



Myositis UK

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Myositis Flyer September 2021

I trust this myositis news flyer will quickly bring you up to date with the latest charity activity. Although we are still experiencing some of the restricting issues of Covid-19 it has not prevented the charity from operating. There is also no doubt that trustee and treasurer, Jo Goode, who facilitates her Face Book Page, The Myositis Community of Great Britain & Ireland has greatly reduced the isolation of people having to live and cope with myositis. Members, family and friends during the past summer months have tirelessly raised funds for which we are very grateful and our London marathon team have continued to train, being focussed on not only the running, but having the myositis cause as the motivation for their effort and determination. This event for Team Muscle will take place on Sunday 3rd of October.

During this period it has been very difficult for the trustees to make financial decisions when considering the next steps to take to advance progress in myositis particularly in medical research. Irene and I are well aware that we are getting on in years and time waits for nobody! Our life time ambition has been to see myositis in all its forms as a group of diseases that can be successfully managed or even, dare I say, cured. However, looking at our level of fund raising, quite remarkable for a very small charity, it will not generate the sums needed to generate the advancement we need to sense that the future bodes well with respect to our and perhaps I expect your dream too.

However, this changed dramatically at the end of last year when the charity was informed that it will be a major beneficiary of the estate of the late Joyce Winifred Norman. She kindly and quietly bequeathed the charity £269,772.71. This is the largest gift the charity has ever received and the trustees were stunned to hear this news. We realised that we could now consider to expand medical research and after being on the back foot the emphasis was now on the front one. Joyce wished that this money will be spent on Inclusion Body Myositis in memory of her husband who died from IBM. In agreement with her wishes this we will do. But what this also means is the charity's existing funds can be allocated to the other diseases we support and give them a boost too.

As a result of this wonderful gift the trustees have needed to consider how we manage and determine developments in myositis research. With this in mind, we are forming two panels of experts. One will be a medical panel and the other a scientific panel. These panels will oversee and consider future projects. Their recommendations will then be put to the trustees in any decision making.

We invited scientists and doctors who have been involved with the charity to a zoom meeting informing them of the legacy and discussing the way as a body we could move forward. As a result of this meeting the panels are in the process of being formed. It was agreed that this was the way forward and the medical profession could be acknowledged for their individual input and for their involvement in the progress of myositis research. It also means that as the charity has a recognised medical structure we can work with other grant funders as equal partners to facilitate a larger project if the opportunity arises.

This wonderful development has been made possible by the sheer kindness of Joyce who valued the charity worthy of this gift. We cannot personally say thank you to her but we will make this gift work in memory of her and perhaps it will create another great step forward in beating this disease.

Les Oakley MBE Chairman

London Marathon 3rd October 2021

Myositis UK "Team Muscle" has five runners taking part in the marathon. Some of them were due to take part in the marathon in April 2020 so they have had a long wait to take part and maintain fitness!

The team members are: Julia Raymond, Eigen Halpin, Stephen Bailey, Prof Hector Chinoy and Mark Emms.

This will be the first “Fund Raising Event” held directly by the charity since the start of the Covid-19 pandemic. The “Team Muscle” runners have between them raised over £3,500 to date. If you would like to support their effort you can donate on any of the following links or on the enclosed sponsorship form.

Julia Raymond - <http://www.justgiving.com/Julia-Raymond2>

Stephen Bailey -

<https://uk.virginmoneygiving.com/stephen-bailey-SAVMLMBONDS333-2020-239449/1>

Eigen Halpin - <https://uk.virginmoneygiving.com/EigenHalpin1>

Hector Chinoy - <https://uk.virginmoneygiving.com/HectorChinoy2>

Mark Emms - <http://www.justgiving.com/Mark-Emms1>

Fund Raising on “Just Giving”

Yograj Deorukhkar is raising money for Myositis UK by shaving his beloved beard off!



Yograj Story; “I am shaving my beard which has been living on my face for just under 6 years to raise money for Myositis UK.

It may not seem like a big deal, but to me, my beard has been one of my most defining features for just under 6 years and all of my adult life! Those around me will know how reluctant I am to shave it but I feel it is important that I raise awareness and fundraise for Myositis UK.

A few years ago, my mum was unfortunately diagnosed with Autoimmune Polymyositis. This brought into my world this relatively rare and unknown condition. Myositis required us to make a number of lifestyle changes and brought to my attention just how much an impact this condition can have on lives. Due to the treatment for this being immunosuppressive, the arrival of COVID-19 has exacerbated the impacts of the condition on our family and everyone else who is affected by the illness.

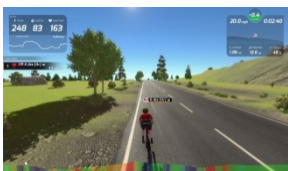
Myositis UK seeks to improve the diagnosis, treatment, understanding and prognosis of myositis. They do this by providing information, relieving isolation, raising funds, and funding research. We found Myositis UK very useful when my mum was first diagnosed as they have a wealth of information about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

Polymyositis and dermatomyositis are thought to be autoimmune conditions. This is where the immune system attacks the body’s own tissues. In these cases it is the muscles, leading to persistent and chronic inflammation. The definitive cause is unknown. Experts think genetic predisposition and environmental factors both play a part.

With all of this in mind, I hope that you can join me in my efforts to raise awareness and help me to fundraise for Myositis UK!”

Yograj has raised £1207 for the charity

Kate Ouellette-Cretsinger - Does TABR Virtually



Kate took part in the virtual Trans Am Bike Race (TABR) which is an annual, self-supported, ultra-distance cycling race across the United States. The route is about 4,200 miles. Kate cycled in memory of her dear friend Carolina Levien.

