



MYOSITIS
Support Group

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Flyer - March 2009

Dear Member,

I trust this first Flyer of the year finds you well. With signs of a hint of Spring in the air suggests for me the start of a challenging new year that will hopefully be as rewarding as the previous one. This New Year is one of hope and I feel sure, success.

LONDON MARATHON

We have 3 runners in this year's marathon, David Edwards, whose father has Polymyositis, has secured his place through the ballot after three years of trying. Our good friend, Frank Littler, has also secured a place through the ballot. The 3rd member of "Team Muscle" is myself! My entry is by our silver bond place. We allocated the silver bond place after last year's marathon to Paul Stiles who had hoped to raise a substantial amount of money for the charity. He set up his fundraising page on Just Giving and had already raised £1,230 when his work situation altered and he reluctantly had to withdraw. However, he will continue to help raise sponsors for the runners. This was the reason that I decided to step in. I have never run a race or marathon in my life and I turned 60 last year! I have a training programme which I am following and I also have a Just Giving page set up to make donations online. There will shortly be a page on our website for you to follow my training but I am also on Facebook, just search Les Oakley on Facebook and sign up as a "Fan" to my page to help raise awareness.



We still hope this will be a bumper fundraising event for the charity particularly if everyone reading this can get behind "Team Muscle" by using the enclosed sponsorship form. You can photocopy or request more forms to pass on to as many helpers as you can.

We are planning a "Supporters Station" on the day along the Embankment near Waterloo Bridge with banners, etc. If you are planning to go to London to watch the marathon, please come and join Irene and the "Team Muscle" crew to cheer us on!

AGM & MINI CONFERENCE

This year's AGM and mini-conference will be at the Holiday Inn Eastleigh, near Southampton on Sunday 6th July. This year we hope to run a slightly different format to include a break out session after lunch for open discussions for each of the illnesses (IBM, PM/DM and JDM) to allow members to directly talk with the specialist(s). We hope this will give more opportunity for questions and for meeting others. This means the meeting will be more informal with less research updates.

Preliminary Programme

10.00 - 10.30	Meet new and old friends with a cup of tea or coffee
10.30 - 11.00	AGM
11.00 - 12.30	Morning Session
12.30 - 1.55	Lunch
2.00 - 3.30	Afternoon Session
3.30 - 4.00	Tea Coffee Break
4.00 - 4.30	Summary and Close

For those members who are staying the night before there is a section on the booking form to give permission to include names and contact phone numbers on a list which will be sent out to other members staying at the hotel so that anyone who wants to can arrange to meet. If you do not wish to meet please do not fill in this section of the booking form.

The AGM and mini-conference is free of charge to members, their partner or carer, parents of children with JDM and health professionals. There is a charge of £25 for others wishing to attend. I have enclosed a registration form and advanced registration is necessary for attendance. Please book early to help us make the necessary arrangements and to avoid disappointment as places are limited.

The Holiday Inn is just off junction 13 of the M3 and close to Southampton Airport and Southampton Airport Parkway train station. There is a free car park at the hotel. The conference room is on the ground floor with facilities for the disabled. If you wish to stay overnight either on the Saturday or the Sunday the cost of accommodation at the hotel is £85 bed and breakfast per room per night (you can cancel up to the date of the conference). You may be able to get a cheaper rate if you book on the internet but you have to pay on booking and cancellations are not refundable. There are also two Premier Travel Inns close to the venue. The Eastleigh Premier Travel Inn near junction 13 of the M3 and the Southampton Airport Premier Travel Inn junction 5 of the M27.

