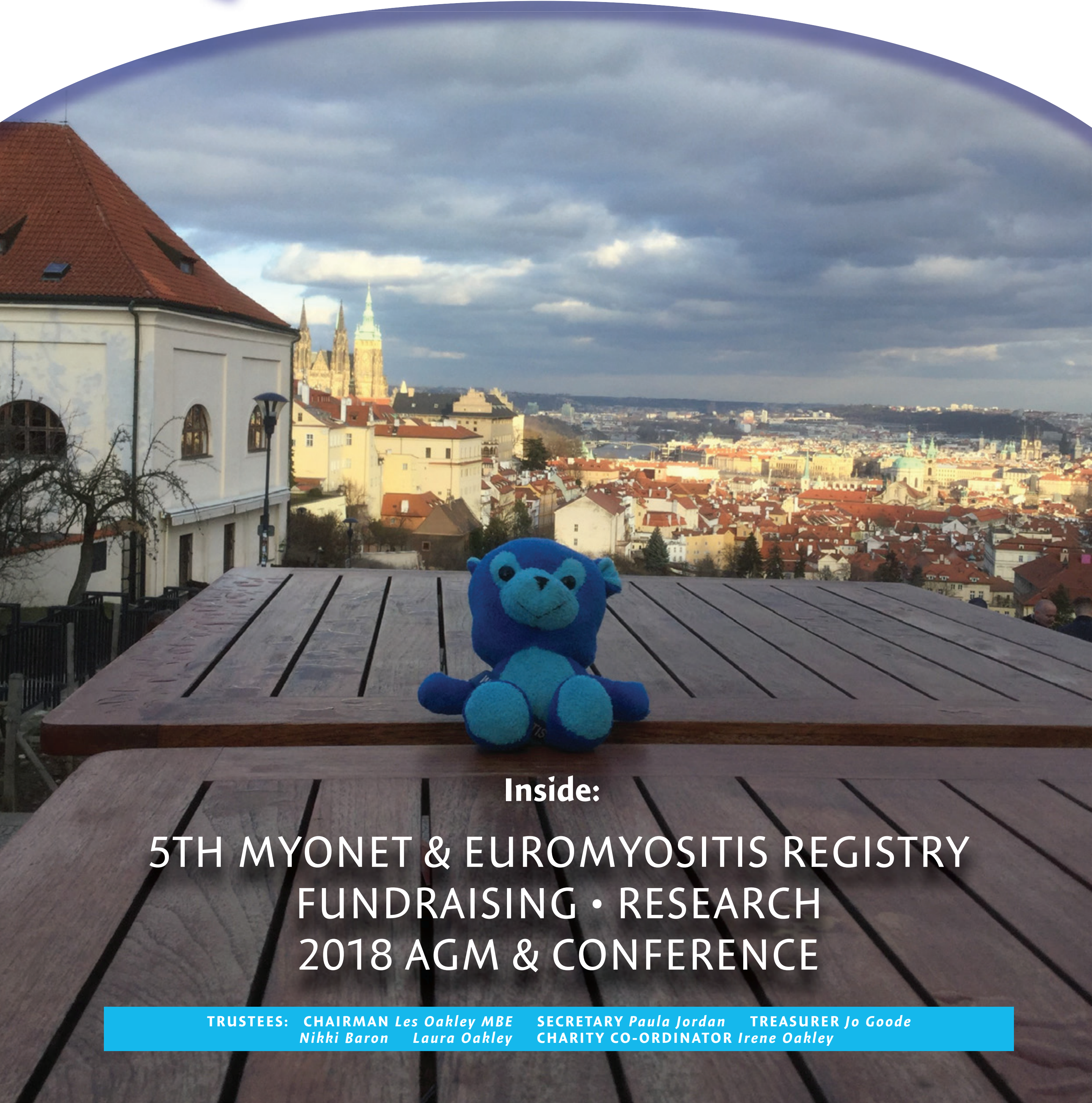
MYOSITIS UK

Autumn 2018

Myositis News



Inside:

5TH MYONET & EUROMYOSITIS REGISTRY
FUNDRAISING • RESEARCH
2018 AGM & CONFERENCE

Autumn 2018

Dear Member

Busy as life is I do enjoy compiling this magazine. Much pleasure comes from all the activities going on around the country whether it be from our medical community in their work or the antics of people doing their upmost to raise funds by any means possible. I am sure you will enjoy reading about their efforts further in these pages. However, I first need to mention the meeting in Prague . . .

Les Oakley MBE
Chairman

Trustees

5th Workshop for Myositis Network (Myonet) and Euromyositis Registry

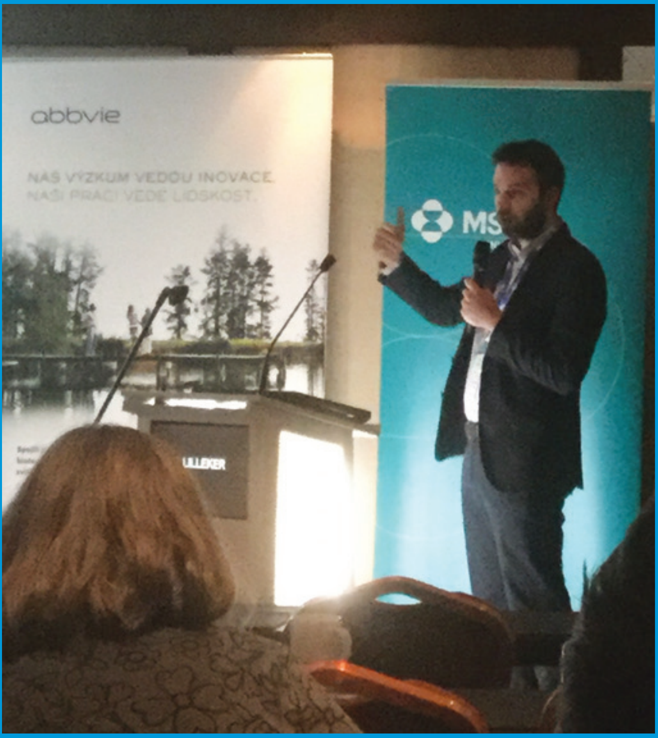
February 1-2, Prague

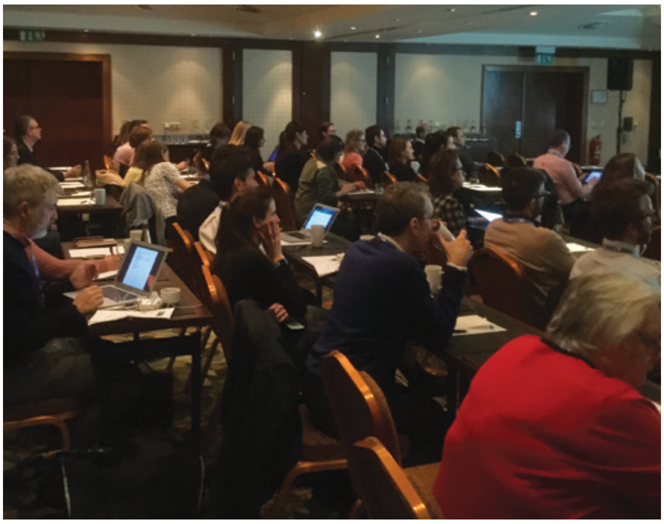
Myself along with Irene and Jo, our treasurer, were fortunate to be invited to attend this meeting. Over the two days there were presentations on the registry, on improvements, access, new aspects and new tools.

Jiri Vencovsky from Czech Republic welcomed everyone and presented the 'history of registry'. Ingrid Lundberg from Sweden presented 'the Euromyositis registry Steering Committee Report'. This was followed by Paul New, from the UK, presenting the 'MyoNet web page', then Hector Chinoy from the UK presenting the 'Myositis Registry'. Neils Steen Krogh from Denmark presented 'Myositis registry – improvements, access, new aspects and new tools'.

