



MYOSITIS

Support Group

Newsletter 66

October 2010

Dear Member,

This newsletter is the first issue of the year coming after the earlier charity news flyers. This compilation has items dating back to the end of last year but it does give a good indication of how busy people involved with the Group have been during the last nine months. It has been a difficult time in the office because of illness. However, things are slowly getting back to normal and we just regret that we could not operate as efficiently as we normally do.

AGM AND MINI CONFERENCE 2010

Irene came up trumps again with another well organised day. With the odd slip up on the hotel's timing, we were passing hot pastries and orange juice around during the AGM which turned into a bit of fun and was actually an ice breaker that we will have to do again! We managed to get through this formal procedure and the trustees were re-elected on bloc.

The conference was well attended. The "meet and greet" in the hotel on Saturday afternoon is proving very popular with members meeting up with new and old faces with many enjoying an evening dinner together. The morning session was chaired by Prof David Scott from King's College Hospital, London. An overview on adult Dermatomyositis and Polymyositis was given by Dr Patrick Gordon, King's College Hospital. Prof Mike Hanna, National Hospital for Neurology, London gave an overview on Inclusion Body Myositis and Dr Clarissa Pilkington, Great Ormond Street Hospital an overview on Juvenile Dermatomyositis.

After a pleasant and unhurried lunch the members returned to their break out sessions for the respective diseases where Dr Stefen Brady, a neurologist and Dr Pedro Cardo, a rheumatologist jointly chaired the IBM session. Dr Clarissa Pilkington chaired the JDM session and Dr Patrick Gordon chaired the DM/PM session.

These sessions were superb and members could ask any question, debate all issues and talk freely in a relaxed atmosphere. For the shyer ones among us they could submit written questions. I sat in with the IBM members and I know they gained much from the talks. The hour and a half given to this period went so quickly because of the open discussion. The doctors were honest with their answers but were keen to express that in IBM, although treatments were in their infancy, there was much optimism for the future.

TRUSTEES 2010 - 2011

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Tony and Jo sat in with the adult DM/PM where this also proved to be a rewarding session. Irene, Paula and Nikki sat in with the JDM where again there was an encouraging discussion. Part of the discussion was on how to get information from adults who had JDM as children. There was interest in calcosinosis which is often a side effect for children. The format for next years meeting was discussed to see if we could encourage more parents to attend. There were excellent questions asked by Katherine a 7 year old with JDM. She wrote her own questions and asked them as well!

We all met up in the main room for a summary session led by Prof Scott. I am sure that everyone who attended found the day worthwhile. We all have different issues and problems. However, I felt there was warmth in the talk and manner of the people there that makes me feel it was a good and useful day.

I am very grateful to the speakers for giving up their time to be with us. It is easy to forget that they have families and busy domestic lives and like the rest of us have normal pressing issues that time has to be found for. This is why I consider these people to be very special. They give us that extra kind thought and consideration to make this day work for us as a charity.

The feed back forms from members attending have been very helpful. Thankfully, overall the day was very worthwhile and all the replies were much in favour and appreciative of the break out sessions.

We are already making plans for next year that will take the conference into the Midlands. We have provisionally set the time to cover the weekend of the 9th and 10th of July 2011.

“Very enjoyable and informative day, great talking to others, very well catered for and organised.”

“Wonderful day, the doctors’ sessions were very informative and supportive.”

“As I am very short of stature, it was difficult to see the overheads. Would it be possible to off set the seats, like one sees at the cinema?”

“A day well spent particularly for a first timer to have the opportunity to hear the experiences of others.”

CHRISTMAS CARDS

This year’s selection of cards are now in stock and an order form is enclosed. There are five new designs and a limited number of packs of previous year’s designs for sale. As well as your own order if you feel you can sell a few more packets of cards to friends or work colleagues, please let us know. The income from the cards is a vital contribution in funding our projects and there are some new developments that we wish to finance. New members may wish to take this into consideration for the more we pull together the more we will be able to get things done. Our older members have heard all this before but then I’m good at beating the same old drum if it helps!



GRAND SUMMER DRAW

Thank you to all who brought or sold tickets for this year’s draw, your support is very much appreciated. There is a list of prize winners enclosed with this newsletter.

LISTENING EAR TELEPHONE NETWORK



The Listening Ear Telephone Network (LETN) is a directory of Myositis Support Group members who have volunteered to be a point of telephone contact to support other members. The LETN is very important as it offers self-help and support to members unable to access the Internet and in particular the Myositis Support Group website Community Pages. The LETN is in need of revision and Paula will be starting this soon. If you would like to volunteer as a point of contact to other members of the Support Group please send a large stamped address envelope to the office and we will send you further information.

Important Amendments to the LETN Directory. It is with sadness I have to inform you of the passing of members Graham Waltham and Mr F Marsh. These members were LETN volunteers and have offered invaluable support to many. If you have previously requested a LETN directory please would you amend these details to avoid any stress to the families should you accidentally telephone their numbers in future.

RESEARCH

MRI STUDY IN INCLUSION BODY MYOSITIS

A study investigating the utility of MRI scanning in patients with Inclusion Body Myositis is being undertaken by Professor Hanna and colleagues at the MRC Centre for Neuromuscular Diseases in London. The study's main aim is to discover the best method of assessing and monitoring the disease by comparing novel quantitative MRI scanning with detailed muscle strength assessment in a group of IBM patients annually for five years. Participants will continue to be enrolled in the study until the end of the year. More information about the study can be obtained from Dr Jasper Morrow: j.morrow@ion.ucl.ac.uk or 0845 155 5000 ext 4259.

MRC CENTRE FOR NEUROMUSCULAR DISEASES

Irene and I were invited to the official opening of the new Queen Square Centre for Neuromuscular Diseases, London on Thursday 10th December last year.



The new adult Centre for Neuromuscular Diseases at the UCLH National Hospital for Neurology and Neurosurgery at the UCL Institute of Neurology Queen Square is a unique development in UK translational medicine for patients with disabling muscle wasting neuromuscular diseases. The brand new centre facilities enable full integration of the highest quality NHS clinical care with cutting edge translational research to benefit patients. Nearly 5,000 adult patients with muscle wasting neuromuscular diseases are assessed and treated at the National Hospital Queen Square each year. Many neuromuscular diseases develop in childhood and the Centre works closely with the Victor Dubowitz neuromuscular unit at the Great Ormond Street Hospital to ensure effective transition to adult care. Neuromuscular diseases include genetic and acquired disorders that often cause major disability and premature death. Examples include muscular dystrophies, myositis, mitochondrial diseases, motor neuron, peripheral neuropathies and disorders of the neuromuscular junction such as myasthenia gravis. Although there have been many important genetic and molecular advances in these diseases there are still hardly any effective clinical care, with research and clinical trials aimed at developing new treatments for patients.

The MRC Centre for Neuromuscular diseases is one of the MRC's translational research centres. It is directed by Professor Hanna and is in partnership between the UCL Institutes of Neurology and Child Health, and the University of Newcastle upon Tyne. The Myositis Support Group is actively involved with the centre where several of our Inclusion Body Myositis members will be taking part in the projects.

Irene and I also attended the two day Annual Neuromuscular Translational Research Conference meeting in Oxford in March where we had a Myositis Support Group Stand. This gave us the opportunity to not only meet with clinicians and scientists in the field but to also meet many PhD students and to get them interested in muscle disease as a career choice.

