



MYOSITIS

Support Group

Newsletter 67

July 2011

Dear Member,

Compiling this newsletter has given me much pleasure. It indicates how well the MSG is progressing and the wonderful support shown by so many people in so many different ways. As with any charity based on health issues there is also going to be sadness coupled to it. However, the love and tremendous goodwill, for me, has been an inspiration and I trust this following news will be rewarding and interesting for you too.

CONFERENCE 2011

This year's Conference and Annual General Meeting is on Sunday 10th July at the Marriott Forest of Arden hotel, Meriden near Birmingham. If you have not yet already booked and would still like to attend please contact the office as soon as possible.

If you are staying at the hotel on the Saturday night we will be hosting "a welcome" in the hotel bar between 3pm and 5pm. Please join us for a cup of tea or coffee and meet up with old and new friends. If you require a meal on the Saturday night I advise you to ring and book a table in advance as Saturday nights can be busy in the restaurant. You can also order food and eat in the bar. The telephone number for the hotel is, 01676 522335.

Conference packs will be sent out approximately 10 days before the date to all members who have registered to attend.



Preliminary Programme

8.45	-	9.15	Meet new and old friends with a cup of tea or coffee
9.15	-	9.45	AGM
9.45	-	10.30	Morning Session – part 1
10.30	-	11.00	Tea Coffee Break
11.30	-	12.30	Morning Session – part 2
12.30	-	1.55	Lunch
2.00	-	3.30	Afternoon Session – part 1
3.30	-	4.00	Tea Coffee Break
4.00	-	4.45	Afternoon Session – part 2
4.45	-	5.00	Summary and Close



FUNDRAISING

LONDON MARATHON 2011

The Team Muscle runners this year were, Frank Littler 4hours 26mins, David Oakley 4hours 55mins, Harsha Gunawardena, James Robinson 4hours 39mins and Deborah Marshall 4hours 49mins.

Irene, Paula, David and me journeyed to London on the Saturday night with the car laden down with our charity banners and reception buffet in cool boxes. We arrived at the home of our dear friend, Sylvie, who lives just off the Jamaica Road where she kindly put us up for the night. We were up at six thirty to claim our railings for our half way support station only to find that they had been removed in road improvements. Panic set in because this is where we had to be for the runners to find us. However a lamp post and an eight foot cane pole came to the rescue. The charity helium balloons were hoisted aloft on the cane and strapped to a lamp post along with our vertical banner with the police turning a blind eye to the situation. Panic over problem solved. We were the only ballooned up charity along that stretch of road and could be seen from a great distance above the crowds.



Frank and Dave stopped for quick refreshments because the weather was too hot for running and it was a matter of forgetting about record times and just completing. It was great fun by the road side and the atmosphere and good will is really heartening. Everywhere is packed on race day and I have never seen any trouble. After twelve o'clock we packed up our site, gave the balloons to kids in the road to enable us to drop off back at Sylvie's and pick up the buffet so that we could proceed to Horse Guards Parade to meet our runners at the finish.

As it was so hot and we had a lot to carry, I thought to hell with the tube and get a cab. Well, that did not go to plan for no taxis



could get anywhere near the Parade. So it was a case of flexing the muscles and dragging off the gear including our charity board and pole through the underground among the throng of thousands on similar campaigns.

Irene, Paula and me huffed and puffed and arrived at Horse Guards Parade where we found a body free, three foot by three foot piece of grass to off load our picnic rug, boxes and bags. For the next two hours I spent holding up our banner at the entrance to Horse Guards Parade where the runners come through,



trying not to be moved on by the police and security. Yes, there's a "jobs worth" where ever you go. However, the runners, families and friends found us with the exception of Deborah and Harsha because Harsha's run ended at 25 miles through injury.

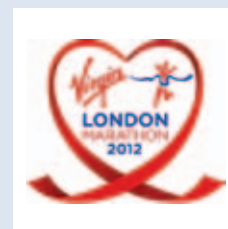
It is always a great atmosphere at the end with much banter and fun. I was determined not to lug all the baggage back through the underground because we catered for everybody finding us. So in the circumstances I bravely saw off the champagne that made for me a much more casual trip back to Sylvie's. I then went for a celebratory pint with David in the pub on the Jamaica Road where everybody congratulated Dave and talked about the run and the charity. What made this so special is that we did not know these people and yet they capped the day for us. After a fine dinner put on by Sylvie we made our weary way home, mission accomplished already thinking about next year.



LONDON MARATHON 2012

If you or anyone you know would like to be part of Team Muscle and take part in next year's London Marathon we would like to hear from you. We have 8 places and they will go on a first come basis.

The only stipulation is that you agree to raise a minimum of £1000 per place due the cost to the charity for the places. This can be raised throughout the year by any fundraising means or ideas you may have. You do not have to rely solely on sponsorship. Please contact Irene in the office by post or e-mail.



FUNDRAISING

FAIRY MASKED BALL

Trustee, Nikki Coleman, worked her socks off with many a sleepless night to make this a resounding success. She writes, "It took place on November 27th 2010 and was held at the Beaulieu Motor Museum, Hampshire. The Ball was in aid of two charities JDM (Juvenile Dermatomyositis) and JDRF (Juvenile Diabetes Research Foundation) as my daughter Katherine has both conditions. The event was a huge success raising a total of £8,250 which was split equally between the two charities. We had great support from local businesses, family and friends. Hendy Ford sponsored the event and gave us £1,500 for the deposit at Beaulieu and this enabled us to get the event up and running. A brilliant balloon display was created at the venue, by Party Bitz of Dibden Purlieu, Hampshire. We had great support from other local businesses, family and friends.



A big thank you goes to Bill Aston who has Polymyositis, who worked his own magic to get some amazing prizes for us including a 42" Plasma TV, tickets for the Sky Sports Rugby, phone, cameras and more! Live music was provided by 'The Shift' free of charge, as they did for our previous fundraising event. Twenty five candelabras, with beautiful flower arrangements were donated by Jan Hoy of Beaulieu. The venue looked amazing and everyone who

be available to anyone to purchase via the Myositis web site. The launch of book and Bear will be at this year's conference and Simon will be attending and signing the books. Thank you to everyone who made this project possible with their valuable input, comments, suggestions and observations. We trust a Teddy-Bo and book will help children and their families understand Myositis in general and Juvenile Dermatomyositis in particular.



attended looked fantastic with the men in dress suits and ladies in gowns all wearing awesome masks and wings. They also donated most generously to our Auction and Raffle."

