MYOSITIS UK

Winter 2017-18

Myositis News

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FUNDRAISING • RESEARCH

2017 AGM & CONFERENCE

Myositis AGM and Conference 2017

Dear Member

This year's conference at the Oxford Belfry hotel, Thame, near Oxford, was a very memorable and successful occasion.

It was nice to be back on track after the disappointment of the previous year when the conference had to be cancelled.

The Annual General Meeting and the following conference held on Sunday 2nd July 2017 were well attended, as was the meet and greet held in the afternoon of the previous day.

It was a pleasure to meet up with new members as well as with members who go back many years. The general conversation was very friendly and uplifting which bode well for the following day. I thank everyone for making the effort to attend, for some came from great distances where the travelling involved, even for the fittest person, must have been tiring.

The Belfry hotel is as good a place as you can get to put on a conference where you need access to break out rooms for the different

illnesses. The staff were most helpful and made every effort to make our time there run as smoothly as possible.

On the morning of the conference it was a very early start for the trustees, making sure the rooms were set up properly with adequate seating, with the sound engineers sorting out the various appliances needed in the rooms. The catering staff were hard at work organising cutlery and preparing refreshments for coffee and tea breaks that would take place during the day.

The Annual General Meeting went smoothly which is always a relief because the unexpected can always happen and the time allocated for this very important procedure kept to schedule. The trustees were re-elected en bloc. Our honorary treasurer, Jo Goode, presented the accounts that had been audited by Bridget Kalloushi. These were adopted by the membership. It was rewarding to see how well the charity had maintained its income and to keep up with funding new and ongoing projects.

Les Oakley MBE
Chairman

Chairman's Report 2016-17

The first six months of the financial year (April 2016) were difficult at times for the trustees and we have not attended as many events as usual. The trustees have supported and attended the fundraising events where needed or requested if they were able to do so.

We are still looking for that special trustee with corporate and grant application fundraising abilities to come on board and continue in this vital role to enable the charity to develop and expand the sound research that has been made in all forms of myositis.

I would like to thank all who raised funds for the charity whether they are members, family, friends or our medical teams. These events and projects have been well reported by the charity and deservedly published in our Charity News magazine and on our relevant web pages. I am particularly grateful to members, family and friends who have donated to the charity in memory of loved ones.

I would like to thank all the medical teams and their support staff for their tireless energy in helping our members with these miserable conditions.

Teddy-Bo continues on his travels and the photographs of him around the world have been quite amazing. His Facebook page continues to be a big hit and I trust you will continue to send in your pictures.

We attended the Euromyositis Registry Meeting held in Manchester which was organised by Dr Chinoy.

Professor Ingrid Lundberg, Karolinska Institute, Stockholm, Sweden, talked about the history and background of Euromyositis and Dr Hector Chinoy gave a talk on the components of the Euromyositis registry.

This was followed by two days of talks and discussion by those attending. Paula Jordan gave a talk on the Patient-Public involvement opportunities. I am very grateful to her for attending as she was seven months pregnant at the time. She now has a very healthy little boy.

Following on from the success of the 1st International Myositis Conference in Sweden in 2015 the next international Myositis conference will be held in the USA in May 2017.

The trustees agreed to offer bursaries to young doctors and scientists with a proven interest in myositis to enable them to attend this meeting. A budget of £10,000 was agreed.

The trustees approved six

applications. Irene and I will also be attending and the trustees agreed the cost for us to attend would be paid by the charity but we agreed to pay for our travel. It is important to attend these meetings to enable us not only to hear what is going on in research around the world but to meet with other patients groups from different countries.

Irene and I attended the two-day 10th UK Neuromuscular Translational Research Conference in London where we were able to have a display table. We were able to give information about the charity to those attending the conference. We also attended along with Jo Goode the UK Myonet meeting in London in October 2016. These are meetings for the medical profession but they kindly allow us to attend and take part.

Laura Oakley joined as a trustee and her main role is to review and update the website which is now five years old! She currently works as a writer in the charity field in London so has a good background knowledge of charity websites.

The community forum on the website is little used as many prefer to use Facebook. At the moment we have to pay an annual fee for the community forum that we use. Treasurer Jo Goode has set up a new forum which is running alongside the community forum at the moment. This site is free to use and is used by other charities. The trustees have decided to cancel the community forum when it is due for renewal in September 2017 and to continue with the free version. This will save the charity money and still give members access to a forum.

I would also like to mention the help to the charity from Simon Chadwick in producing our Myositis News. He always comes up trumps in meeting almost impossible time demands for publications. Our charity auditor Bridget Kalloushi for her help yet again in overseeing the accounts.

My appreciation is also offered to Hon. Treasurer Jo Goode for not only diligently looking after our accounts but also as an overseer for community and Facebook pages and organising the London “Let’s Meetup” meetings. Nikki Baron and Paula Jordan our secretary also play an active role in similar JDM pages and the “Team Muscle” Facebook page.