Dr James Lilleker presented on 'making the most of the EuroMyositis Registry including pearls and pitfalls'. Dr Liza McCann and Dr Niels Steen Krogh gave a presentation on 'Juvenile dermatomyositis in the registry'. 'The current status of Pathology diagnosis of IIM' was given by Dr Boel De Paepe from Belgium.

End of day one finished with discussions on the presentations given.





Day two started with "Autoantibodies" and presentations were given by Dr Zoe Betteridge on 'Autoantibody Prevalence and Clinical Associations'. 'Autoantibody standardisation and how it relates to myositis autoantibody detection' was presented by Johan Ronnelid from Sweden. This was followed by two presentations on TIF proteins. The first was 'TIF proteins and paraneoplastic dermatomyositis' presented by Albert Selva O'Callaghan from Spain and the second was 'Infectious signatures in TIF1g+ patients' presented by Spyridon Megremis from the UK. 'Electrocardiographic findings and autoantibody profile in myositis' was presented by doctors from Denmark followed by a discussion on these presentations.

"Foreum Projects" followed and presentations were given on "IMPROVEMENT" project by Alexander Oldfield and "ASS" project by Lorenzo Cavagna from Italy. A discussion followed.

"Genetics and Mechanisms" was next on the agenda and Simon Rothwell from the UK presented 'Update on the genetics projects' followed by Claire Deakin from the UK with two presentations, 'JDM genetics project' and 'RNAseq data'.

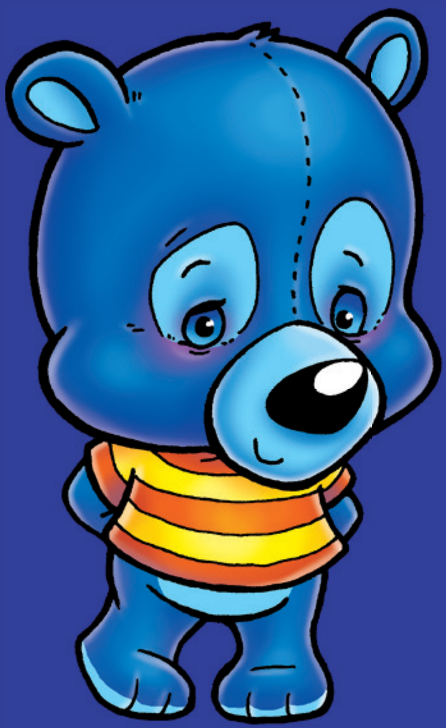
'Genetic background and distribution of derrmatomyositis' was presented by Joanna Parkes from the UK. Lars Ronnblom and Johanna Sandling from Sweden presented 'The DISSECT project, update with focus on myositis'. Again a discussion followed on the presentations.

"Therapy" was next on the agenda and Leandro Ladislau from France presented 'Muscle consequences of type12 interferon, new avenue for the treatment of DM'. Yves Allenbach from France presented 'Preliminary results on refractory DM patients treated by JAK inhibs'.

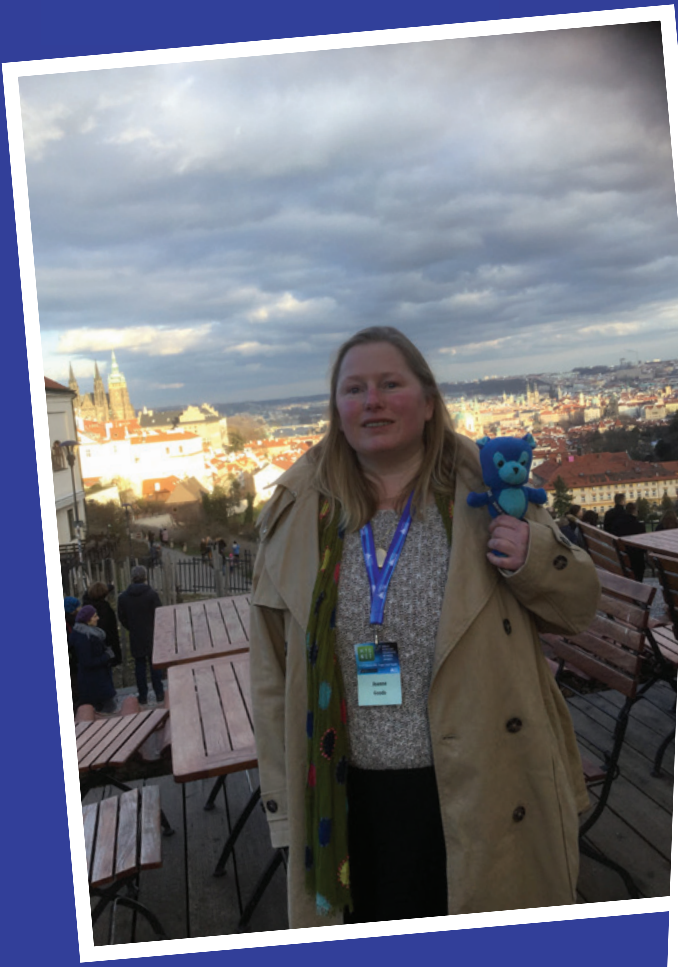
The last presentation on Therapy was by Helene Alexanderson on 'Consensus guidelines on exercise in adults and children with IIM'. A discussion then followed.

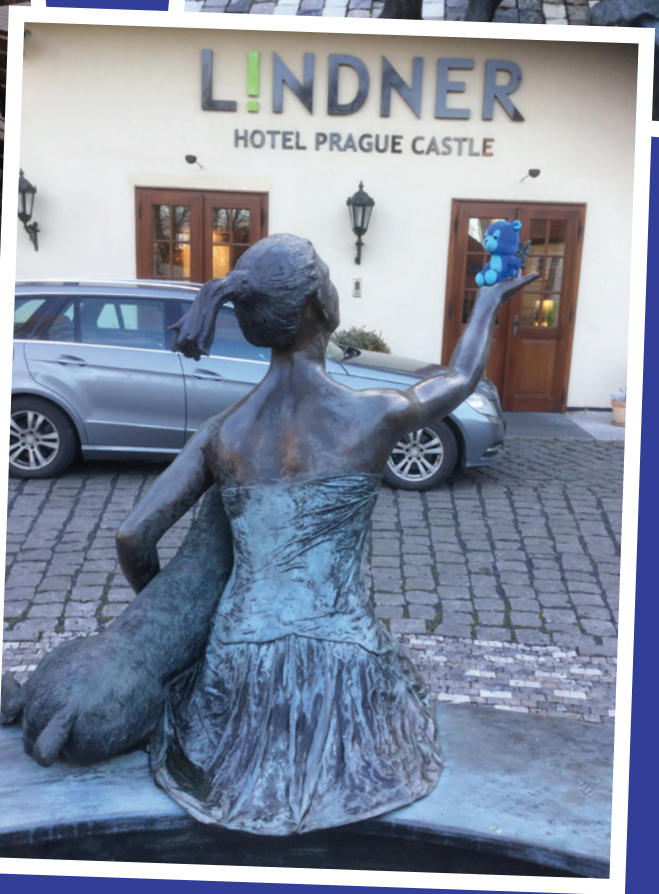
"Various Aspects + General Discussion" Ingrid Lundberg and Fabricio Espinosa from Sweden presented 'Prognostic biomarkers in Euromyositis cohort and preliminary datafrom SweMyoNet' and 'proposal for a new Euromyositis project'. The meeting ended with a general discussion and future plans.

This meeting was extremely interesting in many ways. It showed the amount of work and interest now being undertaken into myositis not only in this country but throughout Europe. A lot of research projects would not be viable without this collaboration and also the data in the registry. I cannot pretend that I understood every presentation but what I did find was that there is now sound research taking place into understanding the mechanisms of myositis which can hopefully lead to improved treatment.



Teddy Bo in Prague





Have you taken photos of Teddy Bo on your travels? Please send in your photos or put them on Teddy Bo's Facebook page.