Money raised for JDM has enabled us to produce a book for children called '[Teddy-Bo's Feeling Tired, A story all about Living with Myositis](#)' and a [Teddy-Bo Teddy Bear](#). This will be given out free of charge to all children in the UK diagnosed with Myositis when they join the Support Group. The book has been written by Simon Chadwick a local author, illustrator and cartoonist who has done a fantastic job putting the book together. Beaulieu's, 'Bear it in Mind', produced the Original Bear based on Simon's art work for which a pattern for Teddy-Bo was made. This was then sent away for mass production and we will be receiving our first batch of Bears soon. Extra copies of the book and Bear will



FUNDRAISING

SOMERSET TO SELBOURNE 100 MILE WALK

Richard Davies writes,

"In early April my wife, Helen and I were taking part in a 100 mile walk for charity. Starting on 3rd April over seven days, covering approx 14 miles per day, we were to commence our walk from the village of Litton to the west of Bath in Somerset. This was to be the fourth time that we had taken the 100 mile challenge. While the walk raises funds for a number of charities we thought that it might be an idea to also raise funds for the Myositis Support Group. When I suggested this to Les Oakley he was more than happy for us to ask for sponsors through his shop. This is a short description of our travels.



SUNDAY 3RD APRIL

We set off from Elm Tree Farm in Litton and joined the Limestone Link. This is a 36 mile path from the Mendips to the Cotswolds. The section we travelled today passes through the old Somerset coal fields. Mining began here in the 16th Century; by 1800 there were 60 mines. Activity peaked in 1868 but by 1894 only 27 pits remained. Our walk took us along the Cam River, which roughly followed the Somerset Coal Canal, which joined the Kennet and Avon Canal at Dundas. We followed the Cam from what was a muddy ditch in woodland to the point where it had become a small river. The canal closed after the opening of the Great Western Radstock to Frome Colliery Railway and we also followed part of the remains of this railway. After lunch the weather which had been good for walking turned inclement and the rest of the day we had steady persistent rain. The day ended with what was described as a "good climb" to Manor Farm at South Stoke. A good climb is the walk organisers' code for an almost vertical precipice!

MONDAY 4TH APRIL

Good walking weather. We rejoined the Limestone Link and most of the day's 700ft of ascent was completed early on. We continued on through Monckton Combe with its impressive Public School, some buildings dating back several hundred years. We cross the River Avon at the Dundas Aqueduct. This magnificent piece of engineering carries the Kennet and Avon Canal over the river. We stop for lunch in Bradford on Avon, an old cloth town with a Saxon church and a much photographed river bridge. The afternoon was fairly easy walking as we first followed the River Avon and later the K + A Canal finishing the day at Broughton Gifford.

TUESDAY 5TH APRIL

Grey and overcast at the start of the day. We had moved forward to start at Stanton St Bernard in the shadow of Milk Hill. After about half a mile we began to climb the hill, the walk leader said that we would follow a route so that we would hardly know that we were climbing. This was stretching the truth somewhat - if you look at an OS map, the contour lines are so close together that they almost touch. Once we reach the top we continue along the ridge passing the White Horse figure carved into the side of the hill in 1812. We stop for lunch beside Martinsell Hill Fort, an Iron Age structure at an elevation of 964ft. In the afternoon we dropped down to the K + A Canal passing a number of locks and the building housing the Crofton Beam Steam Engine, the Boulton and Paul "Cornish" from 1812 is the oldest working one in the world. We finish at Wilton near Hungerford having completed our toughest day with 1100ft of ascent.

WEDNESDAY 6TH APRIL

15 miles and another 1100ft of climb. We climb Haydown Hill, which at 833ft is crowned by Fosbury Camp, an Iron Age hill fort. Following an undulating path, we reach Vernham Dean to have lunch in the village cricket pavilion. We are now bathed in sunshine, with the weather improving all the time. After lunch we passed Upton, over Facombe to Doilley Bottom and finish at Binley.

THURSDAY 7TH APRIL

Clear skies and bright sun all day, good enough to wear polo shirts and shorts. We set off towards St Mary Bourne, and then on to Hurstbourne Priors. We crossed the main railway to Exeter, and then a derelict branch line, originally built in 1880, as the Northern and Southern Junction Railway. This was one of the quietest lines in the southwest, and few understood why it was ever built. We have lunch in the Cricketers Inn at Longparish. The afternoon, apart from being very hot, was easy downland walking, finishing at Stoke Charity.

FRIDAY 8TH APRIL

Our easiest day, only 700ft of climb, and again cloudless skies. We skirt around Sutton Scotney and cross beautiful Hampshire downland, heading to the main rail line to Southampton. Our route takes us over the railway at Wallers Ash tunnel, and then on to East Stratton, where we have lunch at the Northbrook Arms. Most of the afternoon we had permission to walk through private estate grounds around Chilton Candover and Brown Candover. The day ended at Armsworth Park, to the north of Alresford.

SATURDAY 9TH APRIL

Last day! We pass through the old centre of Medstead and the convent school and on to lunch at Bentworth Lodge. We continue through Bushy Leaze Wood, past the Watercress Railway Line, Alton Sports Centre and into Chawton. Here we pass Jane Austen's cottage, and have a good view of the church and Chawton House. Near the finish, we walk through Farrington, with its attractive church and its extraordinary village hall that was originally built as a folly. We finish at Selbourne.



At the end of each day we were treated to a wonderful tea of homemade cakes and sandwiches, all produced by various farmers' wives and other volunteer supporters. 28 people completed the 100 miles, together with 2 dogs with around an average of 50 people walking each day, some of whom had travelled from as far away as Scotland.

This was probably the best "100 miler" that we have done, each year's route being different. This year the combination of scenery, weather and our walking companions made the challenge particularly enjoyable, and we are looking forward to next year's walk, which apparently starts somewhere in East Sussex. All in all we had a good week, and are pleased to have raised £156.75 for the Myositis Support Group."

