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## FLYER - SEPTEMBER 2014

Dear Member,

I trust your summer and now autumn are going well. This Flyer brings you up to date with “bullet point” news.

### AGM CONFERENCE 2014

This year's AGM and Conference held on Sunday 6<sup>th</sup> July in Oxford was well attended and extremely informative. A report will be in the next newsletter.

### INFORMAL AFTERNOON TEA MEETING – 4<sup>TH</sup> OCTOBER 2014

Our Treasurer, Jo Goode, has arranged this informal meeting for members at Brown's Restaurant, Barrister's Court Room, St Martins Lane, Covent Garden, London, WC2N4AG from 2-3pm. This event is free for members and accompanying partner, friend or helper, etc. If you would like to attend please register at [www.meetup.com/MyositisUK/](http://www.meetup.com/MyositisUK/) or on the Facebook page at [www.facebook.com/MyositisUKMeetup](http://www.facebook.com/MyositisUKMeetup)

### GREAT SOUTH RUN

This year we have 4 members of one family and myself running in the Great South Run on Sunday 26<sup>th</sup> October. Steve Gifford and his brother are taking part in memory of their mum along with his son and his uncle. I will be wearing my Mr Potato Head costume again because I enjoy the shouts of “you looked smashed, chipped and boiled spud, etc., on the way round! If you would like to sponsor either myself or “Team Gifford” you can do this on line at [justgiving.com/Les-Oakley2](http://justgiving.com/Les-Oakley2) or [justgiving.com/Steve-Gifford/](http://justgiving.com/Steve-Gifford/) or send donations to the office.



### CHRISTMAS CARDS

Unfortunately, we will not be selling Christmas Cards this year. This is because we have been let down by a supplier which left it too late to negotiate a new profitable deal with another company for the charity. We are very disappointed but hope to be able to have them available next year.

### CHRISTMAS DRAW

We will be holding a Christmas Draw again this year and the main prizes will be 1<sup>st</sup> prize £500, 2<sup>nd</sup> prize iPad mini, 3<sup>rd</sup> prize £100 with many other useful and attractive prizes. Draw tickets will be sent out shortly.

### WRISTBANDS AND PENS

We now have Myositis UK “wristbands” and quality pens available at £1.00 each. Please send your order to the office and add £1 per order for postage and packaging.

### LONDON MARATHON 2015

If you or you know of anyone who would like to take part in the London Marathon next year and would like one of our Gold Bond places please contact the office for an application form. Runners are required to raise a minimum of £1000.

## INSPIRATIONAL BOOK



Debbie Bliss has written a book called, 'Life is Bliss' and it's her inspirational story to fight Dermatomyositis and she hopes the book will inspire others in a similar situation. The book is available from Amazon.com at £10.45 or £2.63 Kindle edition.

## TEDDY-BO



Our cuddly and much loved friend is enjoying a super year travelling with Myositis families and friends and being photographed all around the world posing with celebrities, famous people and land marks. It has been so successful and popular for the charity the trustees would like you to continue sending in these snap shots for the newsletters.

## SOCIAL MEDIA



If you use social media then this is a simple way to keep up to date. We currently have four Facebook Pages, Myositis UK, Team Muscle, Juvenile Dermatomyositis, and Teddy-Bo, his friends, adventures and Juvenile Dermatomyositis.

**Myositis UK** is our main charity Page. It allows us to post messages in real-time and re-post suitable messages from other organisations. It acts as the hub for our other Facebook Pages and is administered by Paula Jordan (Trustee) and Jo Goode (Treasurer).

<https://www.facebook.com/pages/Myositis-UK/428638317246585?ref=ts&fref=ts> (probably easier to type in Myositis UK into your search bar on Facebook rather than type the address in).

**Team Muscle Facebook Page** is for anyone fundraising or supporting fundraising for Myositis UK. It is a great way to promote your event, share your Just Giving Page, upload photos or updates and for supporters to see your event. Initially set-up for our Gold Bond London Marathon runners this Page is now for all fundraisers whatever your activities are. Paula Jordan and Jo Good administer this Page.

<https://www.facebook.com/MyositisSupportGroup>

**Juvenile Dermatomyositis Facebook Page** was initially set-up by Nikki Coleman (JDM mum and Trustee) to raise funds for JDM (namely the Teddy-Bo Project) but has evolved as a great Page for JDM interaction. Now co-administered with Paula Jordan they post information that may help JDM parents ranging from news from Myositis UK to re-tweets from other organisations.

<https://www.facebook.com/pages/Juvenile-Dermatomyositis-JDM/95955942990>

**Teddy-Bo his friends, adventures and juvenile dermatomyositis Facebook Page** is administered by Paula Jordan and Nikki Coleman. This Page allows anyone to follow Teddy-Bo on his adventures as he meets his friends and raises awareness of the inflammatory muscle disease. A distinct Page set-up to allow followers to just follow Teddy-Bo. The Page is for your photos and stories so where-ever you and Teddy-Bo are snap it and post on the Page.

<https://www.facebook.com/TeddyBoJDM>

## NEWSLETTER

Can I have any articles, news, future events, letters, etc., for inclusion in the next publication of "Myositis UK News" as soon as possible. It is these items that make the issue an interesting and helpful read.

Les Oakley MBE  
Chairman