UK MYONET BATH MEETING

Irene and I attended the UK Myonet Bath meeting at the Royal National Hospital for Rheumatic Diseases. The first session was chaired by Prof Neil McHugh. Prof David Isenberg gave an update on ARC Clinical Trials Network. Dr Zoe Betteridge an Autoantibody update – Immunoprecipitation Studies. Dr Bob Cooper an update on AOMIC Studies (Adult Onset Myositis Immunogenetic Collaboration). Dr Patrick Gordon, Standardisation of Histology - Adult IIM (idiopathic inflammatory myositis) and Dr Hector Chinoy on an Endothelial Dysfunction Project in IIM.

The second session was chaired by Dr Harsha Gunawardena where an update by Dr Adrian Miller was given on IBM Network Studies. Dr Richard Campbell gave a talk in Coronary Heart Disease in IIM and ILD – clinical experience at King's.

This led to a general discussion including an overall remit of UK Myonet.

These are exciting times for focusing studies involving Polymyositis, Dermatomyositis and Inclusion Body Myositis and for us to witness the development of the Myonet meetings.

IMPERIAL COLLEGE HOSPITAL

Imperial College
London

The charity has funded a grant of £16,600 to Dr Russell Lane and colleagues to examine in depth, the changes of emerin expression in IBM compared to DM, PM and normal muscle. If this project is successful it may unveil a key mechanism that underlies the imbalanced expression of genes that regulate the inflammatory response and encode for abnormal protein accumulation in sIBM.

PUBLICATIONS

Doctors and researches at the centres (Bath, Manchester, UCL and Great Ormond Street) supported in part by the Myositis Support Group have continued to publish the results of their work in various medical journals and some have resulted from collaborations between the centres. We are only able to reprint the abstracts here in the Newsletter. For further details related to these papers visit PubMed online www.pubmed.com

Pathogenic mechanisms of disease in myositis: autoantigens as clues.

ZE Betteridge, H Gunawardena, NJ McHugh.

Published in Current Opinion of Rheumatology in November 2009 pages 604-9.

PURPOSE OF REVIEW: There is increasing evidence of autoimmunity in dermatomyositis and polymyositis, with strong correlations between particular myositis-specific autoantibodies (MSAs) and clinical subsets. It is now clear that corresponding autoantigens are selectively targeted, have distinct adjuvant properties and are upregulated in target tissues, suggesting a role in disease pathogenesis. This review highlights recent findings including the identification of novel MSAs and studies investigating autoantigen properties and expression in both target tissues and tumours.

RECENT FINDINGS: During the review period, the clinical associations of anti-SAE and anti-p140 have been further described. Studies of autoantigen expression have demonstrated upregulation of Mi-2 in response to ultraviolet (UV) damage and expression of myositis-specific autoantigens in rat newborn skeletal muscle. The role of type I interferon and adjuvant activity has also been highlighted through the identification of the CADM140 autoantigen as MDA5, a protein involved in innate immunity.

SUMMARY: There are now a number of models indicating roles of autoantigens in disease pathogenesis. Our increased understanding of the autoantigenic properties of these targeted proteins will help to determine the mechanisms involved in the initiation and propagation of myositis. In turn, these findings may lead to therapeutic advances including the development of more targeted treatments.

HLA-DPB1 associations differ between DRB1*03 positive anti-Jo-1 and anti-PM-Scl antibody positive idiopathic inflammatory myopathy.

H Chinoy, D Payne, KV Poulton, N Fertig, Z Betteridge, H Gunawardena, JE Davidson, CV Oddis, NJ McHugh, LR Wedderburn, WE Ollier, RG Cooper (UK Adult Onset Myositis Immunogenetic Collaboration & UK Juvenile Dermatomyositis Research Group).

Published in the journal Rheumatology (Oxford) in October 2009 pages 1213-7.

OBJECTIVE: The HLA 8.1 ancestral haplotype (HLA-B*08/DRB1*03/DQA1*05/DQB1*02) is associated with adult/juvenile idiopathic inflammatory myopathy (IIM), but confers a greater strength of association in patients possessing anti-Jo-1 or anti-PM-Scl antibodies. The HLA-DPB1 gene is centromeric to other HLA class II loci and separated by a recombination hotspot. We investigated whether HLA-DPB1 associations differ between anti-Jo-1 and anti-PM-Scl antibody-positive IIM cases.

METHODS: Two hundred and thirty-three adult IIM patients (73% females, 49.4 +/- 13.6 years) with PM (n = 89), DM (n = 88) and myositis associated with another CTD (n = 55) and 85 juvenile DM patients (75% females, 6.2 +/- 3.6 years) were compared with 678 UK Caucasian controls. Patients/controls were genotyped for HLA-DPB1 and DRB1 alleles. Myositis-specific and associated antibodies were identified in cases using immunoprecipitation.

RESULTS: HLA-DPB1*0101 was associated with IIM overall [22 vs 13% controls, corrected probability (P(corr)) = 2×10^{-03} ; odds ratio (OR) 2.0; 95% CI 1.4, 2.9], PM (P(corr) = 7×10^{-03} ; OR 2.5; 95% CI 1.5, 4.4) and anti-Jo-1 (P(corr) = 3×10^{-5} ; OR 4.1; 95% CI 2.1, 7.8). No significant DPB1*0101 difference was present between anti-PM-Scl cases and controls. The HLA-DPB1*0101 association in IIM overall cases was dependent on the presence of DRB1*03. A number of HLA- DRB1*03/DPB1 haplotypes were identified, but only DRB1*03/DPB1*0101 was associated with anti-Jo-1 antibody-positive cases.

CONCLUSIONS: The HLA-DRB1*03/DPB1*0101 haplotype is a risk factor for anti-Jo-1 antibody-positive IIM. Thus, although DRB1*03 is strongly associated with possession of either anti-Jo-1 or anti-PM-Scl, differing antibody associations are observed at the HLA-DPB1 locus.

Quantitative nailfold video capillaroscopy in patients with idiopathic inflammatory myopathy.

LK Mercer, TL Moore, H Chinoy, AK Murray, A Vail, RG Cooper, AL Herrick.

Published in the journal Rheumatology (Oxford) in September 2010 pages 1699-705.

OBJECTIVES: To quantify nailfold capillary density and dimensions in patients with idiopathic inflammatory myopathy (IIM) and compare them with those in healthy controls; to look for associations with microvascular disease in IIM; and to determine whether nailfold capillary density and dimensions change over time.

METHODS: Nailfold video microscopy (x300 magnification) was performed on 24 patients with IIM and 35 healthy controls. Capillary density and dimensions (total width and apical width) were quantified. Patients were clinically assessed and disease activity recorded using the Myositis Disease Activity Assessment Tool. Disease severity and physical function were assessed using the myositis damage index and Stanford HAQ, respectively. Findings were analysed using linear and logistic regression, adjusted for age and sex. In a subgroup of 16 patients with IIM and 27 controls, the process was repeated 6-12 months later and the results were analysed using Student's t-test.

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RESULTS: Capillary density was lower and dimensions were higher in patients with IIM compared with healthy controls ($P < 0.001$ for all). Anti-Jo-1 antibody was associated with reduced capillary density. In the longitudinal cohort, the mean change in capillary density was -1.4 in patients vs -0.4 in controls ($P = 0.07$). Mean change in capillary dimensions did not differ between patients and controls, but some patients demonstrated pronounced changes in capillary morphology over time.