Myositis UK Gala Dinner and Conference Weekend in Oxford

Meet & Greet

The weekend started with the Meet & Greet on the Saturday afternoon in the hotel bar and was a very enjoyable time. It was a pleasure to talk to new delegates as well as catch up with the latest news from our established membership. I know it is a win-win situation for everybody in that room and all were made to feel welcome and included.

Gala Dinner – Celebrating 30 years as a registered charity

Welcome by Les Oakley:

May I thank you all for attending this 30th gala dinner of Myositis UK. I'm so very pleased that you are here and I would like to welcome in particular Helene Alexanderson from Sweden. A gala dinner is usually a formal occasion where guests dress in their refinery. As you can see I'm not suited and booted but just lucky to be here turned out as I am! Hence, as you know, the dress code is casual and comfortable and that's just as well and will do for me.

It is unusual in the charity world to have the same chairman, or chair as I am told is more appropriate title these days, for 30 years. There are many reasons for this and the main one is the charity costs virtually nothing to run from home. By operating like this we have been able to raise money for medical research and not having to fund an office with staff away from my home. This notion has always been the driving force and with a few trustees we have kept the ambition simple and direct.

Along the way I have met with some opposition from members to this course with many a good debate on other avenues that would be beneficial. In a large charity I could envisage these elements would work but without a major financial windfall I could also see a host of problems. The charity has been fortunate that the majority of members held similar views and have left legacies

to help our cause with Valerie Jean Taylor regrettably being the most recent one to show such considerable kindness.

The charity from the very start was not only patient and member-led but was equally driven by doctors treating the disease. Initially it was the late Dr Christine Saunders who understood that the two go hand in hand if any progress was to be made.

As a charity we have nurtured this co-operation and here we are today at this dinner with doctors, scientists and members of the medical profession at the top of their sphere of work still continuing the ethos of Dr Saunders. Over the years I have attended many neuromuscular meetings and have mingled and talked with other charities. Some are amazed that we have this close connection for such a small charity representing a group of very rare diseases. We could ask the question 'why', but we don't, for we are just very grateful to be placed in this position.

In preparing this speech I became aware that the charity is now working with its third generation of doctors and scientists. This is a fantastic progression with the baton being passed to younger and equally enthusiastic people. I'm also aware that it is not the case for me and Irene along with the trustees. Faced with my own mortality only a few days ago we need to consider how we pass our baton on in a way the charity can continue to develop and if now is the time for a younger generation with new ideas to take control.

The internet has changed the way people meet and debate and although our membership numbers are consistent the physical presence at meetings is falling as can be seen in the charity world in general. However, these are considerations for another day. Let's enjoy this evening and our conference and allow our guest magician to weave his magic on this occasion.

The dinner was well received and the hotel put on a very good menu for us to enjoy. A DJ provided music throughout the evening that did not burst our ear drums. The magician moved around the tables weaving his magic. Great fun! There was even time for me and Professor Bob Cooper to say a few words about the charity and the contribution it has given to the world of medical research and the hope for people coping with myositis in all its forms.

I've always been a suited and booted man, but was just as well smart casual was the code of dress for the evening for my attire consisted of a t-shirt and sling! Some of you may recall I was wearing a sling last year after an accident on my bike. It must be a good reason for calling time on cycling in the rush hour.

Annual General Meeting and Conference

There is always a tidal wave of work in the run-up to our national conference particularly as we were holding a dinner the night before to celebrate 30 years as a registered charity. This was not helped by me having what could have been a near fatal road accident during this period. It occupied a week of Irene’s valuable time coping with me in a bashed-up state following the incident. Unfortunately, it meant much of the posters, photographs, display material and literature being left in the office store. However, nice as it would have been to be able to have this material there on the day it did not dampen or detract from a very successful time.

The conference is always important for people living with myositis. The news and talks are really hot topics which have not been presented on the internet or put into print. It truly is an exciting time to gain knowledge first hand and to be able to participate in the proceedings.

The conference started with the Annual General Meeting after a warm welcome from myself and thanking everyone in making the time to attend and showing their support. The review of the year was given by me. Charity treasurer Jo Goode presented the accounts and explained the healthy financial status of the charity. They were accepted as a true and faithful record for the year. As there were no nominations for trustees, with the serving trustees kindly prepared to serve a further year, they were re-elected en bloc.

We could now start our conference in earnest and I was delighted to announce that Associate Professor Helene Alexanderson from the Karolinska University Hospital in Sweden would be our first speaker and talk about exercise and its benefits in all forms of myositis. She is an internationally acclaimed research physiotherapist and I must say we were hanging on to her every word. Progress has certainly been made in this aspect of the disease. She was open to any questions and there were many but everyone was answered truthfully with a great knowledge and understanding of the issues involving exercise. (Helene has kindly provided us with a copy of her presentation. Please email the office if you would like a copy.) After Helene’s presentation the members split up into their disease type breakout rooms to hear about their particular news and progress.

In the Inclusion Body Myositis room we were delighted to have Professor Mike Hanna and Dr Pedro Machado plus their support staff in attendance. There we heard of the great news and update that in the next few weeks a study of using the drug Arimoclomol is now to take place. The Dermatomyositis and Polymyositis room was so well attended more seats were needed. Professor Bob Cooper spoke about Interstitial Lung Disease (ILD) in patients, how overlooked it is and how it can be a problem if not recognised and treated early and the need for study into this involvement. Dr James Lilleker spoke about standards of care. The room was also fortunate to have in attendance on the question and answer panel, Dr Patrick Gordon and scientist Zoe Betteridge.

Unfortunately, Dr Adam Lightfoot who was also speaking could not attend for his car had broken down on the way. Such rotten misfortune for him and even may I say, for us, because his knowledge is greatly respected.

The Juvenile Dermatomyositis room was set up informally with plenty of space, video games and toys for the children. Lucy Marshall spoke about the UK JDM Cohort and Biomarker Study and Dr Charalampia Papadopoulou talked about JDM State of the Art and Future Perspectives. There was also time for parents to talk to each other.

While these meetings were taking place in the informal question and answer session, Helene Alexanderson was drifting in and out of the rooms offering advice where needed.

We all met up as a group at the end of the afternoon where a lively discussion took place about the coming year and other issues relevant to the charity. We had some feedback forms where there were only positive comments about the conference and I reckon, in the circumstances, Irene did a really good job making the weekend enjoyable and informative as possible. A few of these comments have appeared on the charity web pages to support this. I must also gratefully acknowledge that our speakers and support staff gave up their time to be with us and I will always be indebted to them for all they do for us. The charity is also fortunate that my good friends, Margaret and Bruce Cross, manned the reception desk and were the focal point for information for the day. In summing up I thanked everyone for coming as it is not easy for some of our less mobile members and looked forward to seeing them all at the next conference where I feel sure we will learn of further progress being made.

Some of the feedback comments are: “We are new to the charity but we have been made to feel very welcome. The hotel was very good – the rooms were clean and comfortable. The conference rooms were good and we were well looked after by the staff. The doctors were very informative and we found out more about inclusion body myositis in a few hours then we have in several years. It was good to meet other people with the same condition and to exchange thoughts and ideas. Well done to you all for the hard work you put into this conference.”

Dr Zoe Betteridge

After many years, Zoe is leaving her role as a research scientist. She has been a leading investigator and research scientist in discovering new antibodies and their involvement with myositis. The value of her work is internationally recognised and she has presented her findings around the world. I have very mixed views on her leaving myositis research, the most obvious one is that we have lost a very talented scientist. On the other hand it is a very precarious occupation because in her line of work she has had to raise funds to keep her work going. Myositis UK has helped but larger grants are always needed but they are nearly always short-term contracts.

Zoe has now moved into another field of work where she will have a regular income and hours of work so that she can enjoy her other interests and hobbies as well as having job security.

However, Zoe intends to raise funds for Myositis UK in the coming months through her interest in running and cycling. The charity trustees wish her well in her career and are very grateful for the time, commitment and friendship she has given to all of us.

