



# MYOSITIS

## Support Group

Newsletter 63 November 2007

Dear Member,

Following on from the items published in the charity "August Flyer" the Summer Charity Draw has been held and a list of the prize winners is published at the end of this newsletter. My grateful thanks are offered to all the members and supporters who bought or sold tickets for the draw. Trustee, Catherine Risley's partner, Andy, drew the tickets not realising that any gripes for not shaking them up etc., is now fully directed at him! The art of delegation is a wonderful thing.



## AGM & CONFERENCE 2007

The Annual General Meeting that preceded the Conference returned the trustees on bloc. The minutes of the previous meeting were adopted and the accounts approved. The trustees/committee members are; Chairman – Les Oakley, General Secretary – Paula Oakley, Hon. Treasurer – Jo Goode, Trustees – Tony Hindle, Sue Hindle, and Catherine Risley. My grateful thanks to Auditor, Bridget Kalloushi for donating her services.

The feed back from members who attended the conference has been much appreciated and even where there were points of issue the general feeling that the venue was the best the charity has used and the quality of the medical contributions was excellent. As you know all the talks at the conference were recorded and are now available on DVD price £10 including postage in the U.K. There is no other definitive record of Myositis presented in this format and if you ever wondered what was going on in the medical world of Myositis 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.

My appreciation is given to all the speakers and their supporting colleagues for attending and making it an outstanding conference. I must also add it was a pleasure to have Dr Chester Oddis fly over from the United States for his much valued contribution to the day. Of course an anchor man is always needed to make events flow and Professor David Scott has proved again that this unenviable task he copes with consummate ease. Don't just take my word for it for it is all on the DVD.



"Speakers at the Conference"



"Trustees with Chet and Irene (centre)"

However, you cannot have a conference without people. It is you that created the atmosphere and it was great to see so many of you there. The inquiring quality of the questions from the audience opened up much debate and at times was very thought provoking. We had delegates from as far away as Hong Kong and slightly closer but still requiring an effort to attend and give support from Northern Ireland. My only regret is that I did not have time to personally speak or meet with many of you. I suppose this is the price one has to pay for a well supported meeting. Irene and Paula have worked many long hours visiting venues and bringing the many facets of conferencing together to make the day flow. With no formal training it is amazing that Irene in particular has over the years developed these skills and also the ability to negotiate a good deal!



## NEW WEBSITE



Have you visited the new Web Site yet? After a few teething troubles it appears to be up and running. I hate change so I was the best pupil to test the new site on. I was so used to knowing my way round that I am the first to admit I was a bit resentful of the “progress”. However, after knuckling down using the site I can see the benefits and the greater scope plus security the new site now holds. It’s a bit like trading in a much loved but used car. The new one takes a bit of getting used to before the real benefits start to appear. I am very much a Luddite when it comes to computer technology or any other progress if it comes to that matter, so if your like me, stick at it and you will soon appreciate our new technological friend.

## CHRISTMAS CARDS

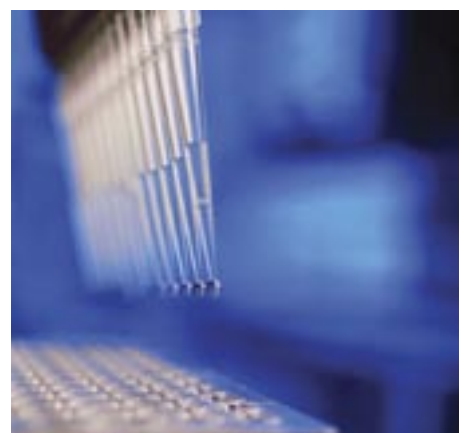
I know we have sent out Christmas card order forms with the August Flyer but another one is enclosed with this newsletter. As well as your own order if you feel you can sell a few more packets of cards to friends or work colleagues please let us know. The income from the cards is a vital contribution 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!

