



MYOSITIS
Support Group

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Flyer-March 2008

Dear Member,

This is the first charity letter (flyer) of the year and this time it has not been too difficult to write an introduction. As many of you may already know, from the website, I have been made a Member of the Order of the British Empire (MBE) in the New Year's Honours List. You can imagine how initially shocked but then proud and honoured I am to receive this award. I understand that many people in the charity and outside of our Group have worked very hard in getting me as chairman this recognition. To all of you, for I will never know all the details and names behind this MBE, I thank you very much. This award is for the charity and for the long and sometimes tedious work put in by my wife, Irene, my daughter, Paula, our treasurer, Jo Goode and the committee. The charity has now been recognised by the Government and Crown and I am proud of everybody connected to it and made it worthy and purposeful.

As a family we are looking forward to our day in London and Buckingham Palace but at the back of our minds will still know that we are there because of Myositis and this is still the issue that we are working for. I am looking forward to giving you a follow up report of this great day for us in the next newsletter.

To read responses to the award visit www.myositis.org.uk/mbe.htm

LONDON MARATHON



This year we have two runners in the London Marathon, James Borrett and Mick Clarke, both obtained their place by the public ballot. Mick served on the committee for many years and has run the London Marathon twice before for us in 1994 and 1995, although he has reminded me that this year he will be walking rather than running. James Borrett on the other hand has been steadfast in training and is hoping to make a fast time. Please support their effort by sponsoring them. I have enclosed a sponsorship form but if you prefer donations can be made online at www.justgiving.com/myositis. Please visit the runners Just Giving fundraising pages to read their stories and why they are running for the Support Group. As James and Mick have been successful in obtaining public ballot places our Silver Bond place has been deferred to 2009.

AGM & MINI CONFERENCE

This years AGM and mini-conference will be at the Holiday Inn Eastleigh, near Southampton on Sunday 13th July. The day will be more relaxed than the large 4-yearly conference held last year. Speakers are yet to be finalised but include Dr Hanna with details of the new neuromuscular centre and Colin Beevor on managing fatigue, along with updates on research projects that have received funding from the Group.

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 (prices at time of print on the web were from £72 per night for a double room exclusive of breakfast). 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.

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.

Preliminary Programme

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 - 12.20	Morning Session
12.20- 12.30	Iris Hazel Memorial Talk
12.30 - 1.55	Lunch
2.00 - 3.00	Afternoon Session
3.00 - 3.30	Questions & Discussion
3.30 - 4.00	Tea Coffee Break
4.00 - 4.30	Questions & Discussion
4.30 - 5.00	Summary & Close

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

LISTENING EAR TELEPHONE NETWORK

The LETN is now 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 12 members (5 DM, 2 PM, 3 IBM, and 2 JDM) who have volunteered themselves as a point of telephone contact to others. It is hoped that the LETN directory will help alleviate the isolation felt by many especially those without a computer and access to the Myositis Support Group website community.



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

IRIS HAZEL MEMORIAL TALK 2008

At the annual meeting in July each year we have "The Iris Hazel Memorial Talk". This is in memory of one of our very first members and benefactors. I would like to hear from anyone who has an inspirational story to tell. Last year Anne Ali gave the talk on her success at gaining her degree through the Open University and coping with Myositis. The year before Trustee, Tony Hindle, spoke about Elaine Aubrey, who was also a Trustee, but sadly had recently died. Because of her illness she had to take early retirement but joined the Territorial Army and took up a hobby by making and collecting handmade dolls clothed in beautiful outfits. 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 I 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 travel especially if something amusing happened! If you are interested please write to or email Irene Oakley (irene@myositis.org.uk).

CONFERENCE 2007 DVD

The Conference 2007 DVD is 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.

NEW JUST GIVING PAGES

In addition to James Borrett's and Mick Clarke's London Marathon Just Giving pages additional new fundraising pages have been added and include those by Lynne Nazer (Sponsored Diet), Rachel Sumner (Bracknell Half Marathon) and Shelley Egan ("Going Blue"). 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 display the fundraising pages of your choice on you Facebook profile.



JUST WALK 2008



We are looking for volunteers to take part and raise funds for the Support Group. Just Walk is a charity walk for anyone who is keen to get their walking boots on and wanting to fundraise for the charity of their choice. The date for this years Just Walk Open Charity Event organised by Across the Divide is the 10 May 2008 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 generate funds for their chosen charity. You, and possibly your friends, can choose to participate in a gentle 15km walk or a whopping 60km. On registration, you are required to pay a fee of £45 per walker for the 15km walk and £65 for the 60km walk. All the money you raise will go to your chosen charity. So, whether you raise £10 or £10,000, your charity will get it ALL. There are no hidden overheads. Your registration fee

covers full event plans and support, T-Shirt, safety staff and pampering people, training and fundraising advice, drinks and snacks at stations along the walk, clearly marked route with free views and a celebratory BBQ at the finish. 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.

WEBSITE AND BUDDIES

I would like to encourage members with internet access to visit our website in particular the community section. Within these pages you can post and answer questions in the discussion forum and search to find people in your area (UK, Eire and overseas) and or with the same diagnosis. When we set up the new website I emailed all those who were listed on the old website to ask if they would register for the new website. However, quite a few of the emails have been returned as the email address no longer exists. This is an extremely good way of contacting others in your own area but it can only succeed if you do your part and register. It is now up to you!

Joy, Lesley and Jilly, each with a different form of Myositis have made contact through the Community Pages and have found the support of each other invaluable;

"I have made some good friends this way and get a better understanding, as we know what we have much better than ordinary people." – Joy IBM

"I also agree, as when I registered on this new site Joy & Jilly emailed me (as we all live near each other), we have met up and plan to do so again, very soon. It's lovely to talk one to one, with someone who is going through the same kind of thing, although I have PM, Jilly DM & Joy IBM their past experiences were invaluable and reassuring to me. Strangely though, it was wonderful to walk along-side others who have that same funny walk as myself" – Lesley PM

"We had a great lunch, talked about various aids and finishing of with Joy demonstrating her petrol nozzle in the car park. We did not moan or bemoan our fate. We did have a funny moment when one of us dropped some money on the floor, and we had to sort out who could bend down, and who could get up etc. All meeting up next week, to demonstrate our "funny walk"! I barely like to think what we look like from behind!" - Jilly DM

WEBSHOP

Commission earned through our webshop www.buyat.com/myositis from the beginning of November to the end of January was £44.11p. From the site statistics 282 clicks were made which resulted in 25 actual purchases. This was rather disappointing considering how many computer users the charity has and how popular online shopping is supposed to be - especially during the Christmas period! Our webshop has a wide choice of well known stores and is simple to use – it just requires a few extra clicks before you shop. If you shop online please remember to visit our webshop first as this is a very easy way to raise funds and costs you no more money. Check it out today and tell all your family and friends about it too!



POST SCRIPT

In closing, I thought I would mention that the interest in Myositis research is increasing but our funds to meet this demand are rapidly reducing due to recent funding of new projects. Please help boost our funds if you can. Updates of these projects will be given at the meeting in July and I look forward to seeing you there.

Les Oakley, MBE
Chairman