“Very Informative sessions and helpful to meet other people with the condition. A great opportunity to pose questions to top professors/consultants. Thank you to them for giving their time and thanks to the committee for arranging the event.”

“As usual the conference was perfectly organised and ran smoothly. The Q&A sessions are a real success and Professor Alexandra’s talk was a real bonus. She was very informative and her delivery of facts was done in a very accessible way.”

It was at this part of the meeting during my summing up that it gave me the opportunity to mention how a Mr Gordon Macphearson became aware of the charity and the financial help and kind words that came with this help from him.

During these thirty two years of being involved with the charity I have received countless help and financial donations to generate the charities aims. However, in every case they have come from people and organisations who were already aware of what I was doing and trying to achieve. It was these acts of kindness along with the efforts of hundreds of other people who have got us to where we are today.

However, Gordon was a complete stranger who came into my place of work about four years ago. He was a tall elderly Scotsman who was inquisitive of how I had been honoured with an MBE some years ago. I briefly explained the reasons why and that our website was well worth a visit to show how broad the subject is about myositis and what we have been doing as a charity. Thirty minutes late he was gone and that would normally be the end of that type of discussion.

Less than a fortnight later the charity office received a donation from Gordon for £2,000. As you can imagine I was absolutely amazed for I have never experienced such kindness resulting from a chance conversation.

I’ve seen Gordon a few times since then and last year he asked me if it was possible to give his 18-year-old grandson, Arthur, a place in the London Marathon. In this year’s event the dropout rate was worrying, more than previous years and making a decision was easy.
I told Gordon that a place had been allotted to Arthur but he would need to raise £1,000 in sponsorship money for the charity. Gordon said it would not be an issue and Arthur was really looking forward to the challenge. The weeks were ticking away towards the run and I had noticed that Arthur had not set up a page on JustGiving to help raise the said money. In fact we were almost at the witching hour and we still did not know even where to send Arthur’s running shirt. Panic for me was starting to set in. This event was looking rather doomed. It was just over a week before the race when I

saw Gordon again. I explained the situation and he said not to worry as all youngsters appear to leave things to the last minute but was sure all was well and just a lack of communication was the issue. As Gordon was leaving he put an envelope on the desk and said that it was sponsorship money for “Team Muscle.” I said, “Put it towards Arthur’s effort” to which he replied, “Don’t worry, Arthur will raise his own money.”

After he left I noticed he had left some papers behind and before running after him I quickly opened the envelope and to my utter amazement he had sponsored the team for £5,000! This, as you can imagine, really quickened my pace and all sorts of emotions were going on in my mind. Luckily he had not left the car park and I managed to pass the papers through his car window at the same time expressing my amazement and gratitude for his sponsorship. As he was driving away he said it was a pleasure and wished the team well. I just stood stunned and thinking why?

We managed to meet up with Arthur along with his mum in a hotel in London the evening before the marathon to pass him his running vest and wish him well in the knowledge he had raised, by that time, well over £1,500 and all my concerns were totally unfounded. These young people are so switched on and he raised his funds within days.

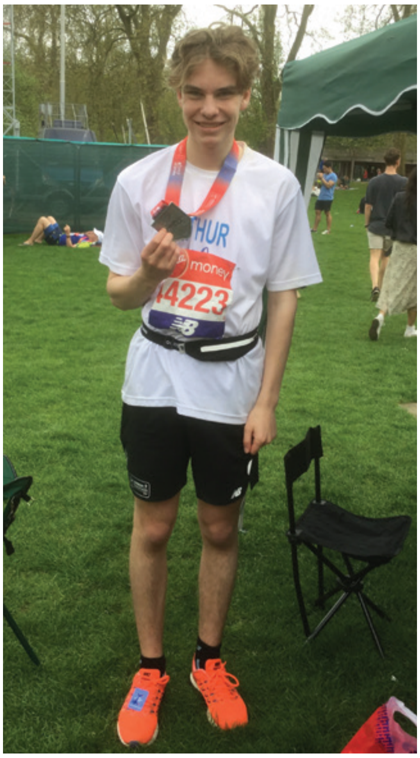
Sadly, a few days after the marathon Gordon suddenly passed away. His dear wife phoned to let me know. You can appreciate the shock to me, and more so, what must have been a great and tremendous loss to his family. To me Gordon was this mystery man, a complete enigma. I needed to know more about him and fortunately could attend a memorial service in his village church. An obituary notice had been placed in the Times newspaper with his family asking for donations in memory of him to be given to Myositis UK. The church was packed and it was there that I was to learn of his character and how much loved he was. The eulogies given, pictured the life of a well-educated family man, successful in business and possessing a great sense of humour, love of the countryside as well as sailing. He had worked in the financial field in Wall Street and London and was particularly clever and talented with numbers. I now realise he had looked at our financial affairs and I presume was impressed by the way the charity was run, particularly for him to recognise us the way he did.

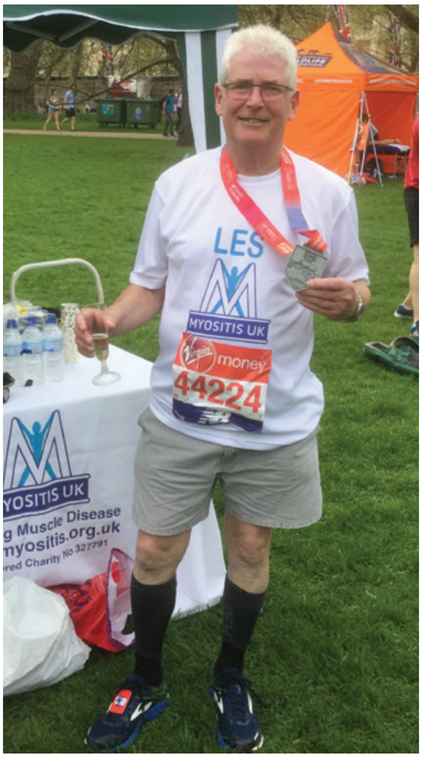
It was a pleasure to meet up with Arthur and his family, albeit on a very sad occasion, and to learn about not only the help Gordon gave to Myositis UK, but the many other charities and organisations he had been very kind and generous to over many years.

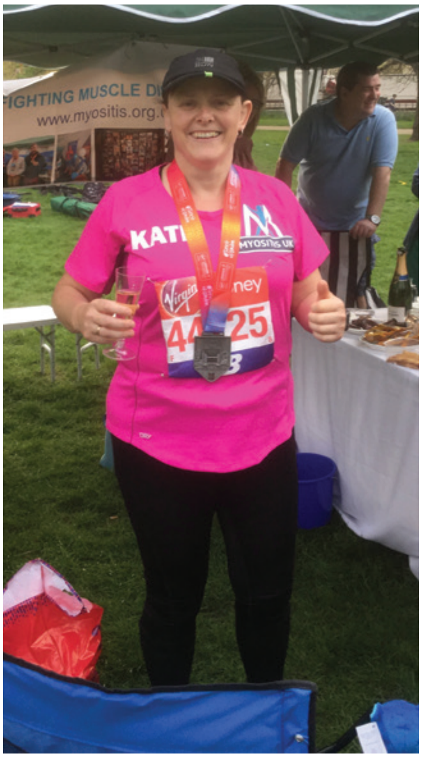
Dr Hector Chinoy

Many of our members were aware that Dr Hector Chinoy was not at the conference this year for I know they appreciate his great contribution in the treatment and research of myositis and for being such a friendly face whose help and company they enjoy. The reason for his absence was because he was running in the Wilmslow half marathon on the same day raising funds for Myositis UK. This is just another example of how lucky we are to have doctors who really do go beyond what is expected or even hoped of them.