## RESEARCH

### THE LETITIA RAWSON FELLOWSHIP

The family of the late and much loved Letitia have funded in her memory the Letitia Rawson Fellowship. The Fellowship is funding a research doctor for six months at the Royal National Hospital for Rheumatic Disease in Bath. Her mother, Mrs Rawson writes, “This is very good use for the money and a tribute to Letitia and we hope will advance the understanding of this horrid illness.”

The fellowship is being held by Dr Zoe Betteridge at the University of Bath. Her work to date has been funded by the Raynaud’s and Scleroderma Association. Zoe attended our conference with her colleague Dr Harsha Gunawardena who presented some of their work in Myositis. The following are two of their abstracts published in medical journals this year.



## Identification of a novel autoantibody directed against small ubiquitin-like modifier activating enzyme in dermatomyositis.

Z Betteridge, H Gunawardena, J North, J Slinn, N McHugh.

*Published in the journal Arthritis & Rheumatism in September 2007 pages 3132-7.*

**OBJECTIVE:** Myositis-specific autoantibodies (MSAs) are directed against cell machinery proteins such as aminoacyl-transfer RNA synthetases, signal recognition particle, Mi-2, and CADM-140. Because serologic subsets can define patients with specific clinical manifestations, the identification of further MSAs may help to identify additional disease subsets within the myositis spectrum.

**METHODS:** Sera from 20 adult patients with dermatomyositis (DM) were screened for autoantibodies. Two patients were further characterized due to the presence of the same novel immunoprecipitation (IP) pattern on sodium dodecyl sulfate-polyacrylamide gel electrophoresis (SDS-PAGE) and similar clinical manifestations. Both patients presented with cutaneous disease, followed by proximal myositis 6 months later. Both patients had associated nonspecific interstitial pneumonia but no signs of malignancy. The novel targets were identified using a combination of IP, SDS-PAGE, and matrix-assisted laser desorption ionization-time-of-flight mass spectrometry.

**RESULTS:** Indirect HEp-2 immunofluorescence on sera from both patients displayed a diffuse, coarse, speckled, nucleolar-sparing pattern. IP revealed the presence of previously uncharacterized bands at approximately 40 kd and approximately 90 kd in both patients. The novel targets were identified as the small ubiquitin-like modifier 1 (SUMO-1) activating enzyme A subunit and SUMO-1 activating enzyme B subunit.

**CONCLUSION:** These findings reveal previously uncharacterized autoantibodies directed against a protein involved in posttranslational modification, the SUMO activating enzyme, in 2 patients with DM who had similar clinical features, including severe skin disease and interstitial pneumonia.

## Anti-synthetase syndrome: a new autoantibody to phenylalanyl transfer RNA synthetase (anti-Zo) associated with polymyositis and interstitial pneumonia.

Z Betteridge, H Gunawardena, J North, J Slinn, N McHugh.

*Published in the journal Rheumatology (Oxford) in June 2007 pages 1005-8.*

**OBJECTIVE:** Autoantibodies directed against the aminoacyl tRNA synthetases are associated with myositis, arthritis, Raynaud's phenomenon, mechanic's hands, fever and interstitial pneumonia, clinically referred to as the anti-synthetase syndrome (ASS). The aim of this study was to characterize the autoantibody profile in a patient with clinical features of ASS whose routine diagnostic testing was negative for the previously identified anti-synthetase autoantibodies.

**METHODS:** Serum from a patient presenting with interstitial pneumonia followed by proximal myopathy, Raynaud's phenomenon and arthralgia was analysed for autoantigen specificity by routine methods including indirect immunofluorescence, immunodiffusion, ELISA and immunoblotting. The autoantibody specificity was further analysed by RNA and protein immunoprecipitation. Novel autoantigens found on protein immunoprecipitation were further characterized using a proteomic approach, combining immunoprecipitation, SDS-PAGE and MALDI-TOF mass spectrometry.