Kate has raised £2,403.24 for the charity

Louanne P-B is making cheeky Lino cut prints for swimmers!

Louanne’s Story: “I am raising money for Myositis UK because my fantastic friend has it and this is for her.”

Louanne has raised £537 for the charity

Benjamin Wright - 3 peaks challenge



Benjamin's Story; "Hi, thank you for visiting my page!

I am doing the Yorkshire 3 peaks which is around 24 miles in 12 hours, I am doing this because my mum was diagnosed with dermatomyositis just over a year ago. Dermatomyositis causes muscle weakness, rashes and inflammation."

Update

"I've completed the 3 peaks and did it in 9 hours 58 minutes under the 10 hour time frame we wanted to complete it in. A massive thank you to Nathan Flat and Andrew Turner for doing the 3 peaks with me. I'd also like to say thank you to my mum, dad and sister for helping me on the way and my Nan, Grandad and auntie Emma for meeting us at the end and cheering us on.

Thank you to everyone for donating to a charity close to my heart and keep smiling :)"

Benjamin raised £1,530 for the charity

Marian Paice - Jackie's Load of Rubbish

I am going litter picking ... 100 Bags (minimum) for Myositis UK because I had a surprise diagnosis in 2020.



Jackie's Story; "Thanks for taking the time to visit my Just Giving page. Between 28th March and 30th April I am raising money for Myositis UK.

What's that? Why? I hear you say.

March 2020 I had Covid, then pneumonia and then pleurisy. I was referred to respiratory and then rheumatology. In October, I was given the news that I have Anti-Synthetase Syndrome (ASS).

Yep... I'd never heard of it either. It's rare, 1:100,000 rare. For me it has affected my lungs and I get bad Raynaud's (icy cold fingers). I am having treatment (a form of lite-chemo) and my last scheduled dose is on 26th March Hence my start date). I am still waiting to find out what happens after that. But it is a chronic illness, so I will have it for good. Fingers crossed there is no permanent damage to my lungs and I will be in remission.

There is very little information out there about the disease. ASS falls under Myositis. Hence my reason for fundraising for the UK charity

So on to what I am going to do. I aim to collect 100 bags of rubbish from my local area in that period. So not only raise money but do something useful too. I have discovered how therapeutic litter picking is during lock down. It is like a meditation, it's good for the environment and gives my daily exercise a sense of purpose.

I understand that many are feeling the pinch at the moment but anything would be gratefully received and don't forget gift aid too.

Donating through Just Giving is simple, fast and totally secure. Your details are safe with Just Giving - they'll never sell them on or send unwanted emails. Once you donate, they'll send your money directly to the charity. So it's the most efficient way to donate - saving time and cutting costs for the charity."

Jackie has raised £893 for the charity

Julie Dervey

Fundraising for Myositis UK - Finding My Way Back To Fitness

I am having a birthday fundraiser for Myositis UK because I want to help to find a cure for Myositis!

Julie raised £50 for the charity

Philippa Neal

Beyond Badminton Half Marathon, on September 18, 2021

Philippa is running a half marathon in memory of her mum who suffered from myositis.

<http://www.justgiving.com/Philippa-Neal1>

Philippa has raised £440 to date.

Jason Sargent

Jason is taking part in the Conquest of Avalon 50km Ultra, on September 4, 2021

<http://www.justgiving.com/Jason-Sargent2>

Jason has raised £50 to date.

Hannah McCarthy

Great North Run 2021, on September 12, 2021



Hannah's Story; "On 12 September I'll be running the Great North Run in memory of my grandad. Running definitely isn't something that comes naturally to me but pre COVID I set myself a goal and signed up, wanting to raise money for Myositis UK. My grandad suffered from Inclusion Body Myositis which is a rare muscle-wasting condition that is currently incurable and Myositis UK raise funds to promote medical research and improve diagnosis, treatment, management and understanding of Myositis.

With COVID the run last year was postponed but I sadly lost my grandad in June this year. For anyone that knew my grandad he was the proudest and most genuine person and always put other people first. After years of him telling me about how he was the fastest runner at school, I'm hoping that if just a fraction of those genes have been passed down to me then I'll be okay on the day. If anyone would like to donate then I will be hugely grateful in helping raise awareness of Inclusion Body Myositis and help Myositis UK to further research into finding a cure for this disease. Thank you!"

<http://www.justgiving.com/Hannah-McCarthy16>

Hannah has raised £750 to date.

Helen Kurtz

Helen's Fibre 4 Fibres Fundraiser

"I'm raising money through creative activities for Myositis UK because more research is needed to fight this disease."

<http://www.justgiving.com/Helen-Kurtz>

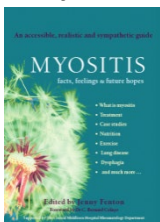
In the Winter/Spring Myositis News 2021 we reported that Helen had raised £11,807 for Myositis UK. She has now to date raised a remarkable total of £19,762 and is still fundraising. What a fantastic effort!

Donations in Memory on Just Giving

We are sincerely grateful for all the donations received in memory of loved ones. It is very heartening when families and friends think of the charity at such sad times.

Also a big thank you to everyone that has donated and fund raised for the Charity.

Jenny Fenton's Book



Jenny, a former Myositis UK trustee, has donated copies of her three hundred plus pages, soft cover book to the charity to give free to anyone who would like a copy. Although this book was published in 2006 and some of the medical content has moved on it is still a valuable resource for understanding myositis and covers a whole range of issues relating to the diseases. If you would like a copy you will only have to pay £3.20 to cover the cost of postage and packaging. Please send a cheque made payable to Myositis UK and your details to the office or email msg@myositis.org.uk for bank details.

The next copy of Myositis News will be published in the autumn. Any items for inclusion will be greatly appreciated.