FUNDRAISING

80's DISCO EVENING

Jean Dunn writes, "Martin Armstrong & Debbie Bradley along with supporters decided to run an 80's disco to help raise funds and awareness for Myositis and Cancer UK. Martin has two sisters, Catherine Sutcliffe and Jean Dunn who suffers with Myositis. Martin would like to thank Jimmy Bradley for his help and DJ Rob Whitley who gave up his time free of charge. Local businesses, Moorlands Bar & Restaurant, Ivy House Ale House, Parfetts, Sharmas, and Neil Sykes in Halifax, West Yorkshire for their kind donations for two worthy causes. With the help of everyone involved they were able to raise £425.40 for each charity, a good night with some fantastic fancy dress costumes and great prizes from the raffle."



CAKE SALE HOLY INNOCENTS CATHOLIC PRIMARY SCHOOL, ORPINGTON

Finance Officer, Mrs Allen writes, "One of our Year 4 pupils at our school was diagnosed with Dermatomyositis in December 2010. The children in her class held a cake sale for the rest of the school and raised an impressive £147.07. They wish to donate the money raised to the MSG and we are very happy to enclose a cheque in this respect."

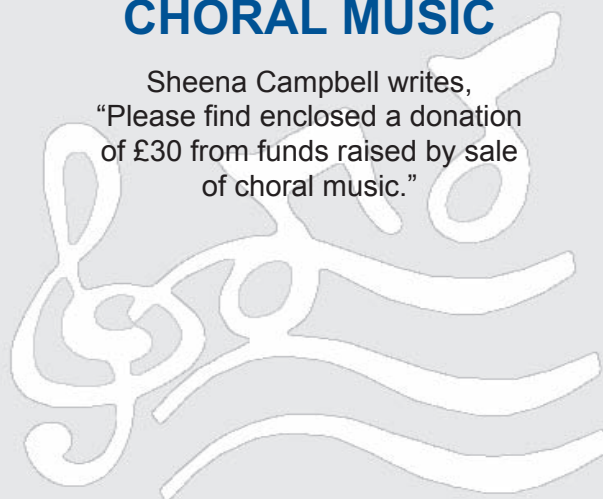
GOLDEN WEDDING

Velda and Norman Payne on their Golden Wedding celebration asked for donations to the Group in lieu of gifts and a collective response raised £380 for the charity.



CHORAL MUSIC

Sheena Campbell writes, "Please find enclosed a donation of £30 from funds raised by sale of choral music."



40TH BIRTHDAY BARN DANCE



Erica Mason writes, "Please find enclosed a cheque for £200 which was donated following a barn dance for my 40th Birthday. Having had Dermatomyositis for the last nine years I have found the Support Groups website informative and of great value. I hope this amount will help to contribute to your valuable work!"

GLEADLESS UNITED REFORM CHURCH – SHEFFIELD

Margaret Siddall of the Tuesday Fellowship at the Church writes, "Enclosed is a cheque for £30 in support of your work. One of our members suffers from Myositis so it was decided that the Group would be our charity for this year."



ITCHEN CORK LODGE HAMPSHIRE

Rod Styles has been raising funds for our cause for some years now and with the help of members he has again come up trumps for us with a donation of £250 raised from a "fun night" in February. What makes this donation very special is that as far as I am aware none of the members or Rod has a connection with the illness. However, they are aware of the progress in research and of the treatment of Myositis and how vital it is that the MSG keeps this work funded.

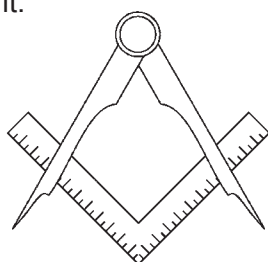
ORCHARD INFANT SCHOOL

DIBDEN PURLIEU – HANTS

Head teacher, Julia Pillon, writes, "The school decided to make this charity one of their chosen charities for Year 2 leavers' performance in July 2010. We are pleased to enclose our cheque for £133.87 representing donations from parents/grandparents to retiring collections from this performance."

MAYFLOWER LODGE No.8815 SOUTHAMPTON – HAMPSHIRE

Secretary of the Lodge, Rod Styles sent a cheque on behalf of the President, Colin Broad and members for £500. We are so very fortunate to have this continued help and the kindness and words of encouragement that comes with it.



GREENHOUSE PRODUCE

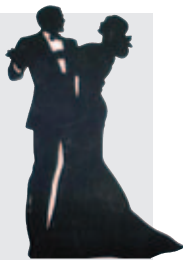
Wonderful supporter and annual fund raiser, Stan Grevett writes, "Hello again. Donation for £100 enclosed from greenhouse produce 2010. Sorry it's down again, will try harder this year, promise. Best wishes to all for 2011."



FUNDRAISING

BLACK TIE BALL

Catherine Sutcliffe writes, "Myself and my niece, Kate Bartle, held the Ball for our respective charities. I was firmly behind our cause and raised £2500 for the Myositis Support Group. I had kind donations from, May Armstrong, Mr & Mrs P McCarthy, Alan and Sue Jennings, Steve O'Shea. A BIG Thank You also to Pete Emmitt who was the MC for the night and did a fantastic job keeping everyone entertained. I hope this will help you continue your good work."



80TH BIRTHDAY DINNER PARTY

Mrs Itter writes, "I have just had my 80th birthday. I had a small dinner party and two of my friends who had known my husband gave me two cheques for the Support Group. I have enclosed these and made it up to £100. My husband suffered with Inclusion Body Myositis for many years and I know what a harrowing condition it is for all concerned."

A NIGHT OF A 1000 THRILLS

Sam McSorley writes, "It is with pleasure that we would like to give you a donation of £830 following our fundraising event held on the 23rd October 2010." This event was held in memory of their dear friend and nurse, Helen Loomes.

Jo Spencer writes, "A Night of a 1000 Thrills is a celebration of Helens life; it's about keeping that smile alive. It's about getting together as a group of people who share a devotion to The Killers and having one hell of a night!! It is also about raising as much money as possible for our 3 nominated charities.

For me this only started in August 2009 when I met Helen at the V Festival Shuttle in Stafford, along with other significant people who know who they are, but this is about Helen, so forgive me keeping them nameless at the moment. I don't know whether you've ever been lucky enough to meet a 'Helen' in your life, but the real life Helen, was one big smile that reached all the way to the ends of every tip of her. A genuine smile, which embraced and included everyone around her. That day I was in Helen's company for no more than 5 or 6 hours maybe, we were there for The Killers, and for those who love those boys as much as we do, time plays no part in those moments. However, the time I spent in Helen's company was significant enough to make a lasting impact.