CONCLUSIONS: Reduced capillary density and increased dimensions in patients with IIM can be quantified using nailfold capillaroscopy, suggesting that nailfold capillaroscopy may be useful as an outcome measure of microvascular disease in studies of IIM.

An update on the immunogenetics of idiopathic inflammatory myopathies: major histocompatibility complex and beyond.

H Chinoy, JA Lamb, WE Ollier, RG Cooper.

Published in the journal Current Opinion in Rheumatology in November 2009 pages 588-93.

PURPOSE OF REVIEW: To update the reader on immunogenetic advances in idiopathic inflammatory myopathy (IIM) over the past 18 months.

RECENT FINDINGS: In Caucasian IIM, despite a shared association with the human leukocyte antigen (HLA) 8.1 ancestral haplotype (HLA-DRB1*03-DQA1*05-DQB1*02), anti-Jo-1 and anti-PM-Scl antibody-positive cases have differing IIM clinical phenotypes. A study of the HLA-DPB1 region has shown that DPB1*0101 is associated with anti-Jo-1 positivity but not with anti-PM-Scl. IIM single nucleotide polymorphism studies have demonstrated associations in the protein tyrosine phosphatase, nonreceptor type 22, tumour necrosis factor alpha and interleukin-1 genes. The GM 13 allotype has been confirmed as a risk factor in Caucasian IIM. In inclusion body myositis, the HLA 8.1 ancestral haplotype may not only influence disease susceptibility but also disease expression. A follow-up study including a meta-analysis of the apolipoprotein E gene in inclusion body myositis suggests that this gene does not confer risk of disease.

SUMMARY: Although a substantial part of the genetic risk for developing adult and juvenile IIM lies within the major histocompatibility complex, recent research suggests that genetic regions outside of the major histocompatibility complex are also potentially involved in conferring IIM disease susceptibility, although with more modest effect sizes. An ongoing and internationally coordinated IIM genome-wide association scan may provide further insights into IIM immunogenetics.

Juvenile dermatomyositis: new developments in pathogenesis, assessment and treatment.

LR Wedderburn & LG Rider.

Published in the journal Best Practice & Research (Clinical Rheumatology) in October 2009 pages 665-78.

Juvenile dermatomyositis (JDM) is a rare, potentially life-threatening systemic autoimmune disease primarily affecting muscle and skin. Recent advances in the recognition, standardised assessment and treatment of JDM have been greatly facilitated by large collaborative research networks. Through these networks, a number of immunogenetic risk factors have now been defined, as well as a number of potential pathways identified in the aetio-pathogenesis of JDM.

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Myositis-associated and myositis-specific autoantibodies are helping to sub-phenotype JDM, defined by clinical features, outcomes and immunogenetic risk factors. Partially validated tools to assess disease activity and damage have assisted in standardising outcomes. Aggressive treatment approaches, including multiple initial therapies, as well as new drugs and biological therapies for refractory disease, offer promise of improved outcomes and less corticosteroid-related toxicity.

Re-classifying myositis.

SM Sultan & DA Isenberg DA.

Published in the journal Rheumatology (Oxford) in May 2010 pages 831-3.

Sorry no Abstract available.

Inclusion body myositis: MRC Centre for Neuromuscular Diseases, IBM workshop, London, 13 June 2008.

D Hilton-Jones, A Miller, M Parton, J Holton, C Sewry, MG Hanna.

Published in the journal Neuromuscular Disorders in February 2010 pages 142-7.

Sorry no Abstract available.

CONFERENCE 2007 DVD

The Conference 2007 DVD is still available to purchase (UK only) at a reduced price of £5 (was £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. Please send your order for DVDs to the office.



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

FUNDRAISING

LONDON MARATHON 2010

“Team Muscle” this year consisted of our Gold Bond Runners, Judy Johnson, Sarah Morgan, Angela Georgiou, and David Oakley. Frank Littler secured his place through the London Marathon ballot. Unfortunately, Ann-Marie Rampley picked up an injury in training and had to drop out.



It was a fantastic day and we had our support station and bunting along our prized bit of railings on the Jamaica Road. Whether you are a runner or a spectator it is a wonderful occasion. The weather was good with only a short shower at the start of the day. Once we saw our runners through this point we packed up shop, took all the gear back to our dear friend, Sylvie, who lives just off the Jamaica road and made our way to Horse Guards Parade to see our runners home. We had a picnic with champagne reception and were joined by the runner's families and friends plus some of the committee making it a fitting end to a memorable occasion. There were a few tears of joy and some very proud people at the end of this event for it is some achievement.

It is also very much appreciated how the membership got behind the runners and raised a lot of money that is still being collected. The event is now our biggest annual fundraiser thanks to you.



Our Times

Frank Littler - 4:12, Dave Oakley - 4:27, Angela Georgiou - 4:41,
Judy Johnson - 5:37, Sarah Morgan - 6:00

Angela Georgiou writes, “It was a very early start but thankfully I had a good nights sleep and felt quite relaxed. It was my second marathon so I think knowing what to expect probably helped a little. It didn't seem that long ago that my dear friend Bridget had asked me if I was interested in running for the MSG and after speaking to Jo about the illness and the support group I didn't hesitate accepting a place. I couldn't believe that the day had finally arrived, almost 4 months of sometimes gruesome training, was now over. My real worry was how warm it was going to be. They had forecast all week for hot weather and I was really worried that I wouldn't be able to cope having trained in freezing temperatures and horrendous rain.

I met up with a friend Natoyah who I was running with and my husband gave us a lift to Charing Cross where we merged with hundreds of other runners. It's quite comforting to be with lots of people in the same boat as you! You also begin to think that each one of these people has a story and a reason to be here. Everything so far seemed very well organised.

We got to the starting enclosure and I felt nerves starting to creep in. Then as if someone up there had been listening to me the heavens opened and it poured with rain for a while, I was so relieved. We handed our bags in and there was time to queue for the toilets.

A few minutes later not very long before the start we thought we should go again but this time the queue was longer so decided to try the women's urinals!! What an invention! How could that be possible, well we soon found out!

We made our way to our pen but decided to push ahead and try and find a pace group but unfortunately they were too far ahead. The countdown started, everyone started to move towards the start. I really had to take some deep breaths to calm down. Then we were off, albeit a very slow start because of the congestion. I felt a sense of relief but then I thought about what lies ahead, a daunting task. I quickly tried to bring myself down to earth and go over my training plan and how I was going to tackle it a mile at a time.

From the start the streets were lined with spectators and staff shouting our names and encouraging words. It really sent a shiver down my spine! The crowd really get behind you and when you feel down they really lift you, but I was also lucky to run with Natoyah and we had decided to stick together and I have to say I don't think I could have done as well without her. We encouraged each other at our low points or when we were hurting, we just kept reminding ourselves we are trying to achieve this not just for us but our charities.

It did get quite warm at times so the showers along the route were very welcome. It was important to keep cool and well hydrated. I was also feeling my feet swell and rub against my shoes something I hadn't experienced in training.

The thing we both looked forward to was seeing our friends and family and it was great that we saw them first at mile 6. I was then looking forward to the MSG crowd and my friends and family at Bermondsey, it was such a lift when everyone cheered us there. I couldn't help shedding a few tears. We realised that we were a bit slower than we had planned because we did a lot weaving in and out of people. But we couldn't worry about it we just had to keep going as best we could.

There was a bit of excitement at one point where we could hear lots of cheers and screaming and we realised that we had caught up with Richard Branson and Natalie Imbruglia! Wow a brush with celebrities, time for a photo!