London Marathon 2018







This year we were down to three runners: Arthur Macphearson, Catherine Buck and myself. I have already mentioned how well Arthur did. Kate was a last-minute stand in before the closing day for entrants. The dropout rate by runners was almost a disaster. Catherine has never run a marathon before and we did not expect her to raise funds for her entry. We knew the members would sponsor the team and Kate only had to get around the course. However, Kate, who works in the London Post Office, in a very short time, raised, £1,240. Amazing!

Unfortunately for her, during the run, she stepped onto a poorly discarded water bottle and hurt her ankle. Nevertheless, she completed the race and it was a pleasure to meet up with her in St James's Park afterwards.

Because of the circumstances I also decided to run but raising money was an issue. Last year people sponsored me but I had to drop out through a nasty injury. However, they all felt it was for a good cause and the return of the money was not an issue and should go towards the team. I therefore felt I could not go cap in hand again. How wrong could I be because the sponsorship money came in again and in a short space of time they sponsored me to the tune of £1,500.

I was also fortunate to be interviewed on "Radio Heart" and give a good plug for the charity.

The three of us ran in the hottest weather recorded for the London Marathon.

It was a great day for the spectators who turned out in their thousands. I understand three quarters of a million people lined the route.

One amusing incident for me was when a spectator held up a notice saying that Mo Farah was just behind me! I wish!

I would love to do this run again but at 69 and prone to injury I feel I should call it a day. However, if the dropout rate is bad again, who knows?

If you or someone you know would like to run next year in this awesome event, please get in touch with the office.

Fundraising

Cokethorpe School

Richard Cook wrote:
"I work at Cokethorpe School in Oxfordshire. As part of a fundraising effort, along with a group of 20 or so sixth formers at the school, we are running a charity 24-hour indoor football match in aid of Myositis UK. The event is also taking place during the Saturday morning of our open morning and we have already contacted the local newspaper and radio station who are going to pop down.
Last summer I ran the Stockholm Marathon and raised over £2,000 for the charity in aid of my stepfather David Pryor who is suffering from Dermatomyositis."

GRF Services

Vicky Cortese of the company Human Resources wrote: "James Borrett, one of our employees, has asked for a donation to be made to Myositis UK. This is in lieu of receiving a gift in recognition of 20 years' service in the company. I am therefore pleased to enclose a cheque for £228 being the cash equivalent of the gift he would have received."
James has kindly previously raised substantial funds for the charity.

Mitsubishi Electric

Junko Rao, PA to the president of the Mitsubishi Electric UK, enclosed a donation for £1,000 writing: "We wish you every success in your fundraising."
As is often the case with many of these most generous donations we do not know who nominated the charity for this gift. Whoever you are we cannot thank you enough for this gesture and perhaps you may be so kind as to get in touch so that we can thank you personally.

Premier League

Roz Donnelly writes:
"Each year, instead of sending official Christmas cards, the Premier League donates a sum of money to charities nominated by its employees. Myositis UK was nominated by Nathan Magyar and I am pleased to enclose a CAF voucher in the sum of £500. The Premier League is pleased to support the valuable work of everyone involved with the charity in this way."

80th Birthday

Cynthia Desmond writes: "I have been collecting various sums of money in my home collecting tin for some time particularly at my 80th birthday. Now I am happy to present to Myositis UK a cheque for £1,000. I'm sure it will be put to good use."

Marian Impey

Susan Smout sent a cheque for £1,000 as a donation to medical research from the estate of her dear, late mum, Marian, who died in March of this year.

Yiewsley Methoist Church, Middlesex

Sheila Palmer, church treasurer, writes: "Please find enclosed our cheque for £60 from a coffee morning held at our church for your charity by Ms Catherine Ireland."

Golden Wedding

Mrs Janet Gould, who is living with IBM, writes: "My husband and I recently celebrated our 50th wedding anniversary and asked for charity donations instead of gifts. I went on to the JustGiving Page and donated £350 and I enclose cheques which bring the total up to £500. We hope this amount will help to continue your good work."
I am sure people reading this news would join me in congratulating you both on such a wonderful occasion – Les

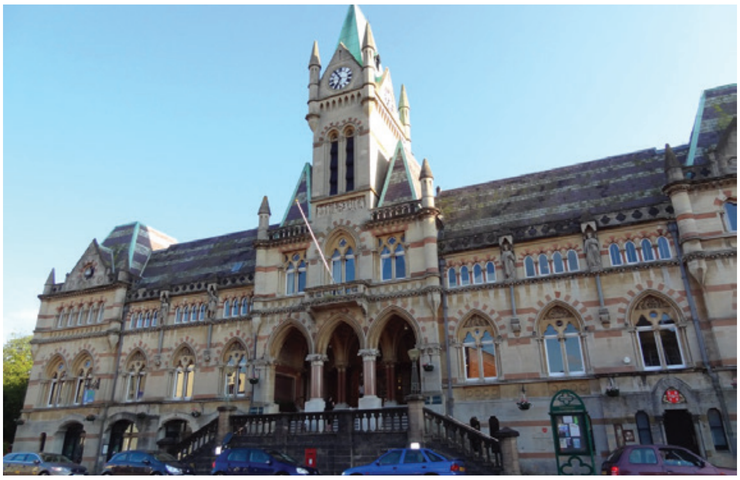
Letitia Rawson

Mum of the late and much loved Letitia, Mrs P Rawson, writes: "Thank you for forwarding the Myositis News and other information about what the charity is doing. It is good to know work continues with research into the illness and learn all about the work that goes into helping people.

"As usual, at this time of year, Letitia is very much in our thoughts and we enclose a donation of £50 to help towards the work of the charity."

Donations in Memorium

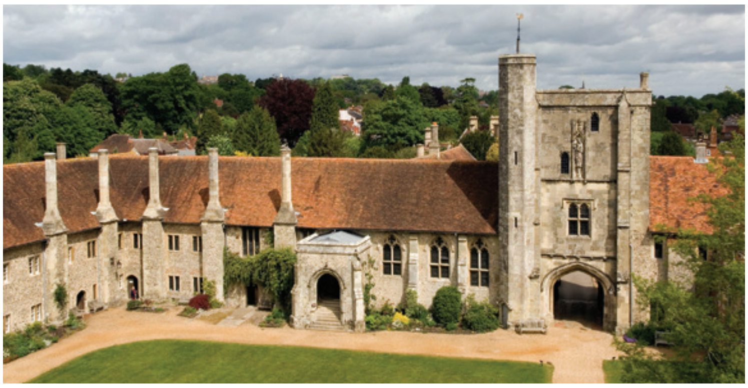
We have received substantial donations in memory of loved ones who either had myositis or a family member had myositis. We are extremely grateful that the charity is remembered at these times of great sadness.



Winchester Guildhall and The Hospital of St Cross

Steve Old writes:
"I am a keen local historian and since taking early retirement (which has turned into semi retirement!) I have been looking into the history of some local buildings and institutions. I saw there were gaps in what was available in printed form for those interested in these buildings, in particular Winchester Guildhall, so I put the result of my research into a couple of A5 folded leaflets with pictures. The leaflets were on Winchester Guildhall and The Hospital of St Cross, Winchester. I had them printed on card locally and decided to sell them for a minimum 50p donation with the proceeds going to Myositis UK.

The first event I sold them at was my evening class on Archaeology which I run at Eastleigh College. They were well received so I decided to offer them at the stand I was manning at the Salisbury Festival of Archaeology and the Heritage Open Day at St Cross Hospital where again they were well received. I still have plenty available for a small donation and will continue to offer them at any event I attend in future. So far I have handed over £50."



Smith & Williamson Christmas Donations 2017

Dean Layzell appealed to his company for Myositis UK to benefit from their Christmas donations. Nick Osler, chairman of S&W Charities Committee, kindly informed Dean that £2,000 had been allocated and to pass on to Myositis UK best wishes from Smith & Williamson.

A family member of Dean's is living with myositis.

JustGiving Pages

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

Manchester Marathon

Meg & Mike took part in the Manchester Marathon 2018, running in memory of their aunt, Jane Corkhill.