Contact details for hotel reservations

Holiday Inn 0870 400 9075 (quote msg when calling reservations) www.HolidayInn.co.uk
Premier Travel Inn 0870 242 8000 www.premierinn.com

IRIS HAZEL MEMORIAL TALK 2009

At the annual meeting we have "The Iris Hazel Memorial Talk". This is in memory of one of our very first members and benefactors. We would like to hear from anyone who has an inspirational story to tell. Any stories for this talk would be most welcome. If you have changed direction with your job, set up a group, taken up a different hobby or anything that you feel you have achieved that would be an inspiration to others to give them hope then we would love to hear from you. If you are a carer or partner of someone with Myositis then we would like to hear your stories because it changes the whole family's life as well. The talk can be very short say 10 minutes or longer! It could even be on your adventures or travels especially if something amusing happened! If you are interested please write or email Irene Oakley (irene@myositis.org.uk).

CONFERENCE 2007 DVD

The Conference 2007 DVD is still available to purchase (UK only) for £10 including postage and packaging (please make cheques payable to Myositis Support Group). This is the most definitive record of Myositis presented in this format and if you ever wondered what was going on in the Myositis medical world then this DVD will give you not only an insight but also a reason to share in the optimism, enthusiasm and hope that was delivered on this day. Feedback for this DVD has been good and some members have purchased further copies to pass on to their doctor.

Conference presentations 2007 included on the DVD:

What has Genetics taught us so far about Myositis
Autoantibodies in Myositis - New Findings
Myositis 101: An Overview of Myositis from the Patient Perspective
Developing the Tools to Assess People with Myositis
Iris Hazel Memorial Talk Studying with the Open University
Insights into the Search for Treatments for IBM
Update on Paediatric Juvenile Dermatomyositis
Myositis: an Update
The Birth of Clinical Trials in Myositis: The RIM Study

Dr Robert Cooper
Dr Harsha Gunawardena
Dr Chester Oddis
Professor David Isenberg
Anne Ali
Dr Michael Rose
Dr Clarissa Pilkington
Dr Ernest Choy
Dr Chester Oddis



Please send your order for DVDs to the office with cheques made payable to the Myositis Support Group.

LISTENING EAR TELEPHONE NETWORK



The LETN is available to Myositis Support Group members on request. The LETN is a directory of Myositis Support Group members who have volunteered to be a point of contact. Thank you to those who have volunteered to be part of this self-help resource. The LETN directory contains profiles and phone numbers of members who have volunteered themselves as a point of telephone contact to others. The LETN directory is to help alleviate the isolation felt by many especially those without a computer and do not have access to the Myositis Support Group website community.

If you would like a copy of the LETN directory please send a stamped addressed enveloped to the office. For further information on how to volunteer please email irene@myositis.org.uk or call Irene in the office who will be happy to send you a Volunteer Information Pack.

FUTURE FUNDRAISING EVENTS & NEW JUST GIVING FUNDRAISING PAGES

In addition to the London Marathon pages of myself and David Edwards, fundraising pages have been added for Miss Banzai's Tunnel Run and Rob Grummitt's Iron Man Austria. Pauline Stokes will be setting up her page soon as she is taking part in the "Just Walk" over the South Down in May. Visit www.justgiving.com/myositis to read their stories. To all you technical people out there that are on Facebook there is a Just Giving application which allows you to display the fundraising pages of your choice on your Facebook profile.



The organisers of the Robert Gordon University Rag Committee in Aberdeen have chosen the Group to be one of the benefactors from their Rag Week starting on the 14th March.

Our thanks to all these fundraisers for supporting the Myositis Support Group and good luck with all your efforts!

JUST WALK 2009



Just Walk is a charity walk for anyone who is keen to get their walking boots on and wishes to fundraise for the charity of their choice. The date for this year's Just Walk Open Charity Event is Saturday 9th May 2009 and details on how to join-up can be found on the website www.just-walk.co.uk. This walk is designed to offer enthusiastic walkers the chance to experience a breathtaking walk over the picturesque South Downs and there is a choice of four distances, a gentle 10km walk, a 20km Walk, a 40km walk or a whopping 60km. On the walk you will be joined by walkers representing loads of different charities all walking for very different reasons. If you want to raise funds for us and get the name of the Myositis Support Group out there please let us know and join up now. Each walk requires an entry fee for which you will receive: full event safety planning and management, full medical support, full logistical support along the route including pick up vehicles, fundraising and training advice, drinks throughout, snacks throughout, power stations along the walk with full support including loos, way marked and safety signed route, event booklet with full advice guidance and map, event t-shirt (dependent on distance chosen), meals (dependent on distance chosen), certificate of achievement and lots of fun! Member, Pauline Stokes, has signed up, why not join her?