Heading into mile 22 my family and friends there again shouting and encouraging us, was a real welcome as I was feeling a little stiff in my quads and thinking, "oh my god am I going to make another 6 miles!" But Natoyah came to the rescue once again! The crowds along the embankment and along to the end were huge and I just kept hearing my name being called more often. Then you start seeing a few hundred yards to go, I just felt like I could fly then and almost at the end a good friend of mine spots me in the crowd and starts shouting, that's all I needed to get me to the finish. The FINISH!!! Once across that line I just felt overwhelmed with emotion! And the tears flowed again, an unbelievable feeling, elation! Natoyah and I hugged, we couldn't believe it was all over! We continued walking, had our tags removed, pictures taken and picked up our bags. Then we had another little adventure when Jonathan Edwards from the BBC doing the highlights show wanted to interview us, how exciting!

I made my way over to the meet and greet area where I met Les for the first time who then took me over to where everyone from MSG were waiting with my friends and family, again more tears. It was a real pleasure to meet Irene, Paula and David for the first time. They had a lovely picnic laid out for everyone. It was also nice to meet the other runners and briefly share our stories. My husband gave me a glass of champagne which was a real treat and very welcome! It was also a relief to remove my trainers and put on a pair of flip-flops.

All in all a fantastic experience and of course it's a great personal achievement. But it was worth all the hard work and pain for a really worthy cause that I was very, very proud to support. I was so lucky to have great friends, family and even strangers sponsor me."

Sarah Morgan writes, “Ever again? Never again!!!! That was two days after completing this years’ marathon for my very first time. But reflecting back now, would I give it another go, most definitely! From the sleepless night the night before, then the frequent trips to the loo, the last few remaining hours before the race starts, the pain in my hips, legs and numbness of feet would not stop me entering the most magical experience again.

Before the race I spoke with people who ran previous marathons and each and everyone said, “enjoy the day and absorb the atmosphere” and they were not wrong. You do not need to absorb the atmosphere, it comes up and sweeps you off your feet. The crowds were absolutely amazing, and when you have your lowest of low moments, you hear someone shout your name, you catch their eye and it lifts your spirits. The bands and musicians and people running in fancy dress help to pass the miles, you make friends for brief moments but share wonderful experiences with them that only you and they will remember. I wish I could have filmed my 26.2 mile. The Myositis support team were absolutely fantastic and given I was the last to finish; they all waited till the end to greet me, with a cup of bubbles - just lovely!!!

If you are thinking of running on behalf of the Group, please, please seriously consider it. I can honestly say it was one of the best days of my life - even though the gingerbread man beat me!”

CHARITY GOLF DAY

Dave Carr, who runs the Abbotsbury Golf Day at the East Horton Golf Club, Hampshire, kindly raised funds for Haemochromatosis Research and for our charity on Friday 4th June. Although I do not play golf I attended the day helping out firstly in the bar on the course, then the “whole in one” putting competition and later I was the “go for” retrieving the professional golfers ball from the green in the “beat the pro closes to the pin” competition. I must have walked miles on a very hot day all in the cause of “charity”. My son, David was competing in a team of four and entered to represent the Support Group so accordingly called themselves “Team Muscle”. There was a splendid evening dinner, entertainment and auction in the club house where we were joined by our wives and partners. We were able to display our banners on the course and several of the players were very interested in the charity and our work. It was a long but very enjoyable well organised and supported day. We have since received a cheque for £3,200. A lot of hard work is put in by Dave his family and friends particularly as this was their tenth year of holding this remarkable tournament.



60th & 65th BIRTHDAY CELEBRATIONS

Rod Styles and friend Steve held a joint birthday party to raise funds for their respective charities. Rod was firmly behind our cause again and raised £235 for the Myositis Support Group. Irene and I were kindly invited along to a local masonic hall in Chandlers Ford, Southampton where we enjoyed music from a first class band and one of the best, mouth watering buffets you could wish for. The evening went with a real swing and a great time was had by all. Our charity is so fortunate that we have people who are not affected in any way by Myositis get behind our cause with a sincere wish to help.

ROTARY CLUB OF SOUTHAMPTON MAGNA

Rotarian Derek Warner writes, “Your charity was nominated by Maurice Geary for consideration by our Rotary Club for a donation. Following discussion at a recent Council Meeting it was agreed to donate £300. I hope that this helps you continue your good work.”

FAIRY PARTY

Nikki and Chris Coleman with the suggestion from their young daughter, Katherine, who suffers from Juvenile Dermatomyositis, set up this charity event on Friday 13th November at the Dibden Golf Club and what a night it was! The work and detail that this family along with their friends put into this was fantastic. No one could attend unless they wore fairy wings which made the sell out crowd a most spectacular sight. There was everything from ladies dressed in dainty, elaborate costumes to men dressed in tutu, tights, and smudged make up that were in the spirit of things but not a pretty sight. As well as a brilliant



band and DJ there was face painting and fundraising head shaving where several men undertook this process. They were egged on by the crowd and no doubt with the added influence of the odd pint or three! So much money was raised that even in the light of day I expect there was no regrets. A brilliant auction was conducted by comedian, Mike Osman, who asked for no appearance fee, along with quality lots that included framed and signed football shirts of local clubs. There was a tombola and a draw with many of the prizes being donated by local businesses whose contributions really made it a success and much appreciated by Nikki and Chris. There was even food of chip butties and yes, you've guesst it, fairy cakes!

It was one of those evenings where the fun started from the very first moment to the time when sadly all good things come to an end. There were limited tickets and many more would have liked to have come to this quite original adult fun night out. When all the sums are done an incredible £5500 is expected to be made. Along with Irene, Paula and my mum, we were grateful that we were there and looking forward to next year where we will be first in the queue for tickets.

Nikki has already organised this year's Fairy Masked Ball. It is to be held at Beaulieu Motor Museum (Brabazon Suite) in the New Forest, Hampshire on Saturday 27th November. There will be a Mexican hot buffet, a band called Shift and a DJ. There will be an auction and a raffle. It starts at 7pm and ends at 12.30am. Tickets are priced at £30 each. The event has already nearly sold out! However, I have a few tickets available, so if you would like to come please get in touch with me at the office.

Nikki has continued her fundraising with a donation of £500 from Waterside Gym Club, £113.50 from Sargents Butchers (Dibden Purlieu) and £51.50 from Tescos (Dibden Purlieu).

CHEST AND LEG WAX (OUCH!)

Edward Henbury had all sorts of misery inflicted on him in the nicest possible way in connection with Nikki Coleman's Fairy Party last year. As a result of this he raised £845 plus employer, ExxonMobil donating £250 as his application for a "Volunteer Involvement Programme" award was successful. The award highlights the importance ExxonMobil places on encouraging citizenship and community activity, and to also raise the profile of volunteering as a valued activity.

ORCHARD INFANT SCHOOL – SOUTHAMPTON

The school that is located at Dibden Purlieu near Southampton made the charity one of their chosen charities for Christmas 2009. Head teacher, Julia Pillon writes, "We are pleased to enclose our cheque for £384 representing donations from parents, grandparents to retiring collections for the children's Christmas performances. Charity trustee, Nikki Coleman, whose daughter has Juvenile Dermatomyositis is a pupil at the school and the money will be directed into the work carried out into JDM at the Southampton General Hospital.