After the AGM, Irene, the charity co-ordinator, presented the audience with a report including photographs of the International meeting for Myositis held in the USA. It was very remarkable to see and hear of the significant progress being made.

2nd Global Myositis Conference

Following the extraordinary success of the first International Conference held in Sweden two years ago the second three-day International (Global) Myositis Conference has been held at the Bolger Centre in Washington DC. It has attracted over 262 delegates from 22 countries. Obviously, the largest contingency was from the United States.

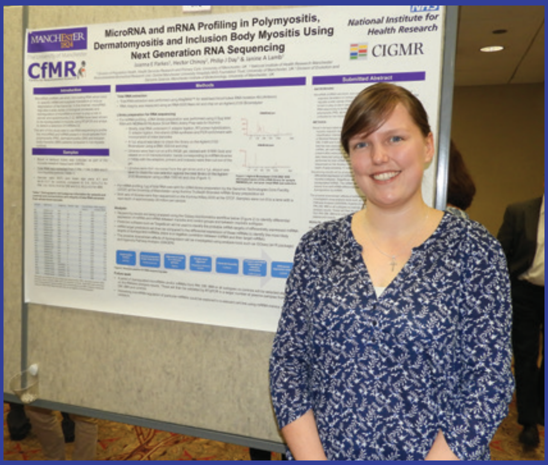
There were 55 doctors and scientists from Europe of which 20 were from the United Kingdom. There were 11 from China, 10 from Japan, 10 from Canada, four from Brazil, two from Australia as well as delegates from Israel, New Zealand, India and Mexico although I understand from Dr Fred Miller that the final figure had crept up a bit since registration.

This is a remarkable number of people from across the world. It was a pleasure to see many new faces involved with the treatment, management and research of all forms of myositis along with well-established doctors and scientists already well known to us. As a result of funds raised by members of Myositis UK we were able to fund or part-fund six medical professionals already working in the field of myositis to attend and be part of this exciting progress offering global opportunities and challenges for future studies and neuromuscular clinical trials. The networking as a result of this conference will, I am sure, develop many new collaborations and friendships.

It was great to meet up with Danial Ponce from France, Corinna Preube from Germany and representatives of the host charities, Cure JM and the Myositis Association.

There were presentations by doctors and scientists from around the world including many from the UK.

It was a very busy and intense programme over the three days with well delivered presentations by the invited speakers creating much debate and deliberation. Although there was such an intensity about the occasion there were also moments where the inclusion of wit and humour assisted to drive the agenda along. Four of these speakers attended our AGM and conference in July.



Joanna Parkes, Phd student, presenting her poster

Joanna Parkes, who is a PhD student and who received a bursary from Myositis UK, was selected to present her poster of her research at the meeting. This was the first time she had presented and I know she was very nervous but she coped with those questioning her very well. It is heartening to see a young scientist with an interest in myositis.

2nd Global Myositis Conference

Dr Fred Miller and Dr Lisa Rider presenting Dr Charalampia Papadopoulou (left) and Dr Zoe Betteridge (right) awards for their work in Myositis and Professor Lundberg (below) for her outstanding achievement and dedication to Myositis.

The organisers of the conference gave special awards to mark outstanding research and commitment in the field of myositis. Among those receiving the awards were Dr Charalampia Papadopoulou from Great Ormond Street Hospital, Dr Zoe Betteridge from Bath and Professor Ingrid Lundberg from Sweden.

One of the daily sessions

It was a very informative and inspiring conference. Although much of what was presented went well over my head. It was great to see so many people in one room with an enthusiastic interest in myositis.

Whatever the occasion you can always take time to enjoy yourself! After such an intense two days it was good to let our hair down. We had a fun night with a great band.

Organisers Dr Fred Miller and Dr Lisa Rider

Dr Fred Miller and Dr Lisa Rider should be very proud of producing a very successful conference and we look forward to the next one in two years' time in Berlin.

Myositis UK Conference reports 2017

Our charity breakout sessions took place after this presentation and I sat in with the Inclusion Body Myositis group, Paula Jordon and Laura Oakley went in with the Juvenile Dermatomyositis group, Jo Goode with the Polymyositis and Dermatomyositis members, and Irene Oakley drifted along from room to room making sure that her schedule remained on course.

Irene planned and organised the whole event on her own from doctors' invitations, to hotel accommodation with special needs and requests, to catering including dietary issues, and toys and amusements for the children. She has quite a remarkable ability to multitask, particularly when alteration to any of these facets of procedure can change at an instant and require prompt attention. I'm sure she was a pragmatic juggler in a former life! Lunch was excellent and if there were any complaints none was mentioned to me. This, again, was a chance for members to talk and exchange information and form new friendships. For me the day was going well and at last I could relax and get ready for the afternoon question and answer session back in our break out rooms.