"We are taking part in Manchester Marathon 2018 for Myositis UK because we want to do Aunty Jane proud!"

Our Story:
"On Friday 19th May last year our sparkly, funny, loving, witty and wonderful aunty, Jane Corkhill, passed away. She had a nasty disease – dermatomyositis – which got the better of her in the end, despite putting up a courageous fight.

On Sunday 8th April, we will be running the Manchester Marathon in her memory and to raise money for Myositis UK who fund research into dermatomyositis. Jane was a beautiful woman, both inside and out, and we are doing this, not only to make her proud, but her family too – a bunch of incredibly strong people.

To add to Jane's memory, pink will be worn in her honour as well as clinking prosecco glasses at the end – two of Jane's favourite things! We will also attempt a human pyramid (a Corkhill tradition), grabbing any extra people we may possibly need! Please show your support in funding this research in the hope that other people stand a chance of surviving. Thank you in advance! X"

They raised £2,580 for the charity plus gift aid.

Team FCB Studios Manchester

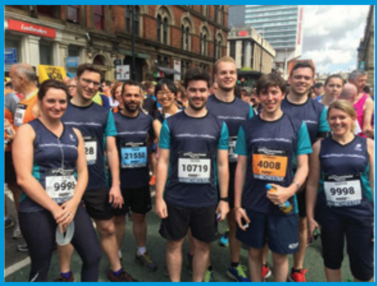
Great Manchester Run 20th May 2018

Team members: Kate Parkes, Adam Booth, David Bates, Michael Jenkins, Peter Mitchell, Jack Baker, Ernst ter Horst, Simon Branson, Kat Hale, Jimmy Corkhill, Aoife Spillane, Susie Morris

Their Story:
"Team FCB Studios Manchester and friends are running the Manchester 10K this year on May 20th!

"This year we are raising money to fund research into dermatomyositis through Myositis UK. We are raising money in memory of our colleague Sophie's mum, Jane, who passed away very suddenly from the disease last summer."

As well as the two previous events held in memory of Sophie's mum, a donation of £1,350 was received from FCB Studios. This makes a total, including gift aid, of £6,767.50 raised in her memory. A further £50 donation has been received from the 'Collingham Open Gardens' event in the village where Jane lived.



Jean MacNab

24-Hour Golf Challenge

Their Story:
“This special challenge for the ladies of West Linton Golf Club, Scotland, was the idea of two members, and has been enthusiastically adopted by the group.

The fundraising event will be a 24-hour non-stop golf relay, with ladies switching in and out of a team of four, playing constantly between 5pm 16th June & 5pm 17th June.

Myositis UK was chosen as the charity to be supported by this event because Andrew, the son of one of the members, was diagnosed with dermatomyositis in August 2017 – a rare, debilitating, auto-immune condition which is incurable, but manageable with medications, and with incredible stoicism, staying power and effort!”

Andrew’s mother hopes to play throughout the 24-hour relay event – which is likely to involve over 30 miles of walking and “several hundred” golf shots!

Thanks for taking the time to visit our JustGiving page.

An amazing £5,067.11 plus gift aid was raised at this event.
After the event Jean wrote:
“Huge thanks to all of you who have been so generous with your support of the 24-hour relay, helping us to reach much more than our initial fundraising target. We need more research to understand more about myositis, its causes and treatments, and really thank you for advancing that cause. We have to look forward - and I also use that as a reason for a final increase in our target figure!

“Photograph from 18th green of West Linton GC, with some of players and supporters there as we completed 140 holes without stopping - amazing!”

Helen Keith

2018 Edinburgh Marathon

I’m running my first marathon in Edinburgh for Myositis UK because my brother, Andrew, has inspired me to do so!

Helen’s story:

“My three brothers are my inspiration. All three have run marathons - Ross in Stirling, Colin in Copenhagen and Nice/Cannes, and Andrew at Cape Wrath. Now it’s my turn, and as hard as every step will be, it is nothing in comparison to what Andrew has had to deal with in recent months.”

Helen raised £5,210.46 plus gift aid for the charity.

Update from Helen:

“I can’t thank you all enough for the incredible support! I really enjoyed my 1st marathon & found it to be an incredible experience. So delighted that fundraising is close to £5000 now - thank you so much everyone!! It means so much to us all.”

Helen is Jean Macnab’s daughter so the family has raised £10,277.57 plus gift aid in total!

Henry Cort:

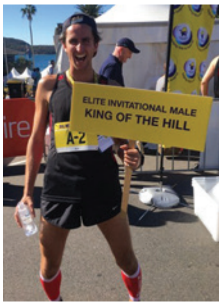
We are raising money and awareness for Myositis UK because of Mrs Lloyd

Their Story:
“Thanks for taking the time to visit our JustGiving page. Our dear friend and colleague, Mrs Lloyd, passed away after a short illness. She has been at the Henry Cort Community College since September 2012, leading the Behaviour Team and as Victorious House Progress Leader since April 2014. Prior to 2012, Mrs Lloyd worked for the Hampshire County Council Inclusion Service. She was an outstanding practitioner who has supported students, staff and parents for many years across the county and will be sadly missed. This loss has greatly affected our college, students and parents. Our thoughts are with Mrs Lloyd’s family at this very sad time.”

The college has raised £1,610 plus gift aid for the charity.

Chris Selman

Running 100km Ultra Trail Australia



“Attempting to run 100km in the Blue Mountains for Myositis UK because we’re here for a good time, not a long-time”.

Chris’s Story:
“And yes, before you ask that is my father! And beside him, smiling away is his loving wife and my stepmother, Helen. Sadly, earlier this year after suffering from myositis plus other conditions for many years, Helen passed away on January 18th.

Helen had a warm heart, caring soul and gave so much to others. In loving memory of Helen, I have decided to put my mammoth 100km run to good use and raise awareness for the Myositis UK charity.

The UTA100 is Australia’s most challenging and prestigious 100km trail running event. There will be stunning views, thousands of steps, an elevation gain of 4,400m over 100km and I will be aiming for a finishing time of 14 hours. Feel free to make donations per step, metre, km or hour!! Thanks in advance” – Chris.

Chris has raised Aus$7,418.46 for the charity.

Bradley's National Three Peaks Challenge

12th-13th May 2018

Team members: Shazan Amin & David Marsh

Bradley's Story:
"We are attempting to complete the National 3 Peaks Challenge to raise money for the Myositis UK charity. The most well known version of the challenge is to scale the 3 peaks in under 24 hours. This might not sound too difficult but the 3 peaks are Ben Nevis, Scafell Pike and Snowden; the largest peaks in Scotland, England and Wales, respectively."

"The Myositis UK charity helps to provide treatment options through supporting research into myositis conditions. There are lots of different types of myositis, but all are characterised by muscle inflammation and weakness. As an autoimmune disease myositis causes the body to attack its own muscle tissue resulting in severe muscle weakness. Sufferers typically have a hard time holding their head up, getting up from a seated position and walking very short distances. In severe cases sufferers have difficulty swallowing, breathing and other complications can be fatal. At present, there is no cure for myositis, only 30% of cases go into remission, leaving 70% of those affected with polycyclic or chronic courses of the disease. I hope that you will agree that the lack of a cure and such a poor rate of successful treatment into remission surely warrants further research."

Bradley:
"Having been diagnosed with Juvenile Dermatomyositis as a child I spent 4 years of my life between the ages of 4 and 8 in and out of hospital. Being on the receiving end of treatment that has enabled me to go from not having the strength to pick myself up off the floor to engaging in sport and martial arts (Tang Soo Do) on a regular basis has really shown me what great work this charity does. I could not imagine a lifestyle without being able to use my muscles freely and I hope by raising money for this worthy cause that I can go some way towards helping others affected by Myositis conditions. Not only will donations help to get sufferers the essential treatment they need, but it will allow them the opportunity to get the pleasure that I have from being able to make full use of my body."