ANGLESEY WALK

Mark Farrar writes, "Why walk Anglesey? Why not? It was a once in a lifetime trip for the lads and brought with it some great experiences and stories to tell. It was also a good chance to make some money for charity whilst on the way. "Some money" turned into £1700!

The walk took place over 9 days (8 days walking) at the end of July 2010 walking the entire circumference of Anglesey starting and ending at Beaumaris. On the way, we visited many of the coastal towns of Anglesey and took part in as many activities and attractions as time permitted. For details of the stages visit <http://www.angleseywalk.co.uk/Checkpoints.html>

We chose to raise money for Myositis Support Group in memory of Jim Law – my Grandad, who suffered for many years with Inclusion Body Myositis, yet managed to keep his spirits high and enjoy his life to the end. In the later years he had to rely on a wheelchair to get around. This 128 mile walk is a fitting tribute, and the Myositis Support Group is an appropriate charity to raise funds for."

Mark and his friends have set up a website to document the time leading up to, during and after the walk, informing of the route taken, places they stayed, activities they did, as well as all of the places and people they saw on the way.

An extract from their website reads,

"It was all his fault – Mark has been visiting North Wales all of his life. His Grandparents lived the dream and bought a caravan just outside of Rhyl before he was born and the rest is history.

Unfortunately time has moved on and sadly the Grandparents and Rhyl base are no longer with us. In recent years Mark has been visiting Anglesey, staying either in Hotels or "tenting" in his fabric castle. He has loved every visit and can't get enough of the place, hence one day when fishing just off the coast of Beaumaris, he thought it would be perfect if he could see the whole island, and probably the best way to do this would be to walk it. Shortly afterwards however, this idea was forgotten about and lost to his mind, until he was chatting with guys in work and reflecting on the Island, and the idea was re-sparked, so with some enthusiastic conversations with his mates, he managed to rope some more people along into the trip and make it a reality.



Mark was in charge of research, planning, updating of the site and making sure all of the gadgets were operational and fully charged for the trip. He didn't like having to carry everything he needed with him as he is normally the guy who packs more than anyone else combined and fills a car of his own when tenting.

Jimmy has known Spud for a crazy long time now, and generally comes along on the tenting trips and fishing trips in Wales. Some of the most memorable have been in Trearddur Bay, Rhosneigr and Bala. He is generally the guy that is annoyingly full of energy and constantly needs to be doing something to keep him happy. No doubt there are going to be lots of incidents to write about involving Jimmy and I am sure we will be posting many photos of his antics.

Qualified as a personal trainer, and in the process of kicking off his own personal training business (watch this space for more info), Jimmy was the guy least likely to break much of a sweat on the trip, so his energy and drive should have been more than enough make up for the lack of both from Spud, however his blisters slowed him down to a more normal pace.

Jimmy would have preferred to do this trip on bikes which is possibly the next trip but the reason that we walked is the Anglesey Coastal Path which conveniently winds its way all around the island offering much better scenery and more of a challenge. Plus, if we did it on bikes, there was a good chance that we would have missed Current Beach and that place holds special yet terrifying memories for Jimmy.

As expected, Matt didn't need any convincing that this was a good idea and agreed to do it without hesitation. The guy will pretty much agree to any challenge or experience, and when there, will find a way to make it a memorable trip. He was the guy most likely to get lost, join a cult, find oil or get abducted so made the trip a good laugh.

Matt spends most of his time building theatre sets in various places round the country but of late has been training to be an arborist (tree surgeon). Any excuse to play with a power tool and if it's up a tree more the better!

Matt and Spud have known each other since they were sixteen. Since then they have been on many crazy holidays and trips where Matt always seems to raise the competitive bar.

Please contact us on angleseywalk@yahoo.co.uk if you wish to sponsor us, provide any donations or just offer congratulations."



You can read more and details, including their Training and Blogs at <http://www.angleseywalk.co.uk>

BRIGHTON MARATHON



My nephew, Nick, took part in the first Brighton marathon and it was also his first ever marathon. He raised over £800 for the Group. It was a very hot day and we spent a lovely time on the beach with Nick's mum and dad having a drink of Pimms whilst waiting for him to pass us after he had slogged and sweated his way around the course having injured his knee during the process! His wife, Michaela along with his friends were also at the finish and were so proud of him. Nick would be the first to admit he is not the right shape for a marathon runner



but he can rightly add this latest trial of endeavour to his other sporting achievements.

Lena and Russ also took part in the Brighton Marathon on behalf of the Group and raised a whopping £1,353.

BERKHAMSTED FUN RUN AND HALF MARATHON

Tracey Pryce writes, "These donations were raised through a (somewhat impromptu) run I did at Berkhamsted! I completed the five-mile fun run in under 2 hours. I'm pleased to say, although my knees suffered a little, my husband, David, completed the half marathon in a very good time of 1.35hours. I hope to be running the same half marathon next year, but I know that David is very keen to run the London Marathon for your cause. We would have no problem in raising the required sponsorship and so would take one of your places if possible."



Tracey and David raised £515 for the Group and ran in memory of Tracey's mum.

STORNOWAY HALF MARATHON - EXXONMOBIL

On Saturday 29th May, Allan and Lorraine Morrison, completed the Stornoway Half Marathon and raised £3567 including £250 from The Exxonmobil Charity Fund of the Brent Delta offshore production platform. Lorraine completed the run in 2 hours 2 mins and Allan completed in 1 hour 51 mins.



Allan writes, "The course was not our average run and the weather conditions were not ideal, but all excuses aside, we did complete it which is a goal in itself. We are in the process of collecting in all the sponsorship and we are very pleasantly pleased with peoples' generosity.

We will endeavour to get all these funds to the Support Group as soon as possible. We would like to thank everyone who donated towards this cause."



Lorraine & Allan Morrison are shown presenting Douglas Morrison (IBM sufferer) a cheque for the "Myositis Support Group."

ROTARY SHAKESPEARE HALF MARATHON



Esther Paul writes, "Following the half marathon I ran on 25th April please find enclosed cheques for £285 representing the amount I have raised for the MSG offline. Online I have raised £515 making an overall total raised of £800. I managed to complete the half marathon in 2 hours 38 mins and thoroughly enjoyed taking part."

Esther has since sent another cheque for £100 making the total raised to £900.

THREE PEAKS CHALLENGE

Paula Oakley writes, "My friends, Dave, Amanda, Sarah, Matt and Rob decided to attempt the 24 hour Three Peaks Challenge on the longest day in June and thought it would be a nice idea to raise a little sponsorship for the Support Group too. The Three Peaks Challenge involves climbing three highest peaks in the UK in 24 hours including the driving. Broken down this equates to climbing nearly 3,000 metres, 22 miles walking and 480 miles driving. Philippa and Ant were the designated drivers who drove them to Ben Nevis (Scotland), then Scarfel Pike (England) and then finally Snowdon (Wales). All made it up (and down) Ben Nevis successfully but there were a few falls on the rugged terrain which meant casualties when it came to Scarfel Pike. After getting three quarters of the way up, Dave and Matt decided the safest option was to turn back. However, Amanda, Sarah and Rob soldiered on and were able to complete Snowdon too. They raised £185 and I know they are all wanting to give it another go next year! I think they are all mad but I may join them for Snowdon but I will be taking the train up the mountain!"



A SIXTIES FUNDRAISING EVENING

John and Janet Arblaster along with family friends and supporters held this event. John has had Inclusion Body Myositis for some years now. However, now that he is retired he can do what he wants to do at his own pace and limits.