IBM Breakout Room

Optimism in the IBM room has always been difficult because nothing in the past has appeared to work or be of benefit to them. However, this year appeared to be a different story and Dr Pedro Machado was very upbeat and honest about the future. We have never had an issue about getting speakers for IBM but over the years it has been very difficult for them to announce good news or ground-breaking progress. This was not the case this year and there are glimmers of hope on the horizon with a new medical trial for Inclusion Body Myositis. This was talked about at great length with a lively and even humorous discussion with everybody participating at some point. The time went very quickly which is a good indicator of a well received and debated discussion.

Before we retired to meet up and unite with the other groups a gentleman from the IBM group said to me, "Les, I've always been a realist and I think I'm just a bit too old and too far along the road for anything to really help me now, but isn't it wonderful news we've heard and that's all I need to give me a boost at my time of life."

JDM Breakout Room

In the JDM room Dr Claire Deakin and paediatric nurse Polly Livermore, both from Great Ormond Street Hospital, led their informal session with parents and children. As well as giving updates on treatments, trial updates and research, they had brought with them various activities for the children. I understand from talking to the parents that it was a very informative day and they really appreciated being able to meet with other families. I think the children had a great time, especially playing on the Wii!

DM/PM Breakout Room 2017

– Report by Jo Goode

Dr Hector Chinoy, James Lilleker and Janine Lamb from University of Manchester kindly gave their time to speak in the Dermatomyositis & Polymyositis breakout room. Our session started by a hasty request of additional chairs as our room was so full! Over 50 in attendance.

Dr Hector Chinoy gave the following update on research:
He explained that research would provide valuable information about how myositis disease behaves, further understanding of disease, future development of effective treatments, improve quality of life, the patient perspective - Help to take forward important research.
He gave the following summary of opportunities for myositis research:

- (UKMYONET) MYOPROSP cross-sectional study – Any myositis patient
- MYOPROSP prospective study – Ideally patients within 2 years of diagnosis or newly diagnosed – MYOACT – specifically for patients starting RTX
- UK MYONET
- Cross-sectional study: Blood test, 1 page clinical proforma, 1,600 patients recruited
- MYOPROSP
- 9+ centre UK study, commenced Sep 2016, MRC/industry funded, 80 prospective cases /year
Also opportunity to collect data cross-sectionally

These research projects are made possible by significant and sustained international collaboration across these rare and heterogeneous diseases.

James Lilleker gave an update of his work on Standards of Care in Myositis. The priorities were identified by Hector Chinoy and Myositis UK members at 2014 annual meeting. A patient survey to understand current care provision was taken: Good practice, Apparent deficits. Draft statements were produced to share good practice and deficits. Censuses building with patients, carers and health professionals.

The key messages were:
- This is the first study done for corticosteroid use in myositis.
- The average duration of treatment for is 1.84 years.
- The most common adverse effect is sleep disturbances.
- Patients' perceptions of worst adverse effects may differ from clinicians'.

Summary of presentation by Janine Lamb-Reader in

Complex Human Genetics/Genomics

Janine Lamb-Reader, of the University of Manchester, UK, explained that IIM are rare, heterogeneous, autoimmune, inflammatory disorders Idiopathic Inflammatory Myopathies. They result from chronic immune activation caused by a combination of environmental exposure(s) in genetically predisposed individuals.

She explained that genetic studies in IIM would give insights into disease pathways and identify genetic similarities and differences between subgroups, and to other immune/ inflammatory disorders.

The following are areas which this form of research could help:

- identify more homogeneous patient subgroups
- Inform disease prognosis
- Inform response to therapy for stratified treatment
- Drug re-purposing from other disorders
- Myositis Specific Autoantibodies (MSA) are closely correlated with clinical presentation.
- Antibody: a protein produced by the immune system to counteract a specific antigen
- Autoantibody: an antibody that is directed against an individual's own proteins

- Differences in genetic associations between serology subgroups
- Strong genetic associations identified for seven autoantibody subgroups
- Novel associations identified
- May be differences between adults and juveniles with the same autoantibody
- Different HLA gene associations between serology subgroups may cause binding of different proteins

Idiopathic inflammatory myopathies are thought to be caused by a combination of environmental exposure(s) e.g. occupational exposures, viral infection, in genetically predisposed individuals.

Environmental exposures linked to IIM include:
Ultraviolet radiation exposure, Smoking, Statins, Microbial infectious agents including viruses, bacteria, fungi and parasites e.g. Epstein-Barr virus, retroviruses, such as influenza & hepatitis, bacteria including streptococcal infection, Mycobacterium tuberculosis and Staphylococcus aureus.

Summary:

- IIM are rare, heterogeneous, autoimmune, inflammatory disorders
- Caused by environmental exposure in genetically predisposed individuals
- Large-scale international genetic studies have identified similarities and differences between IIM subgroups
- Suggests biological mechanisms, overlap with other autoimmune diseases
- Different HLA gene associations between clinical and serology subgroups may cause binding of different proteins
- Role of gene - environment interactions (statins, smoking, microbial infection)

Final Session

The final session saw us all back together talking about issues that affect us. Irene pointed out that next year the charity will be celebrating 30 years of age and should we celebrate it? This led to many ideas and comments of how we could do this. There were so many good suggestions but all would be found wanting in their execution. There was also a cost to be considered. The one issue we surprisingly did not consider is that we need to have our medical friends who are working on our illnesses to attend and an evening dinner looks like the only feasible option where this can be possible. It was also considered that if funds are available we could promote an extra project in recognition of the occasion. Please get in touch while there is still a little time with ideas.

