



## Myositis UK

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### MYOSITIS FLYER SEPTEMBER 2020

Dear Member,

This is our first News Flyer since March and how life has changed since that month. Covid-19 and the resulting lock down was a difficult time I am sure for everyone. It affected people in many ways. For me it was because of my age and for Irene it meant total isolation because of health issues. These reasons also affected our trustees as well and with a national situation affecting the whole of the country and perhaps the world, coping with a different approach to living and to a degree, surviving, it has been a case of making the best of an unknown situation. No doubt, you all have had to adjust because of your myositis background and associated health issues and I trust, like us, you are more optimistic for the future and the changes we have all had to make.

However, we have continued to operate as a charity and much work has been done behind the scenes. Of course all our fund raising events were either cancelled or deferred to next year and beyond. My thoughts go to out to our London Marathon runners who had put in so much in training and raising funds for the charity. Fortunately, they can run next year if the situation in the country continues to improve. I just hope they can fit another period of training in for this event and at the moment the prospects for them are looking good and they all should be running next year should they wish to do so. We will also put on the website when other places are available for next year.

This pandemic has also affected our members who were organising fund raising events that they now have had to put on hold until the situation improves. I appreciate it must be very frustrating for them but I feel sure we all have every reason to be optimistic that these events will take place when it is safe to do so.

The lock down has seriously affected our charity funds and I would like to take this opportunity of thanking members and friends of the charity for making donations during the summer months. Fortunately, the charity has few expenses and we have been able to maintain our financial obligations to the medical research projects we have initiated. Treasurer, Jo Goode, has kept a watchful eye over funding and we are weathering the storm well. The only sad part is we have lost trustee, Niki Baron, who has been a fantastic supporter and fund raiser for myositis, particularly JDM for many years. Her life has moved on and we wish her well, but we know she will always be in the background willing us on and following our progress.



## Taking on the challenge!



Member, Helen Kurtz took on the challenge and knitted socks for the challenge, but that is not all, Helen has been fundraising continuously on Just Giving with her, “**Helen's Fibre 4 Fibres Fundraiser**” where she sells patterns and holds regular raffles.



**To date she has raised £4615 for Myositis UK to help fund research.**

Irene, myself and Paula also took on the 2.6 challenge during lock down as both Irene and Paula were shielding.

## Paula's Story



Thanks for taking the time to visit my Just Giving page. Please read my story, follow my efforts on the Myositis UK Facebook page and if you can sponsor me a little - maybe what you would of spent on a take-away coffee during the working week or some of what you may have spent on petrol now that only essential travel is permitted?

Income to support Myositis UK has fallen drastically during the Covid-19 pandemic and even when the lockdown is lifted social distancing will be required for quite a while. This will affect all the usual fundraisers for Myositis UK.

My 2.6/26 Challenge is to use the cross trainer for 2.6miles for 26 days.

Easy for many, yes I agree, but I've been left with muscle weakness, calcinosis, contractures, stiffness, reduced lung function and general scars of Juvenile Dermatomyositis.



I'm not a cross trainer pro either, my machine arrived last week, I've not used one for years, it's an early birthday present to maintain my fitness as by Shielding I cannot go out on a daily walk (if you read the government's advice Shielders are asked to stay indoors in their home and open a window!). I'm lucky to have a small garden but it's a slope and very uneven. Exercising on it will more likely result in a sprained ankle, hence the cross trainer purchase.

I did a test run on Saturday. It took me about 7 minutes to cross train 2.6km. It's certainly not easy, I'm puffing and my heart rate goes up to 130. However, to make it more of a worthy challenge for sponsorship I decided to change from 2.6km to 2.6 miles for 26 days.

To add a little bit more fun to involve my son we will also be adding in the following during lockdown:

- \*Counting upwards in 2.6 until we reach 260\*
- \*Reading 26 different children's books\*
- \*Dancing to Baby Shark and other annoying Pink Fong tunes for 26 minutes\*
- \*Blowing 26 bubbles\*
- \*Sliding down the slide 26 times\*
- \*Reciting the 26 letters of the alphabet and playing a few alphabet games\*

**Paula raised a total of £513 for Myositis UK**

## Les and Irene Oakley's 2.6 Challenge

Our Story,

As founders of Myositis UK we two oldies, one shielding and one the wrong side of seventy have decided to take part in the 2.6 challenge to raise funds for Myositis UK. Over the next week we will be doing a different 2.6 challenge every day at home and to make it more interesting we will be in a different fancy dress! We will post pictures of our challenges which we trust you will find amusing!!