John writes, "My friends and I (aka) Mid Life Crisis recently held a 60's fundraising evening for The Myositis Support Group at Woolley Village Hall in West Yorkshire in November. The band which consists of members who have played in various groups from the early sixties to the present date, now play for charity, friends and family events in the Yorkshire and surrounding regions with popular favourites from the 50's 60's and 70's. We are pleased to inform you that we raised £643.50 at the event. A good time was had by all dancing the night away with a break for mandatory Yorkshire refreshments of Pie and Peas which provided enough energy for the evening's demands."

60th BIRTHDAYS

DR RUSSELL LANE

Further to Russell's 60th Birthday bash last year his wife Dianne writes, "Dr Dunckley and Dr Vaughan both attended his party but they forgot to make their donation at the time. However, I'm sure it will still be a welcome addition to your funds!" £60 was enclosed".



DAVE BARNETT

Jackie writes, "Please find enclosed cheques to the value of £405 for the MSG funds. This was the total received in lieu of presents for my husband Dave's 60th birthday party. We are delighted to report that my son, Andrew, remains fit and strong. He came off treatment in 1993 and, except for a couple of operations to remove calcium from his fingers, he has not looked back. He has qualified as an electrician and travels all over the country working for his Dad. Hoping you are all keeping well and that Paula is doing well too."

EMBROIDERY

Frances Rankin writes, "I was recently commissioned to embroider some "Paisley" motifs on a chashmere shawl and in lieu of payment ask for a donation to the Support Group. Please find enclosed £60."



LIEU OF CHRISTMAS PRESENT

Victoria Roberts, writes, "Please accept the enclosed cheque which was very generously given to me as a Christmas present by my brother and sister-in-law's parents, Chris and Patricia Sumner."

LIEU OF CHRISTMAS CARDS

Michael Belas writes, "I decided not to buy Christmas cards this year and emailed all my friends and family that the savings made would be donated to a local charity. I hope you can accept this cheque for £50 to the Myositis Support Group which is a much worthy cause than the stationary business and the Post Office."

LIEU OF PRESENTS

Margaret Henderson writes, "My friend and I have chosen to make donations to each others chosen charities instead of birthday and Christmas gifts. I therefore enclose a cheque for £10 on behalf of my friend whose late husband was a myositis sufferer."

NEW FOREST IRON MAN



Aidan Joyce completed the New Forest Ironman Challenge on 27th June and has raised over £1,086 to date. Aidan's father is a Polymyositis sufferer. This is a fantastic effort to help the Support Group.

GREENHOUSE PRODUCE



Stan Grevett writes, "Hello again to all you Lovely People. My greenhouse was not as productive this year but made £120. Les told me he does not have time for gardening. I'm not surprised with all the Support Group work you are all involved in."

GLIDER FLIGHT

Su Wilson writes, "Here's a write up on my Sponsored Glider Flight that I did on Monday 26th April at Lasham, Hampshire. It was nearly cancelled due to predicted showers, so happy it cleared up and went up an hour later than scheduled at 1pm.



Yes, all I can say is that it was an AMAZING and Fantastic experience and would recommend anyone to give it a go! It was so quiet up there, like being a bird. I was pulled up by an aeroplane and got up to 2 to 3,000 feet before being released by the plane and I stayed up for 30 minutes in glorious sunshine.

I went up with instructor, Annie Layley, pictured with me and the glider. Thank you to my dear friend, Dave Hutley, for taking great photos and lifting me into the glider. I must thank everyone for their generous sponsorship, especially to my friends and my husband, Bob and 16 month old son Max who came to watch me on the day and for their friendship and support! Also my parents who travelled all the way from Wales especially to see me go up! My total raised is £2,011, which is fantastic!"



SOUTHAMPTON FOOTBALL CLUB – THE EXECUTIVE CLUB

Southampton fan, member of the executive club and friend for many years, Roger Parsons put our name forward for a donation from the club. The members agreed to help the Group and Irene and I attended the last evening game of last season along with Roger's wife, Lindy where we were kindly wined and dined before the match and we were presented with a cheque for £1000. After the game the lads on my table gave me their raffle tickets for a signed football. My luck was in and one of the tickets won. I was presented with the ball by Southampton goal keeper, Kelvin Davis. I felt like a kid again and was chuffed to bits! I was custodian of the ball for a few weeks and it has now made its way to Nikki Coleman for her Fairy Ball in November where it will be auctioned.



SUZANNE HATT

Suzanne has once again sent donations from her Tarot Readings for £55.

BRITISH DENTAL ASSOCIATION

Nikki West writes, "Please find enclosed a cheque for £54.03 which the staff of the British Dental Association raised for the Myositis Support Group at our recent Festive Coffee Morning."



THE WORSHIPFUL COMPANY OF FUELLERS



The Immediate Past Master, Michael Husband writes, "I am delighted to enclose our cheque for £500 as a donation towards the excellent work of the Myositis Support Group. It is tremendous to see what you have all achieved in the past twenty years plus. I remember well our early discussions about how you might get something done about the illness your daughter Paula was suffering from. Your achievements have been quite staggering as I see from your newsletters."

I am also delighted to see your award of an MBE. I have thought for many years you were most worthy. I know you would wish all your team to have the same but someone has to be the captain of the ship and you have steered it very well."

When Mike was living in Southampton back in June 1990, along with the local members of the Round Table they raised £5,000 for the charity which was a staggering amount of money for the time. Dr Jo Cambridge travelled from London to talk at a lunch time meeting about her work and her involvement with the charity. She then caught the 3pm train back to London to continue her work in her laboratory. The Round Table were keen to follow our progress in the coming years and although like me, Mike is too old for membership of the Table, he has kept us in his thoughts and all these years on has helped again.

THE ROYAL SOCIETY OF ST. GEORGE – TRIPOLI BRANCH

Secretary, Malcolm Watson writes, "The committee and membership are pleased to enclose a donation for £2,500."

The society is aware of the work of the charity and the problems of Myositis. They were pleased to be able to give this help.

THE FOSTER WOOD FOUNDATION

Trustee of the Foundation, Margaret Lodge, kindly sent a donation of £7,500 to be used in the research of Inclusion Body Myositis. The charity is very grateful for this generous help.

FAIR OAK MASONIC LODGE – HAMPSHIRE

In February the Lodge raised £143 for the charity at one of their meetings. The president of the Lodge, Richard Lloyd, and the members have given us so much help over the years. Freemasonry has been very supportive of the charity and our aims. There is no doubt that this ongoing financial help has been a major contribution into the research of the diseases.

CAERDYDD MASONIC LODGE – CARDIFF

Philip McCarthy writes, “We are most pleased that Caerdydd Lodge have donated £75 to the Myositis Support Group as a result of a draw. Our son, Jack has suffered from Juvenile Dermatomyositis for the last three years. Over this time Jack has suffered many low points but thankfully at the moment he is doing well and his JDM is well controlled through medication. Although he is still not as active as he was previously to JDM and still has problems with stamina, it is lovely to see him able to participate with friends in school life, something he could not do when first diagnosed. Thank you for the excellent work the Myositis Support Group does for its members.”

EASTLEIGH MASONIC LODGE - HAMPSHIRE



Irene and myself were invited to Eastleigh Lodge Ladies Festival by a very dear friend, Ray Winkworth and I was presented with a cheque for £1,000 for the Group. We are extremely grateful to Ray, his wife Lesley and the members of Eastleigh Lodge for once again supporting the charity. We had a very enjoyable evening along with many friends.