During the conference we relied on our charity helpers, Margaret and Bruce Cross, long time "members" of the myositis posse, to man the reception desk and hand out programmes, name badges and generally help with information about the day and where the appropriate rooms were located. They are a wonderful couple where helping becomes second nature to them.

I thank everyone who attended particularly the members for filling in the feedback forms to help us in the future.

I also thank members for the kind letters and emails of support and appreciation to everybody who contributed on the day.

Conference Feedback

"An excellent conference. The PM/DM sessions were informative but relaxed. All credit to Dr Lamb, Dr Lilleker and above all Dr Chinoy who was exceptional. The hotel is ideal and I don't really see how you could improve on this conference. Thank you and well done to everyone involved in organising it."

"Thank you so much for organising the conference. It was the first time we have attended (our daughter has JDM). We found the session about current research really useful (Claire Deakin) and it was a great opportunity to meet other families. Thank you for all you do supporting research into the disease."

Meetups

Our Treasurer, Jo Goode, has arranged three Meetups this year, one in Manchester in May, one in Edinburgh in October and one in Ely in November.

Jo writes, “Meetups are a chance for members affected by all forms of myositis and their partners/carers to meet and have a friendly chat over afternoon tea/coffee.”

Manchester Meetup

Over forty people attended our first Manchester Afternoon Tea Meetup on Saturday 20th May 2017, including two JDM families.

Dr Hector Chinoy gave an overview of myositis and spoke to individuals during the afternoon tea.

Another Manchester Meetup is planned for 2018 and Dr Chinoy has agreed to speak again and the JDM Manchester team are interested in attending.

These are comments from a few who attended the Manchester Meetup:

“We had a great time and for the first time we had an opportunity to meet a family in our position. Thank you so much for this, means a lot.”

“Found it really useful meeting people with the same condition and not feeling so isolated”.

“Had a very enjoyable afternoon at the Myositis UK Meetup. Huge thanks to Irene and Joanne for organising and to Dr Chinoy for giving up his time. It was great to meet so many lovely people.”

“Thank you so much for a wonderful afternoon tea and chat in Manchester today. What a wonderful, cheerful, friendly lot of people, despite, in so many cases, such a lot to cope with. I feel really thrilled to have had the chance to meet everyone. Thank you!”

“Huge thanks to Joanne and Irene for organising today’s meet up, a lovely afternoon tea and talking to people who have the same condition as me, and I managed to speak to Dr Chinoy as well for a few minutes, I feel less alone now I’ve met some of you.”

Edinburgh Meetup

Our first Meetup Afternoon Tea in Scotland was held on 7th October 2017 with 17 people attending at the Dalmahoy Hotel & Country Club, Edinburgh.

These are comments from a few who attended the Edinburgh Meetup:

"We had a lovely afternoon, thank you."

"Great to meet up with everyone, especially with Barbara and Tracey again."

"Very good day; sat next to Helen and couldn't understand a word she said!"(Jokingly)

"Thanks for the lovely afternoon, it was good to meet everyone."
Join the Meetup group @ https://www.meetup.com/MyositisUK and an email will be sent to you when future Meetups are announced.
Or follow the Meetup facebook group https://www.facebook.com/MyositisUKMeetup/

Please note: The Meetups are free to Myositis UK members and their partners/carers, but you must book a place in advance.

Meetups are supported and funded by Myositis UK. If you would like to plan a Meetup in your area Myositis UK are happy to promote the event on the Meetup website and reimburse agreed expenses. Contact the office for details.

Fundraising

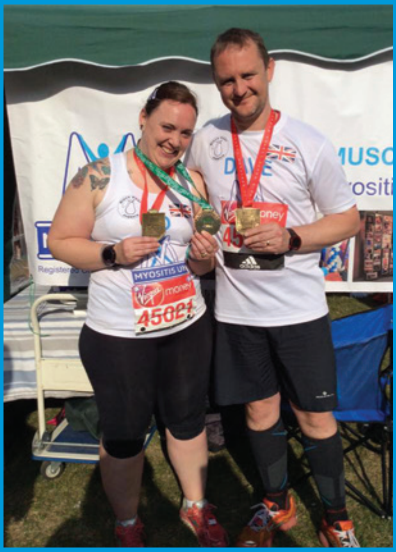
Fordyce Scottish Country Dance Class

Lindsay A Gauld wrote to the charity: "Please find enclosed a cheque for £100 for your cause. The Fordyce Scottish County Dance Class has finished and our club would like to donate the remainder of our money to you."