WALK	FEE	DESCRIPTION
The BIG 60km Route	£65	If you are looking for a real challenge to raise money for your charity then this is the route for you. The route takes you through some of the most stunning countryside in Britain with picturesque villages and towns such as Arundel along the way. It is tough, but the biggest sense of achievement when you cross the finish line.
40km Route	£55	If you feel the BIG challenge above is just a little too far then this route would suit you perfectly. New for 2009 it captures the first half of the 60km route and then drops back down to the finish. This route is still a rewarding challenge to complete.
20km Route	£45 for over 12s £10 for under 12s	The gentle 20km is suitable for all ages and great for walking with a group of family or friends to raise money for your charity. This route takes you through some of the picturesque villages of West Sussex as well as along the beautiful South Downs.
10km Route	£45 for over 12s £10 for under 12s	Get a taste of the Just Walk Event and take part in this great family day out where you can raise funds for you charity.

MEMBERS MEET UP

My meeting with Andi - Jill Mayhew DM January 2009

"I was on the MSG board last year and read a message from a fellow "DMer" saying that she thought she was the only one on her island that has Myositis. I wrote a message back on the board asking her which island and she replied "Cyprus". We commenced to email each other as I was holidaying there in October. After a couple of phone calls while I was there we arranged to meet up. Andi picked me up outside my apartment and then we drove a short distance to a café in Pafos market place. We sat and talked non stop for an hour and a half and in that time I think we confirmed our friendship. We have since kept in contact, mostly on Facebook, and have exchanged photographs of our families. I hope to go again later this year and meet up again and spend longer with each other.

Thank you MSG for finding me a wonderful friend!"

My meeting with Jill - Andi Theodosiou (DM) January 2009

"Not knowing much about my disease (dermatomyositis) what a relief it was when I found the website on the internet 'myositis.org.uk'. On the other end I met a very friendly and welcoming lady named Jill. She loved the fact that I was from Cyprus and holidayed here often and what a surprise it was when she informed me she would be visiting soon. Every now and then there was a message from this friendly, fun-loving and quirky stranger – who answered all my queries regarding the disease as well as always saying the right things to keep my spirits up. When we met that lovely sunny day in Cyprus, it felt like I had known her my whole life and indeed a true friendship has evolved. I look forward to her emails, Facebook comments and visits to Cyprus.....Here's to us!"



Jill Mayhew and Andi Theodosiou

London Group Meeting

Diane Johnson writes,

"A local London Group Support Meeting is being arranged for a Sunday in April 2009 (either 19th or 26th). Do come along, enjoy some food, relax and meet and chat with other sufferers. We have a very interesting speaker who I hope you find inspiring and uplifting. To those of you that have come along to these meetings before, it will be in much the same format as previously (at Jenny Fenton's house). To any new members, do come along and meet others who share your own problems - you may even meet someone that lives very close to you.

The venue is now in East Finchley which I hope many of you will find convenient, especially as we are very close to the underground (Northern Line) which is less than one minute's walk away. If you are interested in coming along, please contact me, Diane Johnson on 0208 444 3635 or email miela.djohnson@tiscali.co.uk. We look forward to hearing from you."

POST SCRIPT

May I take this opportunity of thanking everyone who has written into the office or sent in money to help the cause. I will be reporting on all the fund raising activities in the next newsletter. The support for the charity and the medical departments associated to it are very encouraging. With this support we will continue the fight to beat this group of diseases together and improve the quality of our lives. I do not suffer from the disease but it affects everybody connected to it. Any progress is a benefit for us all.

Yours faithfully,

Les Oakley, MBE
Chairman