**RESULTS:** Diagnostic testing on the patient's serum was negative by ELISA and immunodiffusion. Indirect immunofluorescence using Hep-2 cells was ANA negative, although a strong cytoplasmic speckle was seen. Immunoblotting with the patient serum displayed an unknown positive band at approximately 60 kDa. Protein immunoprecipitation revealed the presence of two proteins with molecular weights of approximately 60 and 70 kDa, and RNA immunoprecipitation revealed the presence of a band corresponding to a tRNA synthetase. Using a combination of immunoprecipitation and mass spectrometry, the novel immunoprecipitation targets were identified as phenylalanyl tRNA synthetase alpha and beta chains.

**CONCLUSIONS:** We report the identification of previously uncharacterized autoantibodies to phenylalanyl tRNA synthetase, entitled anti-Zo. This is the eighth anti-synthetase autoantibody in a patient with anti-synthetase syndrome.

## CREATINE TRIAL

The creatine supplementation treatment trial performed by Professor Scott's team at King's College and funded by the Support Group has been published in the medical journal Arthritis and Rheumatism. This study in over 35 people with Dermatomyositis or Polymyositis investigated the effect of creatine plus exercise versus exercise alone and they concluded that oral creatine supplements combined with home exercises improved the functional performance without significant adverse effects and are effective and inexpensive. We have printed the abstract below but for copyright restrictions cannot reprint these scientific findings in full here. For a copy of the paper please send a SAE to the office stating your request.



University of London

### **Creatine supplements in patients with idiopathic inflammatory myopathies who are clinically weak after conventional pharmacologic treatment: Six-month, double-blind, randomized, placebo-controlled trial.**

YL Chung, H Alexanderson, N Pipitone, C Morrison, M Dastmalchi, C Ståhl-Hallengren, S Richards, EL Thomas, G Hamilton, JD Bell, IE Lundberg, DL Scott.

*Published in the journal Arthritis & Rheumatism in May 2007 pages 694-702.*

**OBJECTIVE:** To test the hypothesis that oral creatine supplements with exercise are more effective than exercise alone in improving muscle function in patients with established dermatomyositis or polymyositis receiving chronic medical therapies who are clinically weak yet stable.

**METHODS:** In a 6-month, 2-center, double-blind, randomized controlled trial, patients were randomized to receive oral creatine supplements (8 days, 20 gm/day then 3 gm/day) or placebo. All patients followed a home exercise program. The primary outcome was aggregate functional performance time (AFPT), reflecting the ability to undertake high-intensity exercise. Secondary outcomes included a functional index measuring endurance and muscle bioenergetics on <sup>31</sup>P magnetic resonance spectroscopy (<sup>31</sup>P MRS). Patients were receiving stable immunosuppressive treatment and/or corticosteroids.

**RESULTS:** A total of 37 patients with polymyositis or dermatomyositis were randomized (19 to creatine, 18 to placebo); 29 completed 6 months. Intent-to-treat analyses demonstrated that AFPT improved significantly at 6 months with creatine (median decrease 13%, range -32-8%) compared with placebo (median decrease 3%, range -13-16%; P = 0.029 by Mann-Whitney U test). A completer analysis also showed significant benefits from creatine (P = 0.014). The functional index improved significantly with both creatine and placebo (P < 0.05 by paired Wilcoxon's rank sum test), with a significant benefit between groups in the completer analysis only. Phosphocreatine/beta-nucleoside triphosphate ratios using MRS increased significantly in the creatine group (P < 0.05) but not in the control group. No clinically relevant adverse events were associated with creatine.

**CONCLUSION:** Oral creatine supplements combined with home exercises improve functional performance without significant adverse effects in patients with polymyositis or dermatomyositis. They appear safe, effective, and inexpensive.