The Waller family, Northern Ireland

Jan Waller writes from Northern Ireland: "My daughter Izzi was diagnosed with JDM in November last year. We have done a lot of fundraising and enclose a cheque for £100 to the amount already sent via bank transfer making a total donated to £500. We hope this helps in some small way and would also like to thank Myositis UK for sending us the bear and book which really helped Izzi."

London Marathon 2017



This year our runners in the marathon raised over an amazing £17,000.

Letitia

Patricia Rawson writes: "I see from your latest literature that you are still hard at working supporting members and fundraising for the illness and it is good to know that this work is ongoing. I can't run a marathon or do much fundraising these days but please find enclosed a cheque for £50 in memory of Letitia."

Valerie Joan Taylor

In our last Myositis News you may recall that I reported that Valerie died in October 2016. I also mentioned that she left a pecuniary legacy to the charity for £10,000. However, at the time of writing I was not prepared for the shock that was to come this year when a cheque came from her solicitors in the sum of £104,120.93. Valerie had made the charity a major beneficiary from her estate.

How do you put into words the enormity of this wonderful gesture she made. She must have thought so much of the plight of people suffering from myositis for she had the illness herself and would have understood the frustration and complexity of just being unwell. We were not fully aware how much she appreciated the work of Myositis UK. The reason being perhaps is that we all tend to just get on with our lives and muddle along. I'm guilty of it myself. It is very difficult these days to keep up to speed with members with so much going on and with so little time to follow and keep in personal contact with everyone. That is, for me, why this legacy means so much. Valerie, it appears, was not concerned by the lack of personal contact but quite content to read about the progress of the charity's work and the members' activities through our publications knowing that one day she was going to make a difference and raise the levels of hope by her gesture of loving kindness.

The trustees have been speaking to myositis research investigators for their ideas on how we could use this money to help in their work. I am sure Valerie would want this to happen for this legacy did not have any restrictions on it and was left to the good will, judgement and integrity for all involved to make sound use of this gift in the coming months. Thank you, Valerie.

Great Manchester Run 2017

Karen Hunter, trustee of AO Smile Foundation, writes: "It is with absolute pleasure I write to you enclosing a cheque towards your work. We are passionate at the Foundation about creating smiles across the UK and one of our core objects is to support those charities our employees throughout AO World are most passionate about. We have recently learnt that our colleague, Joseph Nicholson, has been fundraising for you by taking part in the Great Manchester Run, raising £295 for your charity in the process. We are so proud of him and his sterling efforts that we would like to make a contribution towards his fundraising. Therefore please find enclosed a cheque for £100 sent with our warmest wishes and a big high five for all the amazing work that you do!"

Masonic Lodges help our cause again

A member of the Fair Oak Lodge, Mr Geoff Ford, presented a cheque for £100 on behalf of Fair Oak Lodge who meet in Hampshire.

The members of Eastleigh Lodge, who also meet in Hampshire, presented a cheque to the charity for £250.

Both these Masonic Lodges have given us financial help over the years to enable the charity to continue its work.

Netley Abbey Lodge held a race night at Woolston Bowls Club, Southampton. Members of both and their friends and families had a great evening. £500 was raised on the 'horses', £132 on the raffle and Netley Abbey lodge presented me with a cheque for £1000. This gave a total of £1,632 for the event.

My thanks to the Curnew family and John Wiggington for organising the event.
– Les Oakley.

JustGiving Pages

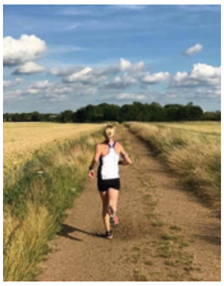
The following news has been taken from JustGiving pages where fundraising for the charity has taken place.

Charlotte Barrett

My brother (Jamie Barrett) and I (Charlotte Barrett) have decided to raise money for Myositis UK because our Grandad, Roy Andrew Barrett, had this illness. Our Grandad struggled with a rare form of myositis for many years which deteriorated his muscles until he could no longer move. He passed away from his illness on the 29th of September 2016. Even though our Grandad had this illness he always had a smile on his face and would always be able to make us laugh no matter what. Today, as it is the anniversary of his death, on the 29th of September 2017 my brother and I have decided to raise money in his memory. Thanks for taking the time to visit my JustGiving page.

Their target was £200 but they exceeded this and have raised £390.

Andy Galway's Birthday Marathon



I am running the Abingdon marathon on Sunday 22nd October for Myositis UK because if I don't run one now I never will! I'm running The Abingdon marathon 26.2 miles to celebrate my 50th birthday for Inclusion Body Myositis, an inflammatory muscle disease. At present there is no effective treatment for this disease which is why research is so desperately needed.

I'm aiming for a Good For Age marathon time. At 50 this is sub 4 hrs. I've been training for this for over a year. It's certainly been arduous at times, my longest run was 20 miles and I was running 50 miles a week for many weeks at the height of my training. I can't wait to get on and run it now.

Andy's target was £500 but she exceeded this and raised £696.