When Helen became ill at the end of last year, I really only knew the seriousness of it all by the length of time she was in hospital. But, you just did not know this woman was ill!!!! She was irritated by being in hospital, but otherwise the smiles continued. She



was made up to be out of hospital for Christmas and I was so happy to be included when she posted out personal letters to a lot of people. But even then I did not realise that her young life was soon to be over. I think you all join me in saying that the shock was horrendous.

Helen O'Hanlon told me that Helen had intended to run the Marathon for charity. I felt that I wanted to finish her fundraising for her and having sounded people out, found that the number of people feeling the same was tremendous."

GREAT NORTH RUN



Member, Terry Sutcliffe writes, "My friend at work, Richard Heaton, took part in the run in aid of the Myositis Support Group.

With the help of his mum, Elizabeth Ashton they managed to raise over £800. Richard slogged his way around even though he picked up an injury a couple of days before the race. He completed the run in a very good time of 2 hours 7 minutes.

Waiting for him at the end was his lovely wife and daughters. Richard would like to thank everyone who donated on Just Giving. He would also like to thank his family and friends, work colleagues and YEDL for their kind donations and support."



TALK – ALAN KINGWELL

Motor car enthusiast, Alan Kingwell, gave a talk at the Alresford History and Literature Society titled, "Captain George Eyston, Forgotten King of Speed." Between 1926 and 1954, Captain George Edward Thomas Eyston broke dozens of speed records at Brooklands, Montlhery, Pendine Sands, & Bonneville Salt Flats, in cars ranging in size from 750cc M.G.'s to the 5,000 b.h.p. Thunderbolt.

As a result of his talk a donation for £30 was given to the charity.

CRAFT SHOP – BALLY MENA, NORTHERN IRELAND

Frances Ferguson sent in a cheque for £442 from tea boxes in her sister, Marilyn's craft shop. Never a year goes by without their help for the charity and the cause.

TALK – PETER CHARLES

Peter Charles, medical researcher at Imperial College, London, gave a presentation at Instrumentation Laboratory, Warrington. He requested the donation for his talk be made to the charity. £150 was received from Holly Turner the credit controller of the company.

THE ROTARY CLUB OF STAFFORD KNOT

Mrs Rosemary Lee writes, "In 2008 I sent you a cheque for over £3000 monies raised at the funeral of my husband, Christopher, who had suffered with Inclusion Body Myositis for many years. Please find enclosed a further donation for £1594.66 raised at a recent charity event organised by the Club. My husband was a Rotarian in another club in Stafford."

LEGAL AND GENERAL

Employee, David Thomas writes, "I have paid into my local branch of Lloyds Bank into your charity account £345 collected from my colleagues through fundraising activities at work including a cake stall, books/dvd sale and a prize draw."

Legal and General matched the amount with £345 and a further two CAF cheques of £5 were also paid into the account making a grand total of £700.

TALK – RICHARD WOODMAN

Author, Richard Woodman, has helped us yet again with a donation of £40 from a talk he gave to Harwick Peninsula U3A.

UNDERWOOD BARRON CHARTERED ACCOUNTANTS

Underwood Barron writes,

“Local businesses were generous in their support for charity at a networking event organised recently

by Underwood Barron Chartered Accountants. The event took place at Underwood Barron’s offices at Monks Brook House, 13-17 Hursley Road, Chandler’s Ford, Hampshire on Thursday 31st March. Over 30

local business men and

women attended and raised £285 for Hampshire based charity the Myositis Support Group.

Underwood Barron’s clients, colleagues and associates had the chance to meet and chat informally with other local business people at the event and to find out more about Underwood Barron’s business and family tax, auditing and accountancy services.

“The evening was a great success and we are thrilled that everyone who attended dug deep for this worthwhile local charity,” said Partner, Clive Underwood.



“We have built up our practice over the years by recommendation and meeting other business people so we are very pleased to be able to help our business clients and associates in the same way.”

Underwood Barron’s four partners and fifteen staff provide a comprehensive service to businesses, families and individuals, which includes specialist tax advice, auditing services, accountancy services and assistance with business reorganisation.”

Further information is available from: Clive Underwood on 023 8026 0555. www.underwoodbarron.com

STORNOWAY HALF MARATHON

Jill Morrison writes on her Just Giving page, “Many thanks for visiting my ‘Just Giving’ page. I am planning to run the Stornoway Half Marathon on 28th of May this year in a bid to raise funds for the Myositis Support Group. The medical condition Inclusion Body Myositis is a disease where by the body’s muscles progressively weaken, and may lead to disability. This was a disease that I knew nothing of until my father in-law was diagnosed a few years ago and in doing this half marathon I am hopeful not only to raise funds but also awareness of this disease and Support Group. Your donations are greatly appreciated and any words of advice or support would be welcomed! Thanks again.”

Jill had a target of £1000 but has surpassed this amount by raising £1,568 to date.

MONEY BOXES



Julie Parton writes, “I have enclosed a cheque for £15. I save all my 5 pence pieces in the Myositis Collection Box.

I thank you for all the superb work that you do on behalf of Myositis sufferers. The research information that you keep us up to date with I personally find informative and extremely useful in my ongoing battle with this debilitating disease.”

Frank Thomas of the Cheque Exchange in Stockport writes, “Please find enclosed a donation of £19 from one of your collecting boxes which I had placed on the front desk in our office. Whilst it is not a huge amount, I suppose as they say, “every little helps.”

Thank you to members and friends who have already sent and continue to send money from their boxes.

BUYAT – ONLINE SHOPPING

Don’t forget to buy goods through our web shop at Buyat. Purchases will cost you no more and the charity benefits from commission such as shown in our last statement for £21.61. We could really improve on this!



www.buy.at/myositis

SWANSEA BAY 10K RUN

Matt Otteson writes, "Please find enclosed a cheque for £200 consisting of funds raised by sponsorship for the run in September of last year. This money is in addition to a further £20 raised through Just Giving set up at the time. I may be looking to participate in further organised running events this year and will look to raise further money to support the charity."



FOLLOW UP FROM NEWSLETTER 66

Nick Bishop's and his friend Jack Whitelegg's run in the **Berlin Marathon** raised, £1196.41 (including gift aid). Nick's wife, Violet has had Polymyositis for over 10 years. A further £20 came from sponsor Jamie Credland's employer, The Economist Group by matching the donation.

Helen Bligh raised £405.87 (including gift aid) from the **Adidas Women's Challenge** 2010.