## IMACS Website



The International Myositis Assessment and Clinical Studies Group (IMACS) who have worked to develop the MITAX and MYODAM indices have acknowledge the financial support given by the Support Group on their website. The Myositis Support Group are now listed on the Sponsors

Page at <http://www.niehs.nih.gov/research/resources/collab/imacs/sponsors.cfm>

We felt it was important that the Myositis Support Group was recognised as it is our members donations and fundraising that assisted fruition of the MITAX and MYODAM indices. I would also like to thank Professor David Isenberg and Dr Lisa Rider who helped to have our "absence" from the Sponsors page (which is funded by the National Institute of Health USA) quickly resolved.

## JDM BIOPSY GROUP

Dr Lucy Wedderburn (Institute of Child Health) has published the conclusions from the JDM Biopsy Consensus Meetings (financially supported by the Myositis Support Group) in the medical journal *Arthritis and Rheumatism*. These meetings were attended by international histopathology experts (International Consensus Group on JDM Biopsy) who worked to generate a scoring system to ascertain which pathological changes on muscle biopsy correlate with disease severity or predict outcome in JDM.



Details of this work can be read in the abstract below but for copyright restrictions we cannot reprint the paper in full. For a copy of the full paper please send a SAE to the office stating your request.

### **International consensus on a proposed score system for muscle biopsy evaluation in patients with juvenile dermatomyositis: A tool for potential use in clinical trials.**

LR Wedderburn, H Varsani, CK Li, KR Newton, AA Amato, B Banwell, KE Bove, AM Corse, A Emslie-Smith, B Harding, J Hoogendijk, IE Lundberg, S Marie, C Minetti, I Nennesmo, EJ Rushing, C Sewry, SC Charman, CA Pilkington, JL Holton; UK Juvenile Dermatomyositis Research Group.

*Published in the journal Arthritis & Rheumatism in September 2007 pages 1192-1201.*

**OBJECTIVE:** To devise and test a system with which to evaluate abnormalities on muscle biopsy samples obtained from children diagnosed with juvenile dermatomyositis (DM).

**METHODS:** We established an International Consensus Group on Juvenile DM Biopsy and carried out 2 phases of consensus process and scoring workshops. Biopsy sections (n = 33) were stained by standard methods. The scoring tool was based on 4 domains of change: inflammatory, vascular, muscle fiber, and connective tissue. Using a Latin square design, biopsy samples were scored by 11 experts for items in each domain, and for a global abnormality measure using a 10-cm visual analog score (VAS 0-10). The tool's reliability was assessed using an intraclass correlation coefficient (ICC) and scorer agreement (alpha) by determining variation in scorers' ratings.

**RESULTS:** There was good agreement in many items of the tool, and several items refined between the meetings improved in reliability and/or agreement. The inflammatory and muscle fiber domains had the highest reliability and agreement. The overall VAS score for abnormality had high agreement and reliability, reaching an ICC of 0.863 at the second consensus meeting.

**CONCLUSION:** We propose a provisional scoring system to measure abnormalities on muscle biopsy samples obtained from children with juvenile DM. This system needs to be validated, and then could be used in prospective studies to test which features of muscle pathology are prognostic of disease course or outcome. We suggest that the process we used could be a template for developing similar systems in other forms of myositis.



## GENETIC WORK

Dr Hector Chinoy has reached the end of his research time at the Centre for Integrated Genomic Medical Research. Dr Chinoy worked closely with Dr Bob Ollier and Dr Robert Cooper profiling the genetics of Myositis using blood samples and clinical data from over 400 persons with Dermatomyositis or Polymyositis and has recently published more of his work in the scientific field.

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The paper related to the abstract below can be read in full online at: <http://rheumatology.oxfordjournals.org/cgi/content/full/46/9/1411> or by sending a SAE to the office stating your request.

