



# MYOSITIS

## Support Group

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### FLYER FEBRUARY 2007

Dear Member,

Even though we are in the month of February I trust it is not too late to wish you a happy new year. This February Flyer is a brief report of charity news and more importantly contains information relating to our charity events and in particular dates which can be "lost" in the pages of our regular newsletters. I would also like to take this opportunity to express my sincere thanks for the donations received over Christmas and the many letters and seasonal cards written in appreciation of the work carried out by the committee. Also to the many members who have contacted me with their new year fund raising activities and events. Full reports will be published in the Newsletter 62.

#### *AGM & Conference 2007*

I can now confirm the date for our larger four yearly conference as **Saturday 14<sup>th</sup> July**. Irene was very busy before Christmas trying to find a suitable venue and after Christmas securing speakers. It is not an easy task finding a venue that meets the needs of our membership. However, I feel Irene has come up trumps with the Marriott Forest of Arden Hotel near Birmingham which is easily accessible by road, rail and air. It is between Birmingham and Coventry in a lovely countryside setting. The nearest train station is Birmingham International.



Irene has secured special rates for those of you who may wish to stay at the hotel. The cost is £92 Bed and Breakfast for a single and £102 BB for a double. If you would like to stay at the hotel please return the accommodation form with your registration form and please note the conditions on the booking form. You can make your own arrangements and book direct with the hotel if you wish. There is also a Premier Travel Inn at Balsall Common which is 3.2 miles from the venue and the cost is £53 per room per night excluding breakfast. There are many other hotels and B&Bs in the area as it is close to the NEC so you may like to make your own arrangements.

I am delighted to inform you that the following have kindly accepted our invitation to the conference; Professor Chester Oddis, Professor David Isenberg, Dr Hector Chinoy, Dr Michael Rose, Dr Robert Cooper, Dr Ernest Choy and Professor David Scott. The Iris Hazel Memorial Talk will be given by member, Anne Ali.

The day should be very informative for all forms of Myositis. I am very grateful to all the doctors for giving up time in their busy schedules to attend, especially Chester Oddis who is travelling from the USA to be our Guest Speaker. Chester Oddis is a professor of medicine in the division of rheumatology and clinical immunology at the University of Pittsburgh School of Medicine,

#### Proposed Programme for the Day

9.00 – 9.30	Tea and Coffee on arrival
9.30 – 10.00	AGM
10.00 – 11.00	1 <sup>st</sup> Session
11.00 – 11.30	mid morning break
11.30 – 1.00	2 <sup>nd</sup> Session
1.00 – 2.00	Lunch
2.00 – 3.15	3 <sup>rd</sup> Session
3.15 – 3.45	afternoon break
3.45 – 5.00	4 <sup>th</sup> Session
5.00 – 5.30	Plenary Session

and is on the Myositis Association (USA) board of directors and medical advisory board. His key interests are in the treatment of rheumatological conditions and as such is principal investigator of the first controlled clinical trial using Rituximab for the treatment of adult and juvenile Myositis.

Our large conference only takes place every four years and with a great line up of expert speakers. I look forward to seeing you there because without members the conference achieves little.

### *London Marathon - Sunday 22<sup>nd</sup> April 2007*

Frank Littler has again secured a place in the London marathon by ballot and will be donning his trainers to run on behalf of the Group. Frank has kindly and successfully run for us many times and I am thankful for him offering again. On average through your sponsorship of our runner(s) the London marathon raises over £2000 each year. This is a key fundraiser for the Group and your continued support is much appreciated. I have enclosed a London marathon sponsorship form with this Flyer for you to support Frank's effort.



### *Silver Bond Entry 2008 - Runner Appeal*



**WANTED**  
**runner**



Runner not necessarily an athlete to train and run in the London Marathon 2008 to represent and raise funds for the Myositis Support Group as their first Silver Bond Runner.

For further details please contact Irene on 023 8044 9708, email [silverbond@myositis.org.uk](mailto:silverbond@myositis.org.uk) or see Newsletter 61.

On the advice of David Bedford (London Marathon Race Director) our Silver Bond entry is being held over till 2008 to give us time to prepare, find a runner, and gain as much financial sponsorship as possible. The Silver Bond is a guaranteed place in the London Marathon which we can only have on application once every five years. Thus, the Silver Bond place is a unique opportunity for our Group to raise a considerable amount of money. If you or if you know someone that fits the criteria outlined in Newsletter 61 please get in touch through the office or by email.

### *Charity Event 28<sup>th</sup> April 2007*

Jean Dunn will be hosting another charity night. Jean and her sister Catherine Sutcliffe both suffer from Myositis and are very active in fundraising for the group. I am sure the event will be a fantastic evening so if you would like to join them please contact Jean on 01606 786711.

### *Rotterdam Marathon*

*15<sup>th</sup> April 2007*

Marjolein Vankralingen is running on behalf of the Group in the Rotterdam Marathon (26 miles). Marjolein works for Vale Royal Borough Council (Cheshire) and is a friend and colleague of Jean Dunn. I am sure you will all join me in thanking Marjolein for her effort and wishing her good luck!