Claire Marshall in the **Three Peaks Challenge** raised £921.92 (including gift aid).

The British Gas Great North Swim, Stuart McSorley writes, "This was a 2 mile open water swim in Lake Windermere. Unfortunately, due to the prevalence of blue-green algae and the impact that this may have had on swimmers' safety the organisers had no choice but to cancel the event. I did defer my entry to this year's event, but I cannot

make the rescheduled date and so with regret have had to withdraw entirely.

I am however committed to taking part in another event that presents a similar challenge, and the event I have chosen is a swim that forms part of the EPIC Lakes Swim Series. The swim is 3.8km (2.36 miles) in open water, and takes place on 19th June 2011 at Derwent Water in the Lake District.

To mark this achievement I am using this specific swimming event to help raise funds for the Myositis Support Group in honour of Helen Loomes; a friend who died in January 2010 from aggressive auto-immune disease, aged just 41.

The Ten Mile Walk organised by **Neil, Lauren and Leah Loomes** in celebration of Helen Loomes life raised, £3768.49 (including gift aid.)

FUTURE FUNDRAISING

I AM GOING TO JUMP OUT OF A PLANE

Alexandra Kenvyn has set up a Just Giving page and writes, "Thank you very much for taking the time to visit my Just Giving page!

No, I'm not trying to kill myself. For my 21st birthday my parents bought me a tandem skydive and I wanted to do some good out of me having fun. I have chosen to raise money for this charity because a close family friend's daughter has recently been diagnosed and is undergoing treatment for Juvenile Dermatomyositis. She has a long road ahead of her with frequent visits to Great Ormond Street Hospital with scary treatment,

especially for someone who is afraid of needles, daily physio, which can be painful, and extreme fatigue. All this is stopping her being a "normal" energetic little girl who is still only in primary school. She is very brave and all her family & friends are thinking of her and in doing this I hope to raise money to help forward the research to find a cure, which currently doesn't exist."

Alex has raised £895 to date of her £1000 target. I am not sure when this event will take place but I wish her good luck and thanks for supporting the charity.

FUTURE FUNDRAISING

GREAT SOUTH RUN

Trustee, Nikki Coleman and I (Les Oakley, Chairman) - the young and the old! are taking part in this year's 10 miles Great South Run in October and are looking for sponsors. Any money out there?



LE TOUR DU VIN

Jeremy Waud writes, "We are organising Charity Wine Run in the Rhone between Thursday 28th and Saturday 30th July 2011.



We are fundraising for the Myositis Support Group.

Following extensive planning and discussion with growers, UK agents and wholesalers, our tour reconnaissance team of Jeremy Waud, Bill Pollard and Martin Athey from Incentive FM Group visited the selected hotel, various restaurants and wineries for two days in early February. The schedule for participating teams is as follows;

- Maximum 20 cars and 40 people,
- One day tasting and travelling in the Northern Rhone and the next in Southern Rhone,
- Flying into Lyon on Thursday morning (Gatwick Easyjet 07.30 arrives 10.15 local time),
- Hotel – Le Domaine De Soyons, near Valence,
- Various Sports car teams will leave Dover on the afternoon of Wednesday 27th July and the balance of the party will have hire cars waiting at Lyon airport on Thursday morning.

A comprehensive competition of a treasure hunt/observation nature will carry on through the event that will provide some entertainment, amusement and fines opportunity throughout the tour!

The entry cost will be £1,100 per team for those driving from the UK, and £1,300 (excluding flights) for those flying to Lyon and using the hire cars that we have lined up. £200 per team of the entry fee will be going to the 2011 nominated charity as a starter. We will aim to raise more money throughout the event.

We are still accepting applications to join in this fun event which is focused on the property sector, but also includes a wide variety of friends from other sectors who will add to the fun of this special event!



DETAILED SCHEDULE

Day 1 Thursday 28th July (Northern Rhone)

Lyon Airport to Condrieu;

- 11.30am** Group A tasting and winery tour at Christophe Pichon of Condrieu whites and Cote Rôtie Reds. Simultaneous tasting and winery tour for Group B at Louis Cheze in Limony, St Joseph area local reds, whites and their exquisite Syrah Rose.
- 12.30 – 1.30pm** Lunch in nearby Chavanay – Auberge Des Vignobles.
- 1.30 – 2.30pm** Group's A and B switch over for tasting at Christophe Pichon and Louis Chez
- 3.30 – 5pm** Whole touring party to rendezvous at Delas Freres just north of Tain at their winery in St Jean de Muzols for full tour of their impressive high tech winery followed by a tasting of Hermitage, Crozes Hermitage, St Joseph and Cornas wines from different vintages.
- Brief tour of the hermitage hill followed by a drive along the west bank of the Rhone to our hotel in Soyons.
- 7pm –** Deutz Champagne reception and four course dinner with Northern Rhone wines from Chapoutier and Jaboulet.

Day 2 Friday 29th July (Southern Rhone)

- 9am –** Drive to Vacqueyras;
- 10.30 – 11.15am** Group A arriving at Domaine Montvac to taste the Vacqueyras and Gigondas reds of different recent vintages plus one white Vacqueyras from 2010 harvest. Group B arriving in Vacqueyras at Les sang De Cailloux, tasting amongst the vats of this fabulous wine with its eccentric and fabled producer – Serge Ferigoule.
- 11.15 – 12pm** Groups A & B switch to corresponding tasting venues in Vacqueyras.
- 12.30pm –** Drive to the nearby town of Beaurnes-de-venise for lunch in the square at Lou Castelet.
- After lunch drive to Chateauneuf-du-Pape.
- 2pm –** A full tour and tutored tasting at the wonderful Chateau Beaucastel. Selected wines for tasting are Cadoulet Rouge 2008, Beaucastel Rouge 2008, Beaucastel Rouge 1995, Beaucastel White 2009, Rousanne (Old Vine) 2009.
- 5.30pm –** Arrive back at hotel in Soyons followed by four course dinner and tasting of Southern Rhone wines at the hotel's Le Chateau du Senateur Restaurant.

Day 3 Saturday 30th July

Depart for home after breakfast.

RESEARCH

GRANT AWARDED – ANDY HISCOCK, UCL

We received the following application for funding from Andy Hiscock research physiotherapist, Institute of Child Health & MRC Centre for Neuromuscular Diseases University College London.