### **Tumour necrosis factor-alpha single nucleotide polymorphisms are not independent of HLA class I in UK Caucasians with adult onset idiopathic inflammatory myopathies.**

Chinoy H, Salway F, John S, Fertig N, Tait BD, Oddis CV, Ollier WE, Cooper RG; UK Adult Onset Myositis Immunogenetic Collaboration (AOMIC).

*Published in the journal Rheumatology (Oxford) in September 2007 pages 1411-6.*

**OBJECTIVE:** To investigate haplotype tagging single nucleotide polymorphisms (SNPs) in the tumour necrosis factor alpha (TNF-alpha) gene, in UK Caucasian idiopathic inflammatory myopathy (IIM) patients.

**METHODS:** A cross-sectional, case-control study of four TNF-alpha SNPs was undertaken, comparing cases of polymyositis (PM) (n = 121), dermatomyositis (DM) (n = 109) and myositis overlapping with other connective tissue diseases (CTD-overlap) (n = 73) with normal subjects (n = 177). Subgroup analyses were undertaken after stratifying for myositis specific/associated antibodies.

**RESULTS:** The TNF-308A allele demonstrated a strong association with each myositis disease subgroup vs controls [PM, odds ratio (OR) 2.8, 95% confidence interval 1.9-4.3; DM, OR 2.5, 1.6-3.8; CTD-overlap, OR 3.3, 2.1-5.1]. The TNF-308GA/AA genotype frequency was significantly increased vs controls (PM, OR 3.7, 2.1-6.3; DM, OR 3.2, 1.8-5.5; CTD-overlap, OR 5.0, 2.6-9.6) suggesting a dominant model. The association was strongest in patients possessing anti-aminoacyl transfer RNA synthetase (anti-synthetase) (OR 5.1, 3.3-8.0) or -PM-Scl (OR 5.0, 2.7-8.9) antibodies. The -1031T allele was also a significant risk factor in DM (OR 2.2, 1.4-3.6), anti-synthetase (OR 2.9, 1.6-5.3) and -PM-Scl (OR 5.6, 1.9-6.4) antibody positive patients. The TNF-308A association was lost after adjusting for HLA-B\*08, but remained independent of HLA-DQB1\*02 (both are alleles forming part of the common ancestral haplotype). The HLA-B\*08/TNF-308A/DRB1\*03/DQA1\*05/DQB1\*02 haplotype was a risk factor in all myositis subgroups vs controls (OR 3.0, 1.8-5.3).

**CONCLUSIONS:** TNF-308A and -1031T alleles are significant risk factors in the IIMs. In the IIMs, the TNF-308A allele is part of the common ancestral haplotype, but is not independent of HLA-B\*08.

## Want to help with the Genetics Work?



It is hoped that using genetic examination to understand the mechanisms underlying specific subtypes of Myositis we will be able to predict prognosis and therefore use suitable regimens of treatment. This is a unique DM/PM resource collected by Dr Cooper and his team at Manchester university. If you would like to help this work it involves your GP taking and sending your blood along with a short questionnaire. Interested? Please contact Dr Cooper's secretary, [jill.grundy@manchester.ac.uk](mailto:jill.grundy@manchester.ac.uk) or write to, Rheumatic Diseases Centre, Clinical Sciences Building, Hope Hospital, Eccles Old Road, Salford, M6 8HD.

# FUNDRAISING

## 26 MILES FOR RICHARD CAMPAIGN

The Campaign organisers write,

“For the past 6 months we have been running the “26 mile for Richard Campaign” in memory of our friend and colleague Richard Armitage who died in September 2005, age 39, from Dermatomyositis.

The campaign included a number of fundraising activities such as, training walks, cake sales, raffles, dress down days and ended with a 26 mile marathon sponsored walk on the 22nd April 2007. One of the joys of the campaign, especially during the monthly training walks, was that we were able to spend quality time with old friends as well as making some new friends on the way. On the day of the 26 mile walk Dorset police staff joined Richard’s family and friends to complete the charity walk around the southern coast of Dorset, which ended with tea, cakes and champagne to celebrate our achievement.