### **CHARITY EVENT**



“MYOSITIS”  
(Rare Muscle Disease)



**Saturday 28<sup>th</sup> April 07**

WINNINGTON PARK  
RECREATION CLUB

**Two Local Bands**  
*Beaver*  
&  
*Midlife Crisis*

*7.30 till midnight*

**£7.00**

Contact Jean Dunn for Tickets (01606 786711)

## Just Walk 19<sup>th</sup> May 2007



I mentioned in October's Newsletter the Just Walk sponsored walking event taking place on the 19<sup>th</sup> May 2007. To date I have no volunteers to take part. Registration for the walk is still open so if this is a challenge that you or someone you know would like to part take in please contact me or [www.just-walk.co.uk](http://www.just-walk.co.uk) for further details. This walk, 15km or 60km treks you over the breathtaking picturesque South Downs (Sussex) and is designed for enthusiastic walkers to generate funds for their chosen charity.

## Just Giving Launched

We have signed up to an online donation facility with the justgiving website. As well as making donations to the Myositis Support Group fundraisers can host their fundraising activities and events.



## Web Shop

During the months up to Christmas our web shop, [www.buy.at/myositis](http://www.buy.at/myositis), was very active. To all who have visited and used the site, thank you. If you've yet to check out the shop or have not done so for a while please do as more stores have enlisted including, Waterstones, HMV, Superdrug, Tesco and Next flowers. Through the webshop we have earned over £130 commission to date. Additionally, every purchase during the Christmas and January Sale period raised an additional 25p.



Raising awareness of the webshop is important as it is a very simple way to generate funds. Member, Maggie Hall, has helped us design a webshop leaflet for distribution to family, friends, work colleagues or customers. If you would like copies of this please email [webshop@myositis.org.uk](mailto:webshop@myositis.org.uk) and we will be happy to post them out to you. In addition we have set up a Webshop News Alert email to keep our online shoppers up to date with new stores and great offers which are continually being added. Register for our Webshop News Alert by emailing [webshop@myositis.org.uk](mailto:webshop@myositis.org.uk) with Webshop News in the subject.

## Everyclick

The Myositis Support Group has signed up to the search engine [www.everyclick.com/uk](http://www.everyclick.com/uk). By using the everyclick search engine funds are generated every time an internet search is performed. We signed the charity up in October and it has raised £25. If you are an Internet user I would encourage you to switch to the everyclick search engine as the more it is used the greater amount of money we raise. Like our webshop the set-up and running costs are nothing in terms of money and effort. So any funds raised through everyclick is a bonus. Please change from your current search engine to everyclick. I was a keen user of Google but everyclick is able to meet my requirements most of the time. For more details about everyclick please visit their website. We look forward to seeing an escalation in our registered users, currently there are only 4!



## *Listening Ear Telephone Network*

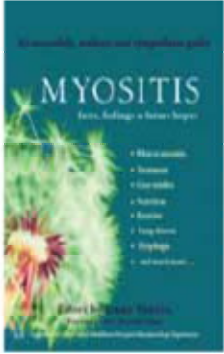
The Listening Ear Telephone Network is now being compiled and printed. Paula's request in Newsletter 61 was met and she is pleased to have volunteers to cover all the illnesses, (DM=5, PM=3, IBM=3, JDM=3). The Listening Ear Telephone Network will be a folder containing the telephone numbers of volunteers who have experience of living with Myositis. The volunteers (sufferers, carers and parents) of this network have volunteered their telephone number for others to contact. It is intended that the telephone network will be a self help resource aiming to alleviate isolation and offer support through talking to each other. New volunteers are always welcome and if you are considering volunteering to the Listening Ear Telephone Network please email or write to Paula and she will send you further details. By enquiring you are not committing yourself at this stage. Paula can be contacted by writing to the office or emailing [paula@myositis.org.uk](mailto:paula@myositis.org.uk).

## *Want to help with the genetic work?*

Blood samples for the genetic research of Dr Cooper and Dr Chinoy are welcomed. It involves your GP taking and sending the blood along with a short questionnaire. Interested? Please contact Dr Cooper by e-mail at [Rcooper@fs1.ho.man.ac.uk](mailto:Rcooper@fs1.ho.man.ac.uk) or his secretary, [jill.grundy@manchester.ac.uk](mailto:jill.grundy@manchester.ac.uk) or write to, Rheumatic Diseases Centre, Clinical Sciences Building, Hope Hospital, Eccles Old Road, Salford, M6 8HD.



## *Myositis Book*



**Myositis**  
**Facts, feeling and future hopes**  
**An accessible, realistic and sympathetic guide**  
Edited by Jenny Fenton  
£14 including postage and packaging  
Thoughtful Publications, PO Box 46214, Ealing, London W5 1YF

## *Newsletter 62 Articles Wanted*

The deadline for articles for inclusion in Newsletter 62 is 1<sup>st</sup> March 2007. All fundraising events and mentionable donations since the last Newsletter will be included. Many of you have written to me with your fundraising plans, if you would like to write an update on how things are proceeding please do so. The response to my request to step up a gear for fundraising has been encouraging and I thank you for your efforts. Also wanted are good news stories, your experience of services, and aids that make everyday life easier. Please send your story to the office or email [newsletter@myositis.org.uk](mailto:newsletter@myositis.org.uk) and if you wish to include a photo that would be great. For it is this information that makes the newsletter interesting reading.

## *Postscript*

In conclusion I would like to express my appreciation for the many hours of dedicated work by Irene, Paula and of course our treasurer, Jo. I also look forward to meeting you in person at the conference on Saturday 14<sup>th</sup> July. There, I've written it again. In passing did you see the television hospital drama programme ER where the word Polymyositis was mentioned in one of its scenes?

Les Oakley  
Chairman