Shazan:
"I have trained with Bradley for a while now and I would never have known that he had a condition primarily affecting the strength in his legs if he had not told me. Bradley and I train together a lot and we both have the work of charities like Myositis UK to thank for the ability to do so. I know we are all up for the challenge and I fully support Bradley in his effort to complete this challenge to show just how far he has come."

David:
"I'm excited to be supporting Bradley on his very personal challenge to raise money and awareness for Myositis conditions. Bradley is now a very talented martial artist competing on the international stage for Great Britain. This could not have been possible without the treatment he received. Unfortunately there are more people who don't recover from this condition than those who do. Funding for research is desperately needed to improve the remission rate and hopefully find a cure for those affected by this condition."

"Thank you for taking the time to read this, any donations will be greatly appreciated by us and the charity"

They raised £2,645 plus gift aid for the charity.

The following personal donations were also made through JustGiving:

Ann Gibbens
£50 + £12.50 Gift Aid
“Another contribution to celebrate our friends Janet & Richard Gould’s 50th Wedding Anniversary. Our love and congratulations to you both. Ann & Tony G xx”

Alan Wicksted
£250 + £62.50 Gift Aid
“I feel this charity needs all the funds it can raise to fight this horrible condition.”

Richard & Janet Gould
£350
“This is money raised at our 50th anniversary celebration instead of gifts. Together with cheques made payable directly to Myositis, we raised £500. We hope will help the charity’s excellent work.”

Anne Littlewood
£35
“From all at Golcar Slimming World Group, Huddersfield.”

Hilary Saunders
£50
“Together we will find answers and solutions.”

Mark Foster-Brown
£75.00 + £18.75 Gift Aid
“Inspired by Arthur Macpherson”

Dr Hector Chinoy

Wilmslow Half Marathon, 24 June 2018

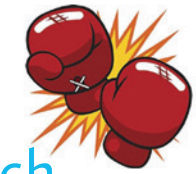
Hector’s Story:

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

My clinical and research work involves looking after patients with myositis and trying to find new and more effective ways of managing the disease. I signed up to the Winslow Half Marathon months ago and it was unfortunately cancelled due to bad weather, and rearranged on the actual day of the Myositis UK annual general meeting. I would have liked to have gone along to the meeting, and to stay involved, I told a charity that I will use the run to fundraise instead. Myositis UK have already funded some really important research into the field of myositis that we have co-ordinated through The University of Manchester, so I can promise you that your donation actually will make a difference!”

Hector raised £1,043.10 plus gift aid for the charity.

Julianne Rooney



Boxing for Myositis Research

Julianne’s Story:
“Six years ago my mother was diagnosed with polymyositis, an autoimmune disease which causes the body’s immune system to attack muscles. Polymyositis is considered a chronic condition with no cure and the exact cause is unknown.

The rareness of the diseases makes qualitative research at a single centre and even in a single country difficult. I am raising money through my first boxing match to fund treatment/therapy trials and provide community support to patients in the UK and abroad.

“The boxing match will take place in London on April 21st and tickets will be £20 - if you’d like to come watch, your £20 donation will go directly to the fundraising. (There will be several fights to see with the great bunch of people I’ve been training with!) If you can’t make the show, donations of any amount are still hugely appreciated. Please share and contribute if you can!”

Julianne raised £210 for the charity plus gift aid.

Research

This year myositis research, studies and data collaborations have continued and developed. Myositis doctors, scientists and researchers have been able to publish some of this work in medical journals. It is wonderful to see their work expanding and leading to new ideas. You may note below another publication by Dr Zoe Betteridge. Myositis UK has supported much of her myositis serology research into myositis specific and myositis associated antibodies; their discovery, analysis and how they can provide information towards a patient's clinical picture. Her work at Bath University under Professor Neil McHugh has established itself as a UK lead for myositis serology analysis.

Dr James Lilleker has kindly sent a copy of "The patient centred standards of care for adults with myositis" manuscript which he says may be distributed amongst members. If you would like a copy please email msg@myositis.org.uk or send a large stamped addressed envelope.

Below is a short list of published work, typically those that involve Myositis UK (funding of salary, research consumables, dissemination of information, 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.

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 & Rheumatology, October 2017. Free Access PMID: 29106061

Published in Arthritis, Research and Therapies, August 2018. Free Access PMID: 30092841

Genetic background may contribute to the latitude-dependent prevalence of dermatomyositis and anti-TIF1-autoantibodies in adult patients with myositis.

Parkes JE, Rothwell S, Oldroyd A, Chinoy H, Lamb JA; Myositis Genetics Consortium (MYOGEN).

Published in Arthritis, Research and Therapies, June 2018. Free Access PMID: 29884237

Using serum troponins to screen for cardiac involvement and assess disease activity in the idiopathic inflammatory myopathies.

Lilleker JB, Diederichsen ACP, Jacobsen S, Guy M, Roberts ME, Sergeant JC, Cooper RG, Diederichsen LP, Chinoy H.

Published in Rheumatology (Oxford), June 2018. Free Access PMID: 29538753

Splicing variant of WDFY4 augments MDA5 signalling and the risk of clinically amyopathic dermatomyositis.

Kochi Y, Kamatani Y, Kondo Y, Suzuki A, Kawakami E, Hiwa R, Momozawa Y, Fujimoto M, Jinnin M, Tanaka Y, Kanda T, Cooper RG, Chinoy H, Rothwell S, Lamb JA, Vencovský J, Mann H, Ohmura K, Myouzen K, Ishigaki K, Nakashima R, Hosono Y, Tsuboi H, Kawasumi H, Iwasaki Y, Kajiyama H, Horita T, Ogawa-Momohara M, Takamura A, Tsunoda S, Shimizu J, Fujio K, Amano H, Mimori A, Kawakami A, Umehara H, Takeuchi T, Sano H, Muro Y, Atsumi T, Mimura T, Kawaguchi Y, Mimori T, Takahashi A, Kubo M, Kohsaka H, Sumida T, Yamamoto K.

Published in Annals of the Rheumatic Diseases, April 2018. Abstract only PMID: 29331962

EULAR/ACR classification criteria for adult and juvenile idiopathic inflammatory myopathies and their major subgroups: a methodology report.

Bottai M, Tjärnlund A, Santoni G, 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, Danko K, Dimachkie MM, Feldman BM, García-De La Torre I, Gordon P, Hayashi T, Katz JD, Kohsaka H, Lachenbruch PA, Lang BA, Li Y, Oddis CV, Olesinka M, Reed AM, Rutkowska-Sak L, Sanner H, Selva-O'Callaghan A, Wook Song Y, Vencovsky J, Ytterberg SR, Miller FW, Rider

LG, Lundberg IE; International Myositis Classification Criteria Project consortium, the Euromyositis register and the Juvenile Dermatomyositis Cohort Biomarker Study and Repository (JDRG) (UK and Ireland) .
Published in Rheumatic and Musculosketal Diseases, November 2017. Free Access PMID: 29177080

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

Lilleker JB, Bukhari M, Chinoy H.
Published in Rheumatology (Oxford), February 2018. Free Editorial PMID: 29529264

Genetics in inclusion body myositis.

Rothwell S, Lilleker JB, Lamb JA.
Published in Current Opinion in Rheumatology, November 2017. Free Access PMID: 28777108

Risk factors and disease mechanisms in myositis.

Miller FW, Lamb JA, Schmidt J, Nagaraju K.
Published in Nature Reviews Rheumatology, April 2018. Abstract only PMID: 29674613

Expression of myxovirus-resistance protein A: a possible marker of muscle disease activity and autoantibody specificities in juvenile dermatomyositis.

Soponkanaporn S, Deakin CT, Schutz PW, Marshall LR, Yasin SA, Johnson CM, Sag E, Tansley SL, McHugh NJ, Wedderburn LR, Jacques TS.
Published in Neuropathology and Applied Neurobiology, May 2018. Free Access PMID: 29770465

Autoantibodies in myositis.