COFFEE MORNING

Jacquie Durkin writes, “I enclose a cheque for £50 raised at a coffee morning. Thank you Les and the team for the work you give and the support received.”



VIE PARTY

Paula Oakley writes, “Earlier in the year I went to a Vie Party (formally Virgin Vie) and thought this would be a fabulous way to help the Support Group especially in the current economic climate where charities are experiencing donor fatigue. Vie has some fantastic cosmetics, aromatherapy and home ware items and all are very tempting. So, I held my own Vie Party a few weeks ago in aid of the Support Group. When you hold a party you earn commission to spend on Vie items and I thought these would be ideal to donate to the Support Group for their future raffles. I invited all my friends and neighbours (and my mum’s and sister’s friends too), we had a wonderful evening sampling all the “lotions and potions” and with their help £65 was raised for me to spend on Vie items. The Vie consultant, Heather, ran my party and she was very helpful at advising me on how to convert the commission into the most gifts that would make wonderful prizes. I also held a small raffle on the night which raised £41, my thanks to my mum Irene, friends Amanda and Jenny who donated prizes and also Heather who donated Vie Pamper vouchers and items too. I raised over £100 to spend and used with the Vie offers purchased over £200 worth of Vie products for the Support Group. I really recommend this as an alternative way of fundraising to benefit the Support Group as not only was it an enjoyable event it was also a lovely opportunity to catch up with my girlfriends.”

GOLDEN WEDDING ANNIVERSARIES

BERYL & RAYMOND ROWE

Beryl Rowe writes, "My husband, Raymond and I recently celebrated our 50th Wedding Anniversary and our family and friends insisted that we had a "do" organised by them. It was a tremendous success with over 150 guests, friends, relatives and neighbours attending. We stated that we only required "presences" and not presents but people could make donations to the Myositis Support Group if desired.



As a result we collected £1085 which we have gift aided. Keep up the good work."

MR & MRS MATTOCK

David Mattock writes, "Please find enclosed cheques to the value of £1290 which was collected at our Golden Wedding Party on June 13th 2010. We asked for donations instead of presents. Included in this amount is £35 donated by my wife who has been knitting scarves for friends."

MILDRED & EDDY NAYLOR

Mildred Naylor writes, "In celebration of our Golden Wedding monies were raised for charity. Enclosed please find £100 towards the splendid work you do for sufferers."

RUBY WEDDING ANNIVERSARY

Sue Edwards writes, "Please find enclosed cheques totalling £215 which friends sent us in recognition of our Ruby Wedding Anniversary. The donations we received were divided between the MSG and another worthy cause. I was diagnosed with Dermatomyositis ten years ago. May you continue to receive the support that enables you to fund research into Myositis."



WEAVER VALE HOUSING TRUST – NORTHWICH

Frances Sant writes, "Staff at the Trust nominated your charity as their chosen monthly, "giving something back" dress down day which was held on Friday 4th May. This was in response to a request from a member of staff who has a close relative with Myositis and is aware of your good work and support. Therefore, on behalf of the staff, please accept this donation of £117."



CHARITY BOOK STALL

The bookstall out side of my place of work has raised over £39,000 to date. I am particularly grateful to members, Diane and Brian Hird who have supplied books during this time via Tony and Sue Hindle who deliver them when visiting Southampton.



MONEY BOXES

Thanks to all the members who have filled up our charity money boxes and have either sent the contents into the office or paid them directly into the charity bank account. We know the card board boxes are a bit flimsy if handled a lot but if required we can give you a more robust plastic box. Just write into the office. These can also be used at fund raising functions along with large charity collecting buckets if you have a need for them.

IN MEMORY OF LOVED ONES

At times of much sorrow the charity is very grateful to families who have collected and donated to the Group in memory of Loved Ones. We also offer our gratitude to members who set up Just Giving pages to raise money in memory and to people who have bequeathed gifts in their wills to help the charity.

FUTURE FUNDRAISING

10 MILE WALK

Neil, Lauren and Leah Loomes write, "In celebration of Helen's life and her work as a wonderful nurse, on Sunday 29th August, along with family and friends we will be walking 10 miles from Macclesfield General Hospital to Stepping Hill Hospital, along the Middlewood Way.

We hope to raise funds to support her charity, the Myositis Support Group and thank you for all your help."

They have set up a Just Giving page and have raised £1145 to date.

THE BRITISH GAS GREAT NORTH SWIM THE EXTRA MILE

Stuart McSorley writes, "Before this year I had never swum anywhere other than in swimming pool, never swum in a wet suit and had never tried to get in the water at the same time as about 100 other people ! But after neither sinking nor drowning during my inaugural Open Water Swim in July at the Royal Victoria Dock in London (as part of the British Gas Great Swim series), I have been bitten by the bug and come October will have taken part in a total of 4 open water swims.



One event especially is really going to test my abilities. The British Gas Great North Swim the Extra Mile, held on the 5th of September at Windermere in the Lake District, will see me having to swim not just 1 but 2 miles! Needless to say I'm excited and terrified in equal measures.

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

I would really appreciate it if you could show your support for both Helen and myself, and donate whatever you can."

Stuart has set up a Just Giving page for donations and to date has raised £300.

THREE PEAKS CHALLENGE

Claire Marshall writes, "On Friday 13th August 2010, 13 of us (lucky for some) will attempt to complete the National 3 peaks challenge in 24 hours. This will involve a trip of 475 miles in total and 26 miles of hiking up and down (at times in pitch black) Britain's highest peaks – Ben Nevis, 1,344 metres (4,409 ft), Scafell Pike, 978 metres (3,209 ft) and Snowdon, 1,085 metres (3,560 ft).



As part of this intrepid team, I would like to raise some money for the Myositis Support Group. A close childhood friend was diagnosed with Dermatomyositis in 2004, she has always maintained a positive outlook, despite some tough and uncertain times over the last few years. I hope if I can raise some money, this contribution, however small, will go some way to helping the charity.

Claire has set up a Just Giving page for donations and to date has raised £655.

SKY DIVE

Cate Lambert writes on Just Giving, "I have a "things to do before I die" list and number 1 is, "jump out of a plane!" Let's hope it's not the last one I get to cross off - yikes! So, I thought I would do a charity skydive to coincide with my 40th birthday in the Summer.

I have chosen to raise money for the Myositis Support Group. I am now privileged to know two amazingly brave and inspirational young ladies who live with the condition Juvenile Dermatomyositis.

The Myositis Support Group does a fantastic job in providing information and support to sufferers and their families and also raises awareness and much needed funds for research.

Jumping out of a plane is the easy part compared with asking people for sponsor money!" Cate has set up a Just Giving page and has raised £500 to date.

ADIDAS WOMEN'S CHALLENGE 2010

Helen Bligh writes, "I'll be running (and maybe walking, just a bit) to raise funds for research into JDM, a rare skin and muscle disease. My friend's four-year-old daughter Charlotte is a sufferer, and has undergone countless hospital trips, procedures and more needle sticks than anyone should have to endure. Despite this, she remains one of the most cheerful and polite little girls I have ever met (and of course, one of the bravest too). It would be amazing to even raise a little bit of cash for this deserving cause - it doesn't have to be much, every single penny will help."



Helen has set up a Just Giving page for sponsors/donations and to date has raised £250.