Andy writes, “Myself and Liz Dewar (also a physiotherapist at the MRC centre) are hoping to commence a new study looking into the incidence and causes of falls in people with IBM and how this might correlate with physiotherapy service they have access to, as this is has yet to be investigated among

the IBM population, and even the current IBMnet database won't address these issues. As with all research studies, we have to find appropriate funding and I was wondering if the Myositis Support Group might be able to help us out. We are planning the study as a postal questionnaire and so would need only minimal funds to cover postage, envelopes etc.”

We had a meeting with Andy in London to discuss the questionnaire and put the proposal to the trustees and it was agreed to fund this project in the region of £500.

GRANT AWARDED – ADRIAN MILLER ARIMOCLOMOL TRIAL, UCL

The trustees approved funding for Dr Adrian Miller to continue his work in Inclusion Body Myositis at the MRC Centre for Neuromuscular Diseases. The funding is for five months from April to August

2011. After this he will return to his neurology training programme, where he will continue to be trained to be a consultant in muscle diseases. The cost of the funding is £21,470.

UK NEUROMUSCULAR TRANSLATIONAL RESEARCH CONFERENCE – LONDON

Irene and I attended the well supported two day conference in London where we had a charity stand. We were able to talk to the delegates about myositis and hand out information including Jenny Fenton's book.

The MRC Centre for Neuromuscular Diseases aims to bring together clinicians, scientists, patient organisations and patients in order to advance UK translational research in neuromuscular diseases.

This is a particularly exciting time in the field as a range of science discoveries are revealing an increasing number of therapeutic targets. The Centre aims to work with all its partners to support the development of a clinical trials culture for patients with neuromuscular diseases. They will continue to work hard to form effective research and clinical links with as many other UK neuromuscular groups as possible.

EUROPEAN SCIENCE FOUNDATION SPONSORED INTERNATIONAL MYOSITIS GENETICS CONFERENCE – MANCHESTER

This was a two day conference attended by Irene, Paula and myself. It was a meeting for doctors and scientists and delegates came from the USA, Europe and the UK. The conference was very complex and scientifically based. Paula also attended the steering committee meeting of the EuMyoNet Group in her role as a patient representative which was held prior to the conference.



Novel autoantibodies and clinical phenotypes in Adult and Juvenile Myositis.

ZE Betteridge, H Gunawardena, NJ McHugh.

Published in Arthritis Research & Therapy in March 2011 page 209.

Autoantibodies targeting intracellular proteins involved in key processes are detected in patients with idiopathic inflammatory myopathies. These myositis specific autoantibodies have been increasingly demonstrated to correlate with distinct clinical phenotypes within the myositis spectrum. This review highlights the clinical associations of the myositis specific autoantibodies, with particular attention to the recently identified and characterized novel myositis autoantibodies: p155/140, p140 (MJ), CADM-140 (MDA5), SAE, and 200/100.

A national registry for juvenile dermatomyositis and other paediatric idiopathic inflammatory myopathies: 10 years' experience; the Juvenile Dermatomyositis National (UK and Ireland) Cohort Biomarker Study and Repository for Idiopathic Inflammatory Myopathies.

N Martin, P Krol, S Smith, K Murray, CA Pilkington, JE Davidson, LR Wedderburn; Juvenile Dermatomyositis Research Group.

Published in Rheumatology (Oxford) in January 2011 pages 137-45.

OBJECTIVES: The paediatric idiopathic inflammatory myopathies (IIMs) are a group of rare chronic inflammatory disorders of childhood, affecting muscle, skin and other organs. There is a severe lack of evidence base for current treatment protocols in juvenile myositis. The rarity of these conditions means that multicentre collaboration is vital to facilitate studies of pathogenesis, treatment and disease outcomes. We have established a national registry and repository for childhood IIM, which aims to improve knowledge, facilitate research and clinical trials, and ultimately to improve outcomes for these patients.

METHODS: A UK-wide network of centres and research group was established to contribute to the study. Standardized patient assessment, data collection forms and sample protocols were agreed. The Biobank includes collection of peripheral blood mononuclear cells, serum, genomic DNA and biopsy material. An independent steering committee was established to oversee the use of data/samples. Centre training was provided for patient assessment, data collection and entry.

RESULTS: Ten years after inception, the study has recruited 285 children, of which 258 have JDM or juvenile PM; 86% of the cases have contributed the biological samples. Serial sampling linked directly to the clinical database makes this a highly valuable resource. The study has been a platform for 20 sub-studies and attracted considerable funding support. Assessment of children with myositis in contributing centres has changed through participation in this study.

CONCLUSIONS: This establishment of a multicentre registry and Biobank has facilitated research and contributed to progress in the management of a complex group of rare musculoskeletal conditions.



THE FOLLOWING 4 ARTICLES HAVE BEEN INCLUDED BY KIND PERMISSION OF THE MUSCULAR DYSTROPHY CAMPAIGN

GREAT NEWS FOR NEUROMUSCULAR CARE

The NHS took encouraging and groundbreaking steps earlier this year when they called on all ten Specialised Commissioning Groups (SCG) in England to prioritise neuromuscular services in their annual work plans.

The neuromuscular service plan, which will benefit people with muscular dystrophy and related neuromuscular conditions, came out of discussions with members of the All Party Parliamentary Group (APPG) on Muscular Dystrophy.

Teresa Moss, Director of the National Specialised Commissioning Team, told MPs and Peers that it had been agreed that neuromuscular services would be a priority in the annual work plan of each of the ten SCGs, covering key issues such as:

- specialist physiotherapy provision in the multi-disciplinary team
- access to specialist equipment
- an audit of unplanned emergency admissions for patients with neuromuscular conditions
- making sure there are well equipped neuromuscular professionals across England
- a single service specification defining specialist neuromuscular services.

The APPG on Muscular Dystrophy interrogated NHS bosses on the proposals for NHS reforms, the impact these would have on people with neuromuscular conditions, and how services would be commissioned, planned and delivered under the new NHS Commissioning Board.

Dave Anderson MP, Chair of the APPG on Muscular Dystrophy, said the new plans followed the Walton Inquiry and the hard work led by campaigners, parliamentarians, clinicians and people living with muscle disease.

“However, it’s vital that we don’t take our foot off the accelerator. Patients and families across the country – many living with devastating, life-limiting conditions – need to see the impact of these

changes, on the ground, as soon as possible,” he said.