McHugh NJ, Tansley SL.
Published in Nature Reviews Rheumatology, April 2018. Abstract only PMID: 29674612

Clinical signs and symptoms in a joint model of four disease activity parameters in juvenile dermatomyositis: a prospective, longitudinal, multicenter cohort study.

van Dijkhuizen EHP, De Iorio M, Wedderburn LR, Deakin CT; JDRG.
Published in Arthritis, Research and Therapies, August 2018. Free Access PMID: 30111380

CD19+CD24hiCD38hi B Cells Are Expanded in Juvenile Dermatomyositis and Exhibit a Pro-Inflammatory Phenotype After Activation Through Toll-Like Receptor 7 and Interferon.

Piper CJM, Wilkinson MGL, Deakin CT, Otto GW, Dowle S, Duurland CL, Adams S, Marasco E, Rosser EC, Radziszewska A, Carsetti R, Ioannou Y, Beales PL, Kelberman D, Isenberg DA, Mauri C, Nistala K, Wedderburn LR.
Published in Frontiers in Immunology, June 2018. Free Access PMID: 29988398

Juvenile dermatomyositis: Latest advances.

Wu Q, Wedderburn LR, McCann LJ.
Published in Best Practice and Research Clinical Rheumatology, August 2017. Abstract only PMID: 29773272

Efficacy and Safety of Cyclophosphamide Treatment in Severe Juvenile Dermatomyositis Shown by Marginal Structural Modeling.

Deakin CT, Campanilho-Marques R, Simou S, Moraitis E, Wedderburn LR, Pullenayegum E, Pilkington CA; Juvenile Dermatomyositis Research Group.
Published in Arthritis and Rheumatology, May 2018. Free Access PMID: 29342499

Myositis UK Research Grants

The trustees have approved the following grant applications:

- £12,000 to Dr Pedro Machado to cover the cost of the scans to continue his research.

Pedro wrote: “We would like to extend our exploratory study to perform Abeta amyloid PET imaging in a subset of the 20 oldest IBM patients to identify the prevalence of in vivo Abeta1-42 amyloid deposition in the brain and compare with age and gender matched control data available from ADNI.

In collaboration with Eli Lilly and Company, we hope to receive 20 doses of Florbetapir (Amyvid®) free of charge (normal cost £810 per dose). PET-CT scanning will be done at the Institute of Nuclear Medicine UCL at a cost of £600 per scan including a clinical read. We, therefore, estimate the total cost of PET-CT scanning will be £12,000.”

- £19,800 to Dr Simon Rothwell to cover the cost of consumables in Immune Cell Profiling of Myositis Patients Starting Rituximab Therapy.

Simon sent the following message: “Hector has sent me your letter confirming funding for my project “Immune Cell Profiling of Myositis Patients Starting Rituximab Therapy”. I’d like to thank you personally for this and all your support over the years. I look forward to working on this important project, and sharing the results with Myositis UK.
Please pass on my thanks!”

- £25,000 to Dr James Lilleker to fund the salary (and overheads) of a clinical fellow to work on the Myositis Guidelines project for six months. Whilst this project is being overseen by the British Society of Rheumatology, no material funding is available. A full-time clinical fellow working on the project will help to ensure that the work is completed in a timely fashion, for the benefit of clinicians and patients alike..

Congratulations

Trustee Nikki Baron and her fiancé, Lionel, were married in June this year. I am sure that you would all like to join me in sending our warmest wishes and congratulations to the happy couple.

Myositis UK Meet-ups

Myositis UK Meet-ups give the opportunity to meet and chat with others about myositis.

We may have doctors as guest speakers BUT please note they are unable to give personal medical advice at the Meet-up (as this is not covered by their insurance).

Jo Goode, Myositis UK's treasurer, arranged two Meet-Ups earlier this year.
The first one was in London on Saturday 21st April and was well attended. Dr Patrick Gordon held a question-and-answer session.

The second was in Manchester on Saturday 19th May and was also well attended and the guest speakers were Dr Hector Chinoy and Dr Liz McCann.

Unfortunately, there were a number of people who had booked to attend and did not turn up which has regrettably led to the trustees considering making a nominal charge. No decision has been made yet as we would like to continue to offer it free to members.

To find out when the next meet-up is please visit the meet-up page online.
You must register and RSVP on the Meet-up page AND be a Myositis UK member to attend for free. http://www.meetup.com/MyositisUK/

Christmas Cards

**They are back!
We are selling Myositis UK Christmas Cards this year. This was always one of the ways the charity used to raise funds and awareness until a couple of years ago when, at that time cost, especially postage, became too expensive to make it worthwhile. We hope you like this year's cards and look forward to receiving your orders!**

Christmas Draw

We will be holding our Christmas draw again and tickets will be sent out during October.

Dermatomyositis – Can you help?

“The British Association of Dermatologists are creating a new public-facing website for patients to help provide the advice and care needed when looking for or undergoing treatment. As such, the BAD are looking to speak to patients who might be willing to come to London for a few hours, to film a short video that will be part of the website’s design.

“The BAD would like volunteers to talk about their journey, from when symptoms first appeared through to the present day.

This would include the patients’ treatment pathway, for example: Who did they see? What sort of treatments have they tried? What has helped? They would also like volunteers to speak on the impact this has had on their lives, both physically and emotionally, however mild or severe.

“Each edited video will last around 3 minutes. Volunteers don’t need to be ‘media trained’ or have any experience of being filmed at all, what is required is honest accounts from relatable people about their experience of skin disease and seeking treatment, both positive and negative.

“As thanks for volunteering, volunteers who will go on to be filmed will receive £50 and travel costs will be reimbursed and the referring charity will also receive a donation of £25.

“To apply, the BAD would initially like you to send a short video telling your story, so that the most appropriate stories are then filmed. No need for any professionalism; it’s recommended you send in a phone video for simplicity - quality and background are irrelevant. We won’t use the videos in any way and they will be deleted, and if creating a video on a mobile is not possible, we might be able to do a video call or normal phone call instead.

“It only needs to be a minute or two long, and in your summary, you may want to include some details such as:

- The name of your skin disorder and what it is,
- how long you’ve had it,
- do the symptoms come and go or are they always the same,
- a bit about your path to diagnosis (e.g. did you see a GP for a long time first, did you get referred to a dermatologist, did you have many tests),
- what sort of treatments you have tried and what has worked for you,
- what’s it like living with your disease, either physically or emotionally or both
- any positive messages for someone who is recently diagnosed (with any skin disease), or advice for someone who thinks they have a skin disease but doesn’t know where to start seeking help

“Anyone who is interested in learning more before applying can contact the Communications Team at the British Association of Dermatologists by emailing comms@bad.org.uk or ringing 0207 391 6084.

“The BAD is mindful that many people visiting the site may not even have a diagnosis yet, so responsible portrayals are needed. This means not terrifying people or making them feel seeking treatment is hopeless. For many diseases, help is available from NHS dermatologists - although this is not always straightforward. However, while the aim is to ensure not to deter people from seeking help, this is very much a platform for patients to share their own experiences without any agenda, so feel free to offer suggestions on what you’d like to share with other people who may be new to dermatology.

“On behalf of the British Association of Dermatologists, we would like to say a massive thank you in advance to everyone that wants to take part in our project that will hopefully help so many people get the care they need.”

Website

Trustee, Laura Oakley has undertaken an extensive review of the charity website. This has led to a complete new website being developed in a format which she will be able to administer herself and will be optimised for mobile phones and tablets. It should be completed in the next couple of months.

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 12noon 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 will they please get in touch with Irene or me.

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. 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 where-ever 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

Articles for Myositis News

We would welcome any articles you may like to share in Myositis News. Perhaps you have found something which might be of use to others, helpful tips for travelling etc. Please email articles to the office and include any pictures if you have them. – Thank you

MYOSITIS UK

146 Newtown Road, Woolston, Southampton, SO19 9HR
t 023 8044 9708 e office@myositis.org.uk www.myositis.org.uk