Challenges are: 26 hops, 2.6K walk around the garden, skipping rope 26 times, 26 jumps on exercise trampoline, 26 times up and down the stairs, 26 claps on Thursday for our NHS and 26 attempted goals in football!!

**These may be easy challenges for some but not for us!!**

If you can, please support the charity and us in our lock down.

General fundraising has been hit very hard by the COVID-19 pandemic.



***We raised a total of £871 for Myositis UK. Thank you to all who sponsored us.***

### **Annual General Meeting and Conference**

Unfortunately, due to the Covid 19 restrictions, we were unable to hold the AGM and conference this year but we hope that next year it will take place and the provisional date is Sunday 13<sup>th</sup> June 2021 at the Oxford Spires Hotel, Oxford. The hotel have been very helpful and had their share of problems during these unprecedented times. We were very fortunate and grateful to have two Zoom meetings for the charity organised and chaired by Dr James Linaker and Prof Hector Chinoy. These were very helpful, particularly during those early weeks and very much appreciated by all who logged in. However, because of the intense medical situation and the need for doctors and medical personnel to treat the pandemic another zoom meeting was not possible. This is a changing picture and perhaps in the near future these can be arranged again. If you can, keep a look out on the website or social media pages.

### **Research**

Many of the research projects that Myositis UK are supporting with funding had been progressing but have now been delayed as a result of the Covid-19 pandemic. However, here is a brief update of the work of the speed funding grants to date.

#### **“Speed Funding Grants” – updates**

**Kyla Britson (USA)**, writes,

“Thank you so much for reaching out. I would be very happy to write a summary of my project for your newsletter. I can also include some figures/images of the xenografts.”

“If you think any of your members would be interested, I am going to be hosting a virtual thesis seminar on September 16th at 1pm EST (5pm GMT). Prior to COIVD, I was going to have my seminar in March, but we decided to postpone as infections increased. Initially, we were optimistic we would be able to hold an in-person seminar later this year, but that seems increasingly unlikely with the way the U.S. is handling the pandemic. I know how involved and proactive myositis patients and their families are about seeking information and research about myositis and I'm sure many of them would enjoy participating in my seminar.” - ***Please see enclosed leaflet for further details***

**Erin Wilfong (USA)**, writes,

“In collaboration with the Bonami lab, we have been able to identify Jo1 specific B cells circulating in the blood, and we are working on a manuscript with this data at present. We also looked to see if B cells invaded the inflamed lungs of patients with anti-Jo1 positive IIM, and this does not appear to be the case based on the patient samples available to us. Finally, we continue to work on transcriptional profiling of B cells in IIM and are tweaking the protocols for our transcriptional analysis. We did have some substantial delays in research with COVID-19, but hopefully I will have some transcriptional data to share by Christmas.”

“I want to thank Myositis UK for funding this award and I look forward to sharing additional findings.”

**Saskia Lassche (The Netherlands)**, writes,

“We have continued working on the project. The muscle-on-chip model is further refined and we have isolated IgG from serum. We were almost ready to start adding these to the muscle bundles when covid-19 struck - as you can understand we weren't allowed to start new experiments at the time. I happen to have an appointment with Jessica de Greef at Leiden University Medical Center later this week to discuss the project - I can send you a full update after I speak to her.”

***We hope to be able to have more updates in the next newsletter***

### **Christmas Cards**

You may recall from our last Flyer that we will not be producing a new range of Christmas cards for this year as the venture just did not meet expectations. However, we are selling off the stock at reduced prices and we look forward to you helping us making this a break even venture.

The Christmas Draw is taking place and we trust you will give it your full support. As well as the cash prizes the donated gifts are very acceptable and worth winning. I have a problem that my contacts for prizes have been reduced as a result of the economic situation and although this year is not a problem, next year will be. If you can help please let me know. *Draw tickets will be sent out with the next “Myositis News”.*

### **Virtual London Marathon**

The 40<sup>th</sup> edition of the London Marathon is now a “Virtual” run which will feature elite races in St James's Park, including the blockbuster head-to-head between Eliud Kipchoge and Kenenisa Bekele. On the same day, runners around the world will take on the 40th Race as the event goes virtual.

Message from the London Marathon,

*“The 40th Race will still take place on Sunday 4th October, but it will be a race of its time, an event for the world of now. The greatest athletes in the world will be taking part and we hope your supporters will too – taking on the 26.2 miles from home, with their loved ones and their communities supporting them.”*



One of our marathon runners, Stephen Bailey, is taking part in the “virtual race”. If you would like to support him his fundraising page is:

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

If you have any news or articles for the next “Myositis News”, please email them to [les@myositis.org.uk](mailto:les@myositis.org.uk) or post to the office by 18<sup>th</sup> September – Thank you