Ann Lucas

In memory of our Dad, John Williams, we are raising money for Myositis UK because Dad was a sufferer of Inclusion Body Myositis

For many years Dad was severely disabled by this crippling and debilitating rare disease, Inclusion Body Myositis (IBM). Over the years Dad's muscle strength slowly and gradually declined. To say he suffered is a gross understatement – but he never gave in to it. He fought it to the end.

As a family we took care of Dad at home, Mum being his main carer despite having health issues of her own. He had professional home carers, too, but Mum took the brunt of the care. It was a demanding job.

So we are determined to do all we can to help others with this disease. We look forward to the day when there is a cure and Inclusion Body Myositis is something everyone has heard of. Please help that journey for current and future sufferers and their carers. This is the greatest way we can honour the memory of our Dad who would have been so up for this.

Ann, Mark and Neil Williams set a target of £500 but to date have raised £1,648.

Matthew & Nicola's Disneyland Paris 10K & WDW Half Marathon

Nicola and I have signed up for two Disney themed races (what else?!) The Disneyland Paris 10K (taking place on Saturday 23rd September 2017) and the Walt Disney World Half Marathon (taking place on Saturday 6th January 2018). We have been training hard since the beginning of April, when we could only just run one minute!

We have decided to run these two races to help raise funds for Myositis UK. Myositis UK was established in 1986. It is a charity specific for the inflammatory myopathies; Dermatomyositis, Polymyositis, Inclusion Body Myositis and Juvenile Dermatomyositis.

This charity is something quite close to me. As many of you know, sadly my mother, Susan, passed away in 2007 at the age of 55. My mum was a keen fitness instructor for many years and ran her own classes (Petherfit) and raised huge amounts for charity and Children in Need. Being the 10th anniversary of her death, I wanted to help raise awareness of this illness/disease and hopefully raise lots of money for this wonderful organisation.

They have raised £335 of their £500 target. We wish them well for their second run, the Walt Disney World Half Marathon, on the 6th January 2018. If you would like to sponsor them their Justgiving page is: https://www.justgiving.com/fundraising/matthew-kirby3

Richard Cook

I am running the Stockholm Marathon on Saturday 3rd June 2017 in aid of Myositis UK to raise awareness and help to fund vital research to improve the treatment of rare inflammatory myopathies.

Thank you to everyone who has supported me in my training so far, I have been very humbled by the generosity of many of my family and friends. Only three weeks to go now. A special thank you to everyone in Year 7 at Cokethorpe School who helped me to run a charity cake sale this week in aid of myositis raising over £200 for my cause.

Well done to Richard who ran the Stockholm Marathon in 4 hours 11 minutes. Richard's fundraising target was £2,000 which he exceeded and raised a total of £2,365.

Dan Colletts

I have decided to enter the Bournemouth Marathon, with the aim to just enjoy and complete! In doing so I am hoping to raise money for a charity very close to my families heart, myositis. Support will be greatly appreciated, thank you.

Dan's target was £500 but he has exceeded this and raised £678.

Jessica Harvey

My hair that is cut will be going to the Princess charity that will make it into a wig. Any funds raised will go to Myositis UK. I have chosen this charity as it has affected a close friend and I would like to do as much as I can to help find a cure.

Jessica has raised £218 which has exceeded her target of £150.

JustGiving Pages

Suzella Buhlmann

Race At Your Pace 100 mile Challenge, May 2017

I am aiming to walk 100 miles during May (2017) for Myositis UK because May is Myositis Awareness & I suffer from Myositis.

I suffer from Antisynthetase syndrome with the specific strand of myositis being Dermatomyositis. This causes weakness, pain and inflammation in my muscles and joints as well as giving me interstitial lung disease and constantly leaving me ill and fatigued.

Antisynthetase is extremely rare and is classed as a chronic illness with no cure. The money raised will support research to hopefully one day finding a cure and raise the awareness of this deliberating condition as well as the medications used their effectiveness and side effects.

I wanted to do something to raise money and awareness of this condition. This will be a challenge for me due to my health conditions as well as a floating joint I have just been diagnosed with in my foot. This charity has supported me in forums, helped and guided me throughout my journey from awaiting diagnosis to this day.

This charity is very close to my heart. Please donate what you can.

This is the first time in about 9 months I have felt like I have kicked Myositis in the butt. I feel like I have achieved and accomplished so much. These walking challenges are keeping me focused and have made me lose weight plus it raises awareness and much needed funds to great causes. I'm so happy I have exceeded the 100 mile challenge totaling 139.41 miles and exceeded my target and have raised £280.

Natalie Butler

Norwich Half Marathon 9/4/17 & Hackney Half Marathon 30/4/17

This year I am completing the Norwich Half Marathon on the 9th April and Hackney Half Marathon on 30th April. Like most people who are completing sporting events I have chosen a charity – Myositis UK.

Not many people may know but as I started high school I was already quiet unwell with Dermatomyositis. It's a very rare disease. I could hardly walk, underweight, hair falling out, mouth ulcers, joint pain and tiredness. It was so difficult to get about that my Dad would carry me up and down the stairs. It was pretty bad at the time but, needless to say once I was diagnosed and received treatment, all was good.

