving Page, upload photos or updates and for supporters to see your event. Initially set-up for our Gold Bond London Marathon runners this Page is now for all fundraisers whatever your activities are. Paula Jordan and Jo Goode administer this page.
https://bit.ly/2NUK7vE

Juvenile Dermatomyositis Facebook Page was initially set-up by Nikki (JDM mum and Trustee) to raise funds for JDM (namely the Teddy-Bo Project) but has evolved as a great Page for JDM interaction. Now co-administered with Paula Jordan they post information that may help JDM parents ranging from news from Myositis UK to re-tweets from other organisations.
https://bit.ly/2pgkyHq

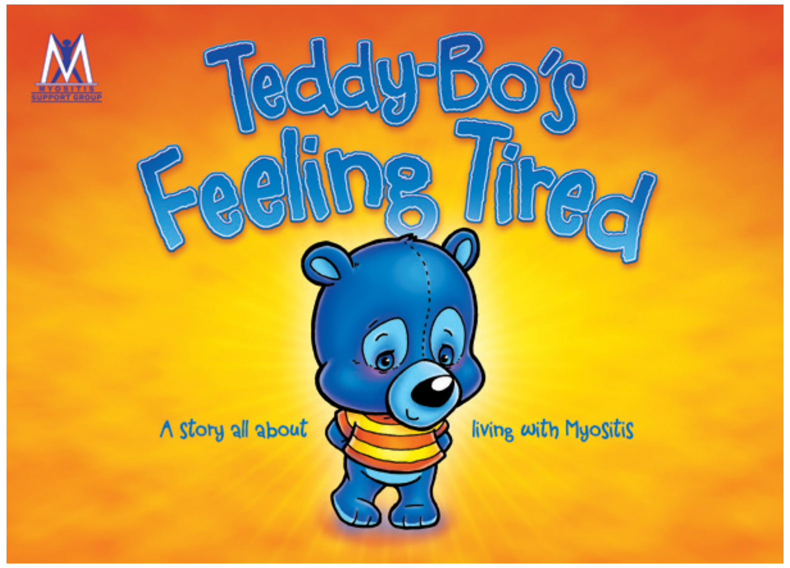
Teddy-Bo, his friends, adventures and juvenile dermatomyositis Facebook Page is administered by Paula Jordan and Nikki Baron. This Page allows anyone to follow Teddy-Bo on his adventures as he meets his friends and raises awareness of the inflammatory muscle disease. A distinct Page set-up to allow followers to just follow Teddy-Bo. The Page is for your photos and stories so wherever you and Teddy-Bo are snap it and post on the Page.
https://www.facebook.com/TeddyBoJDM

Myositis UK's Twitter page:
https://bit.ly/2MFhdv6

Myositis UK's Online Community Forum on Healthunlocked:
https://bit.ly/2peyZMc

Myositis Forum UK – UK-only facebook group administrated by Myositis UK Trustee Jo Goode
https://bit.ly/2D6lgkB

Myositis UK Meetup:
https://bit.ly/2xgY0ek



Merchandise

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

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

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

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

Postscript

Thank you to everyone who has helped the charity and for making this magazine an interesting and helpful read.

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