BUPA GREAT NORTH RUN 2010

Richard Heaton writes, "Hi all, I'm running The Great North Run on the 19th September in aid of the Myositis Support Group. My friend at work, Terry Suttcliffe's wife Catherine, has this very rare disease. The disease can be very disabling and can cause much distress and pain."



All forms Myositis involve chronic, or persistent, muscle inflammation. This muscle inflammation almost always results in weakness of muscles, falling down frequently, swelling of feet and legs, loss of strength and pain in the muscles and joints, some become exceedingly fatigued. With monthly hospital appointments and daily medication and weekly injections it helps keep Catherine's disease under control."

Richard has set up a Just Giving page for sponsors/donations and to date has raised £85.

BERLIN MARATHON

Nick Bishop writes, "As some of you know, I have committed to running the Berlin Marathon in September this year. I'm not a complete novice when it comes to running but this is my first marathon and I can't pretend not to be just a little bit apprehensive. I am, however, as some of you know, training relentlessly."



Running the marathon is partly about achieving an ambition but it's also about raising funds for a good cause. Everything I raise will be given to the Myositis Support Group, which helps sufferers of myositis, a very rare autoimmune disease. The reason why I am raising funds for this charity is because my wife has the misfortune to be a Myositis sufferer. If you're interested in knowing more about what life is like with myositis then please have a read of the short description on the Just Giving page I've set up.

Finally, if you'd like to help me reach my target of raising a £1000, I'd be mighty grateful for your help. Here's the Just Giving link <http://www.justgiving.com/allaboutViolet>. Many thanks."

WEBSHOP

Our webshop is fairly inactive at the moment, which is a shame, as it is a very simple way to help the Support Group raise funds without any cost to yourself. If you shop online, especially in the forthcoming months for your Christmas shopping please visit our webshop to see if the shop you wish to purchase from is listed. Many of the well known high street stores (Marks & Spencer, ASDA, B&Q, Game, Habitat, HMV, Littlewoods, Superdrug, Thorntons, and Waterstones) are as well as popular online stores like Amazon, Play, Very, Snapfish and Expedia. You will pay no extra for your purchases if you go via our webshop and the Support Group will earn a commission. So, for an extra click on the mouse you can help us raise funds!



Visit <http://www.buy.at/myositis>

MEMBERS NEWS

GRADUATION – KIRSTY JOHNSTONE

Morag Johnstone writes, “Just a short note to let you know Kirsty gained her degree in Nutrition and Dietetics from Robert Gordon University, Aberdeen. Although unable to find a job in this field she is now working in the oil industry in Aberdeen. We are all very proud of her as she has had some ups and downs on the way.”



AUDREY CUMMINS – IN MEMORY

Joy Solomons writes, “When I was first diagnosed, like all of us we are bewildered to find ourselves in a position of actually very few people knowing or understanding our condition. I had looked up the buddies list and emailed Audrey as my very first contact. I then spoke to her and in her wonderful way she explained so much. I will always value this as it helped me so much.

As for Audrey she was always so positive about keeping active. She used to walk around the home and up and down stairs (even when this was very difficult). She had (I think) taken part in the Creatine tests and was very conscientious about taking it. Even if it had to be put in her intravenous feed.

I met her only once at a Southampton mini convention. Her daughter brought her. This was my first convention and my first time of meeting other people and hearing medical people talking about Myositis. She in her fashion insisted in sitting with me whilst we had our lunch. She of course was not eating. I remember saying to her “doesn’t this bother you?”

We talked on many occasion after that and she was always on the IBM site. Then her husband got cancer and very sadly died. Also her daughter had a recurrence of cancer. These were her main concerns from now on.

After her husband died she decided to go on a cruise, obviously taking a carer. Having had an operation just before going, this went horribly wrong whilst away. (Anyone wishing to look back at the IBM pages will see the saga that happened). I think it was mid 2008 on the site. But still she did not allow this to spoil the cruise.

Sadly it was the swallowing that helped to cause the pneumonia but I am sure she went out fighting.

Audrey was only a small lady but I am sure a lot more of us will remember her lions roar on an issue on the web pages that needed attention or action.

God Bless you always Audrey. We all will think of you and thank you.”

Audrey Cummins was a very active member particularly on the Support Group website Community pages, offering support to many. She sadly passed away earlier in the year and the Myositis Support Group sent condolences to her family.

MEETING UP – SUFFOLK



Members Joy, Esme, Lesley, Jill and Dave along with Joy’s husband Mervyn and Jill’s husband Tony met up for lunch at the beginning of December. They plan to do so again soon so please get in touch with Joy via the Community pages on our website if you wish to join them



YOUR STORIES

We would love to hear more of your “Good News” stories for future newsletters. Have you just got married, celebrated the birth of a baby, has your child returned to school full time, have you passed your driving test, graduated, gone back to work, off all medication and discharged from hospital. We would love to hear from you. Please send your story to the office or email les@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.

BENEFIT REFORMS

The new government will be making changes to the Disability Living Allowance benefit. The marked change will be a medical test which will apply to all new and existing claims from 2013. It is hoped to be a simpler process than the present complex forms but at present it is very difficult to find the proposed details of what is envisioned for the new assessment process and the revision of the eligibility criteria. A Google search on the internet reveals many responses from Charities to the reforms made by Chancellor George Osbourne in the Budget. It may be that a system other than box ticking will be of benefit to persons needing DLA help with myositis, especially as the Disability Handbook of Background Information for decision makers on the Department of Work and Pensions website does not even have Inclusion Body Myositis listed. Extraordinary, considering IBM is now viewed as the most common muscle disease in persons over the age of 50 years. Dermatomyositis and Polymyositis are listed.



Until 2013 new and renewal applications will follow the current form filling process which says "You will not usually need a medical examination when you claim for DLA" outlined on the Direct Gov website www.direct.gov. However, thereafter all new and every DLA recipient will be assessed within 3 years of the programme starting.

If you would like a say on shaping the "21st Century Welfare" you can become involved in the consultation online which ends on 1st October 2010 at www.dwp.gov

Further interesting pages for reference on the subject www.bbc.co.uk/ouch and

<http://www.disabilitynow.org.uk/latest-news2/medical-test-for-dla>

Furthermore, there are also many interesting articles on the Disability Now website relating to the Fit to Work rather than a traditional Sick Note which came into place this April, an article on a report from the Citizens Advice Bureau on problems with the new Work Capability Assessment which determines people's eligibility for Employments Support Allowance (previously Incapacity Benefit), and Fuel Poverty. <http://www.disabilitynow.org.uk/latest-news2/campaigns>

OFF TO UNIVERSITY?

If you are off to university you may be eligible for a Disabled Students Allowance. These grants help disabled students study on an equal basis with other students by covering extra course costs you may incur because of your disability. For example paying for specialist computer equipment, helpers or extra travel costs. Disabled Students' Allowances are paid on top of standard student finance, are independent of household income, do not have to be repaid and can be applied for by full-time, part-time and postgraduate students. For more information visit



http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/HigherEducation/DG_10034898 and download the booklet "Bridging the Gap" – Guide to Disabled Students' Allowances in Higher Education or contact your local education authority.

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.

POST SCRIPT

I wish to thank members, family and friends for the many private donations to help in our work and to families of loved ones who have made donations in their memory. It has been a pleasure to compile this newsletter detailing all the activities of members and supporters in their help for the charity.

Finally, thank you for supporting the Grand Summer Draw this year and enclosed with this newsletter is a list of prize winners. Over a £1,000 has been raised.

Les Oakley, MBE - Chairman



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