My first goal was to be able to run to the end of the road, less than ½ a mile. This is why I run, not all the time because it would be untrue to say I have been running ever since but why I have always tried to be fit and healthy.

Natalie had a target of £100 which she exceeded and raised £230.

Tracy Nicholson

I was diagnosed with Dermatomyositis on the 21st March 2016. The hospital thought I had viral influenza. When it was proven it wasn't that I had a visit from a Rheumatology doctor. The relief after he examined me and said I think I know what's wrong with you was unbelievable.

Dr McLaren is my Rheumatology doctor and he specialises in Dermatomyositis and I'm so glad to have him in my corner.

I have had a huge support network since leaving hospital, from Dr McLaren and his team, Occupational Therapy, Physio, Psychology and family and friends, but most of all my husband who has been with me every step of the way. I don't know where I would be without him.

My Dermatomyositis is currently being well controlled with my medication that I must now take for the rest of my life and they are pleased with my progress (although it's slower than I would like) but I'm learning to be patient and take each day as it comes. It has been a hard adjustment learning to live with this but each day is a school day.

I was asked to join the UK study before I left hospital which I agreed to, hopefully to be able to help in some small way with research into Myositis.

Almost a year on and I am currently in remission I now want to give something back and try and raise funds towards the research into Myositis to try and help to find a cure for this disease. I am hoping to hold various fundraising events throughout 2017.

A huge thank you to everyone who attended the Easter Coffee Morning in the Bowling Club. Grand Total of £912.79 raised for Myositis UK.

Thank you to everyone who handed in Raffles and Home Baking, to Room 101, Jaks Flowering Fancies, Kirkcaldy Kawasaki, Fife Country, Frank Watson, Health and Beauty by Ruth, Karen's Kraftastics and Susan Hunter for their Donations, and to all the helpers, I couldn't have done it without you. I am totally overwhelmed by all your kindness and generosity. Thank you.

Tracy has raised £1,286.24 exceeding her target of £1,000.

Joe Nicholson

Great Manchester Run Half Marathon, 28 May 2017
Joe raised £345, which exceeded his target of £300.

JustGiving Pages

Paula Jordan

Race at Your Pace Challenge

To celebrate my 40th birthday I decided to complete the September Race at Your Pace Challenge. You choose your distance and it has to be completed over one month. I entered the 25 mile challenge but decided to walk 26.4 miles and call it a Broken Marathon. I will never be able to run a marathon but there is no reason – with a bit of planning and dedication – that I couldn't achieve a broken one!

I was diagnosed with Juvenile Dermatomyositis just before my 6th birthday although looking back you could see I had been slowly declining in health for at least a year before.

My immune system was finding fault with my muscles and sought to destroy them. This resulted in a child who was once an active gymnast and dancer becoming a lethargic, tearful girl.

Our GP diagnosed hay fever, then sinusitis and eventually labelled me (a 5-year-old) as psychosomatic. Persistent parents meant I later received my true diagnosis (by a paediatrician at Southampton General Hospital) and a future that no one thought could be positive.

Juvenile Dermatomyositis is very rare and in 1983 the lone treatment of steroids (no cure) and exercise for a time scale of unknown did not bode well. Life got complicated when a week after my diagnosis I turned blue and lost the ability to swallow and talk. I was referred to the Muscle Clinic at Hammersmith Hospital under the care of Professor Dubowitz. Children before me, diagnosed with JDM, led a life in wheelchairs or even died.

My diagnosis came at a time when there was a 'little bit of knowledge' about the disease. It doesn't mean that my JDM journey was problem free. I experienced multiple setbacks, relapses and calcinosis right into adulthood. After my first serious relapse my consultant sat on a stool by my bed in the Hammersmith Hospital opposite my mum and said, "I just don't know what to do now."

By agreeing to be a guinea pig for unproven treatments I was eventually responding to medications and able to reduce the steroids. I was left with permanent muscle weakness to my limbs, but most greatly to my arms and neck, a contracture in my wrist and various calcinosis as well as periods of overlaps into rheumatoid arthritis, scleroderma, Raynaud's, ulcerative colitis, psoriasis and syrogens.

I became medication free in 2013 with the motivation of becoming pregnant. After a couple of miscarriages, with an unproven conclusion that my immune system was somehow destroying the pregnancies, I set upon a regime of medications to try to sustain a pregnancy. I was overjoyed when my son was born in June last year.