Health Minister Earl Howe wrote to Lord Walton of Detchant in March following a meeting between the Minister, his officials and the Muscular Dystrophy Campaign. In his letter, Earl Howe states, “There are weaknesses in commissioning, which are behind the patchiness and problems accessing vital services for those living with these dreadful conditions, their families and carers.

“A national working group has recently been set up, led by the East of England SCG, with representatives from all SCGs to identify and scope what is happening nationally in the commissioning of neuromuscular services. It has been acknowledged that all regions are facing similar challenges in the commissioning of services for neuromuscular patients...this national group will give added support to the delivery of the recommendations arising from these regional reviews of neuromuscular services.

“A provisional work programme has been identified to be taken forward with each SCG region having responsibility for a particular service improvement area.”

Robert Meadowcroft, Chief Executive of the Muscular Dystrophy Campaign, said, “We welcome this as the first step towards a coherent, national approach to specialist neuromuscular services – thanks largely to the hard work and determination of our supporters across the country backed up by our Parliamentary supporters.

“However, there is still a long way to go, and we must increase our campaigning work now more than ever before. The economic climate and reform to the NHS must not delay progress in this vital area.”

To find out more about the national approach for neuromuscular services and the APPG for Muscular Dystrophy, contact campaigns@muscular-dystrophy.org

SUMMARY CARE RECORD

In order to improve the safety and quality of patient care, the NHS is to introduce Summary Care Records. These electronic records will give healthcare staff faster, easier access to essential information about you, to help provide you with safe treatment when you need emergency care or when your GP practice is closed.

The Summary Care Records will be gradually introduced across England and your local NHS will send you a letter and information pack before they start making Summary Care Records in your area. We are telling you about this, so you have time to think about your choices, as you can choose not to have a Summary Care Record. If you decide to have a Summary Care Record it will contain important information about any medicines you are taking, allergies you suffer from and any bad reactions to medicines that you have had. Giving healthcare staff access to this information can prevent mistakes being made when caring for you in an emergency.

You may want to add other details about your care to your Summary Care Record, and you can ask your GP for the additional information to be included. Suggestions would be to include:

- This person has a neuromuscular condition and is at risk of various complications which may be important if they are admitted to hospital.
- There are known respiratory and cardiac complications associated with some muscle diseases and oxygen administration may reduce respiratory drive in patients with hypercapnia.
- Some muscle problems are associated with risks during anaesthetics.
- If a person with a muscle problem is immobilised due to fracture or other reasons, they may be at risk of permanent loss of mobility. Early mobilisation may be indicated.

Visit www.muscular-dystrophy.org/nhscarerecords for more information.

HOLIDAY DREAMS ... AND THE REALITY

We're all going on a summer holiday. Or are we? It can be difficult for disabled people to plan carefree holidays in the same way as their non-disabled peers. Not all resorts and hotels and airlines have good access, and it can be frustrating trying to find suitable venues and means of travel.

The Muscular Dystrophy Campaign information service has put together a factsheet to help you plan and choose your destination to ensure your holiday is fun and trouble-free. In addition, the young campaigning group, Trailblazers, carried out an investigation into tourism and wrote a report highlighting factors that can affect young disabled people on holiday, such as booking holidays, accessibility in hotels, air travel, accessibility at tourist attractions and disability awareness in the tourism industry. If you'd like a copy of the report – All Inclusive? – call Bobby on 020 7803 4807 or email trailblazers@muscular-dystrophy.org

For example, what equipment will you need for your holiday? Will you need a raised toilet seat, a mobile hoist, a wheelchair? Are you able to take your equipment with you, or will you need to hire or borrow some of it? The factsheet includes details of

companies that hire or loan equipment that you can contact after doing an assessment.

If you are a manual wheelchair user, it is a good idea to have your wheelchair checked before you leave to lessen the chances of it breaking down. Consider taking a spare inner tube, as well as a puncture repair kit and some tools with you.

Powered wheelchairs might need different consideration: is it essential to take it with you, or can you hire one when you get there? Can you use your charger if you travel abroad, or will you need to get a special adapter? Check with your airline about transporting your wheelchair, and ensure that your travel or home insurance covers your powered wheelchair or other equipment while you're on holiday. It is always worth servicing the wheelchair before you go, so it is less likely to break down while you're away.

If you plan your trip well in advance, you can find out as much as you can about how to get there. The Disabled Persons Transport Advisory Committee (DPTAC) is an independent body set up by the government, and they provide information about road, rail, air or sea travel, car ferries, the Euro tunnel, parking, as well as travelling with oxygen. Visit them at <http://dptac.independent.gov.uk/door-to-door/> or call them on 020 7944 8011.

TOURISM FOR ALL

Tourism for All is a voluntary organisation that provides free information and advice about travel for disabled adults and children, carers, single parent families and elderly people, for travel in the UK and elsewhere in the world. Visit their website at www.tourismforall.org.uk for advice on accessible tourism. As an additional bonus, some of the hotels and self-catering accommodation inspected and listed by Tourism for All are offered at discounted rates for members through its reservation line 0845 124 9973.

The Rough Guide to Accessible Britain, at www.accessibleguide.co.uk is another useful resource for planning your holiday in the UK. Visit their website and order a guide to accessible holidays, with all the latest, up-to-date information.

In choosing the destination for your holiday, make sure

to find out about accessible activities and how you can get out and about, before making any bookings. If you like beach holidays find out if the accommodation has beach wheelchairs or if you can rent one. If you are travelling abroad you might find it useful to bring translated information on your condition in case of an emergency. When arranging insurance, check that the travel insurance covers medical treatment and does not exclude "a pre-existing medical condition". It is often worth shopping around to make sure you get best value for money.

The Equality Act 2010 makes it illegal for insurance companies to charge a disabled person more for an insurance policy without evidence that proves that the disabled person is a greater risk than a non-disabled person. For anything further you want to know about holidays, call our Information Line on freephone 0800 652 6352 or print the factsheets from our website: www.muscular-dystrophy.org/factsheets

STRIDES AHEAD FOR NEUROMUSCULAR DATA

A new national database that will facilitate research, audit and standardise clinical assessment of patients with neuromuscular disorders, has been developed in the UK.

Known as the National Neuromuscular Database, it will contribute to national and international initiatives in the field of neuromuscular disorders. Its development has been supported by the Muscular Dystrophy Campaign and the MRC Centre for Neuromuscular Disease.