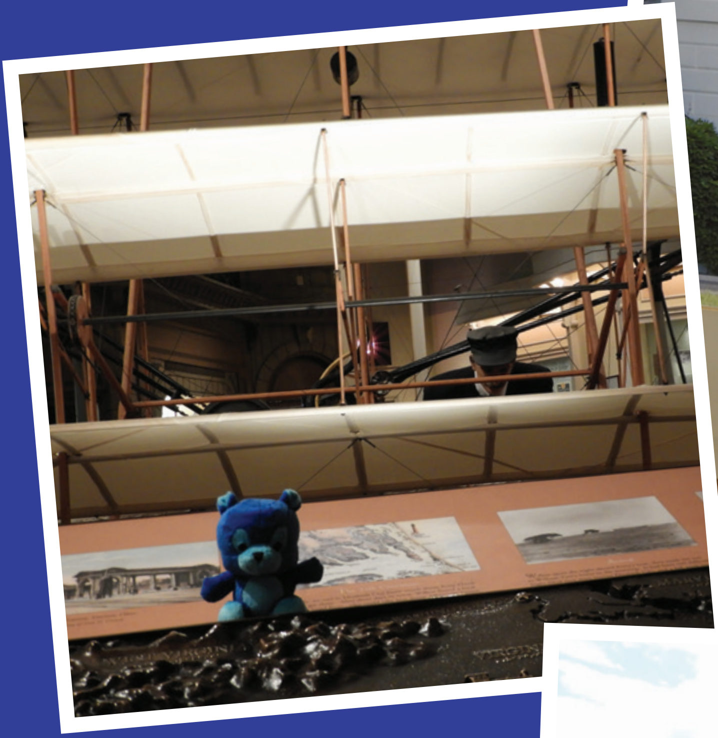
Finding time to walk the Broken Marathon wasn't a problem but finding the energy was! Being a petite mum with muscle weakness to an energetic toddler leaves me exhausted! But, I did it! I completed six walks over varying distances. All walks were different and all but one were started from my front door.

I was joined by my sister, husband and son for a couple of the walks but I mostly walked on my own and chatted to locals on the route. I never dawdled, I took the walks seriously and wanted to do them at a decent pace. I tracked my routes on my Garmin watch and iPhone and took photos to share with the people who were sponsoring me.

I asked for donations in lieu of birthday presents and was humbled to see people unknown to me were sponsoring me, too. I raised over £600 and I am grateful to everyone.

Teddy Bo in the USA

Teddy Bo had an exciting visit to the USA this year! Not only did he attend the 2nd Global Myositis Meeting but he also visited many sights in Washington DC and New York.



Teddy Bo acting as "King Kong" on the Empire State Building.

Research Updates

The myositis centres and collaborations have continued to develop their studies and research over the past six months.

Working internationally they have now begun to publish a consensus for reclassification of dermatomyositis, polymyositis, inclusion body myositis and juvenile dermatomyositis. Even today doctors often refer when attempting a diagnosis to the Bohan and Peter criteria published in 1975!

There is a strong international desire to modernize and correct the classification criteria for the inflammatory myopathies to account for the improved understanding of the disease types. The difficulty is, the more we know, the harder it is to benchmark into fixed boxes.

As we are all aware myositis is virtually unique to an individual and many affected have overlaps into other conditions which can further complicate. But, with longitudinal data gathered by registries and centres collaborating it is now starting to become possible to categorise some symptoms, with serology, genetics, treatment responses and long term outcome. You may notice (first publication listed) that there are even collaborative groups working with collaborative groups to achieve suitable classifications.

Details of some of these, typically those that involve Myositis UK (funding of salary, research consumables, dissemination of information, etc.) are below. 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.

2017 European League Against Rheumatism/American College of Rheumatology Classification Criteria for Adult and Juvenile Idiopathic Inflammatory Myopathies and Their Major Subgroups.

Lundberg IE, Tjärnlund A, Bottai M, Werth VP, Pilkington C, de Visser M, Alfredsson L, Amato AA, Barohn RJ, Liang MH, Singh JA, Aggarwal R, Arnardottir S, Chinoy H, Cooper RG, Dankó K, Dimachkie MM, Feldman BM, Garcia-De La Torre I, Gordon P, Hayashi T, Katz JD, Kohsaka H, Lachenbruch PA, Lang BA, Li Y, Oddis CV, Olesinska M, Reed AM, Rutkowska-Sak L, Sanner H, Selva-O'Callaghan A, Song YW, Vencovsky J, Ytterberg SR, Miller FW, Rider LG;

Published in Arthritis & Rheumatology, October 2017. Free Access PMID: 29106061
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Rider LG, Ruperto N, Pistorio A, Erman B, Bayat N, Lachenbruch PA, Rockette H, Feldman BM, Huber AM, Hansen P, Oddis CV, Lundberg IE, Amato AA, Chinoy H, Cooper RG, Chung L, Danko K, Fiorentino D, García-De la Torre I, Reed AM, Wook Song Y, Cimaz R, Cuttica RJ, Pilkington CA, Martini A, van der Net J, Maillard S, Miller FW, Vencovsky J, Aggarwal R; International Myositis Assessment and Clinical Studies Group and the Paediatric Rheumatology International Trials Organisation.

Published in Rheumatology (Oxford), November 2017. Free Access PMID: 28977549

The EuroMyositis registry: an international collaborative tool to facilitate myositis research.

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Published in Arthritis & Rheumatology, May 2017. Free Access PMID: 28382787

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