The database was originally set up by Professor Francesco Muntoni and Dr Adnan Manzur (Dubowitz Neuromuscular Centre, Great Ormond Street Hospital) to aggregate data from children with Duchenne muscular dystrophy (DMD) and Spinal Muscular Atrophy (SMA) followed in all the major paediatric neuromuscular centres in the UK. More recent developments include the conditions Inclusion Body Myositis (IBM), the congenital muscular dystrophies and myopathies.

It has active links with national and international initiatives and advocacy groups, including the TREAT-NMD Network of Excellence; Action Duchenne; the Myotubular Trust; the Jennifer Trust; Cure CMD.

The NorthStar DMD module of the database is the longest standing, with 500 individuals registered. Data has been provided to facilitate national audits in boys with Duchenne muscular dystrophy of:

- glucocorticoid steroid use
- prevalence of vertebral fractures
- prevalence of Vitamin D deficiency
- body mass index.

Data is also contributing to international developments in the field of outcome measures for clinical trials:

- International meeting re Clinical Outcome Measures in Duchenne Muscular dystrophy – summary data from the North Star data set was presented at this meeting held in Washington, USA in June 2010. This was a National Institute for Health initiative organized by TREAT-NMD and Children's National Medical Centre and supported by CureDuchenne, the Foundation to Eradicate Duchenne and Ryan's Quest
- North Star Ambulatory Assessment (NSAA) - the NSAA was developed as part of the work of the network as a functional assessment tool for ambulant boys with Duchenne muscular dystrophy. Formal evaluation of the scale has been undertaken using Rasch methodology.¹

The National Neuromuscular Database provides a powerful tool to enhance the understanding of the longitudinal history of complex neuromuscular disease; facilitating optimal standards of clinical care and offering a useful resource to research initiatives.

1. Mayhew A, Cano S, Scott E, Eagle M, Bushby K, Muntoni F, The North Star Clinical Network for Paediatric Neuromuscular Disease. Moving towards meaningful measurement: Rasch Analysis of North Star Ambulatory Assessment in Duchenne muscular dystrophy. *Dev Med Child Neurol.* 2011 Mar 17. doi: 10.1111/j.1469-8749.2011.03939.x. [Epub ahead of print]

Further information on this project and its developments can be found on the clinical databases section of the Muscular Dystrophy Campaign website.

Our thanks to the Muscular Dystrophy Campaign for allowing us to reprint this information. For more information or to read the Muscular Dystrophy Campaign's magazine, "Target MD", please visit their website at <http://www.muscular-dystrophy.org/>

WEDDING

Lesley Statham (nee Judge) writes, "Hi Les, I am a member of your Support Group and my husband David has IBM. David is on the IBM drugs trial which he started last December. In the same month David and I finally got married after 16 years together! We didn't tell any of our family and friends until after the event and had a fabulous time in North Yorkshire at the Swinton Park Hotel – just the two of us. We then told everyone and had a lunch party for friends and family the week before Christmas. Thank you for all the work you do and see you at the Conference."



GREAT GRANDCHILD

Anne Ali writes, "Here's some good news for the newsletter! We are Great-grandparents again - and I'm still in my 50s! On January 31st, at 8.12pm our Great-grandson Reo arrived, weighing 7lb 5oz, a brother for Bethany who is 2 years 9 months. Mother (our beautiful Granddaughter Sophie) and baby are doing well."



ANTI SRP PATIENTS

If you are a member who has Anti SRP (signal-recognition particle) myositis then another member would like to hear from you! Please contact Irene by post or email if you wish to get in touch.



WELFARE ADVICE

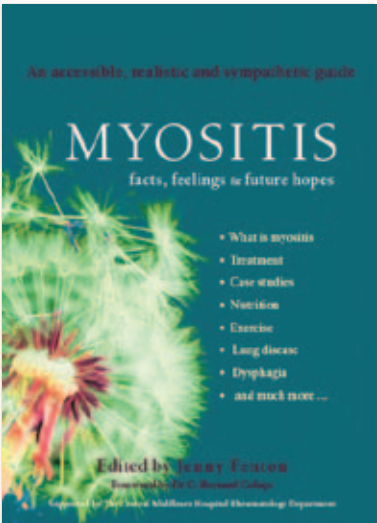
Janet Horton can be contacted at, 1 Fellstone Vale, Withnell, Chorley, Lancs, PR6 8UE. She will be pleased to help Myositis Support Group members regarding welfare advice. You can also speak to her by telephone on a Monday or Friday between 10am and 12noon on 01254 832463. If you telephone please tell Janet you are a Myositis Support Group member for she helps members of other organisations as well. Janet cannot give any medical advice. Any member requiring information of this nature will they please get in touch with Irene or me.

LISTENING EAR TELEPHONE NETWORK

The Listening Ear Telephone Network is a self-help resource for members of the Support Group. It was first launched in 2006 and now is in need of updating. Current volunteers to the LETN will receive a mailing from Paula in July/August; however, there is room for more members to volunteer themselves to be a telephone contact. The LETN consists of a booklet containing brief profiles and their telephone numbers – all are volunteers who have experience of living with Myositis. The booklet is only available to Support Group members on request but details of this resource are included in all new member welcome packs. You do not have to be a volunteer to use the LETN. The LETN aims to alleviate isolation and offer support through talking to each other. If you would like to become a volunteer in the LETN please email Paula and she will send you further information. If you would like to receive a copy of the LETN but not necessarily become a volunteer please also message Paula and she will be able to send you a copy when the updated version becomes available later in the year. Please email info@myositis.org.uk and put LETN in the subject line.



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Reviewed by Dr G. Rowland Colledge
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POST SCRIPT

I look forward to seeing you at the conference on July 10th. From the numbers attending I feel sure it is going to be another worthy event. Also many thanks for private donations, news and information submitted for inclusion in this newsletter.

It would be great to hear of Good News and any other articles for inclusion in the next newsletter. Please send your articles and photographs to the office or email msg@myositis.org.uk. For it is this information that makes the newsletter interesting reading.

Les Oakley MBE Chairman

The opinions expressed in this newsletter are not necessarily those of the Myositis Support Group. We do not endorse any product or treatment mentioned in this newsletter. Our aim is to keep you informed on latest issues. You should always consult your doctor before changing any medication. Whilst every effort is made to ensure the information contained in this newsletter is accurate, the Myositis Support Group accepts no responsibility or liability where errors or omissions are made.



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