Richard’s family have been very involved in the campaign from the start. His parents, Patrick and Tarja commented, “When the idea of the marathon walk was suggested, the whole family were deeply touched and keen to be involved in one way or another. Our loss has been hard to bear but the support, thoughtfulness and kindness of his colleagues at Police HQ had been a great comfort. The fact that people are prepared to do a massive 26 mile sponsored trek shows how much they thought of him. Richard had an excellent, rather irreverent sense of humour and would surely have hoped that during the walk the participants would laugh and groan at the excessive length of it.”

After the walk Tarja sent the following message to those that participated, “Yesterday left the most wonderful feeling about the goodness of people I’ve ever felt and I hope everyone who took part knows how much it has meant to us.”

As organisers, we would like to reiterate Tarja’s comment, as we have also been overwhelmed with people’s support and generosity and are pleased to enclose a total of £6,067.26. Also enclosed are the sponsorship forms, which you hopefully can claim some additional funds through gift aid.

We would like to request that the money be used for research into Dermatomyositis. I believe Patrick Armitage has echoed this request in a previous e-mail to you requesting that the money go towards a pilot or mainstream project specifically designed to research aspects of the disease.

All who contributed and supported the campaign would like to know that in some small way our efforts have contributed to the research and hopefully successful treatment of this disease in the future.

We would like to thank all of Richard’s family, friends and colleagues who have generously supported the campaign and wish the Myositis Support Group success in finding a cure.”

Since the above letter was received a further donation of £436 in sponsorship money has been received. Campaign organisers, Maice Sanders, Penny Ford, Jane Hansford and Kerry Gwilliam have now raised over a fantastic £6,500 for our cause.

We have also received cheques to the value of £55 from one of the walkers Simon Merry who asked for donations to the Group rather than gifts for his birthday.



## LEIGHTON BUZZARD MAY DAY FAYRE

Member, Val Humphries writes, "My daughter Natalie ran a stall in support of the Group. Unfortunately the weather was not very kind at all and we experienced some very heavy rainfall which was so disappointing after all the lovely weather we have had over the last few weeks. The turnout however was quite reasonable and I am pleased to say that I banked over £140 which included some money from one of your collection boxes."



There was some interest shown in the Group and several members of the public took away leaflets to read. I would like to thank Natalie so much along with her partner Barry and friend Louise for this help. Natalie managed to keep it a secret until a couple of days before so you can imagine how delighted I was. I would also like to mention Louise's mum and dad who generously donated £25 which covered the cost of hiring the stall for the day. I know every donation however big or small is really appreciated by all of us, whether it be sufferers, family and those involved with the Myositis cause."

## LAST CHRISTMAS

Jayne Guy writes, "Please find enclosed a cheque for £26, Once again my team at work (HBOS Plc) has donated to charity instead of sending Christmas cards. All are happy to support the Myositis Support Group as I am a sufferer."

## BBQ

Jacqui and Ian Gregory write, "Well we've just about recovered from the BBQ on Saturday 14th July. The turn out was fantastic around 120 people and the weather was fine. We just asked for donations in the bucket and run a raffle. The raffle alone raised £300 (300 strips of 5 at a £1 each), then we found another £896.42 in the bucket, which our son rounded up to £900. So, a total of £1200 was raised which Ian's employer, BP, will match making a total £2,400."

## HALIFAX PLC

Employee, Peter Simpson writes, "My colleagues and I have been collecting for charity throughout the year and your charity is one of the four we agreed to help. I have pleasure to enclose a cheque for £265 which we wish to donate to the Myositis Support Group."



## MONEY BOXES

Thank you to the many members and friends who have and are raising funds by these boxes. Your help is very much appreciated. If you require more boxes or need a new one please get in touch with Irene in the office.



## EVERY CLICK



When using a search engine on your computer use every click. Their donation to date stands at over £120. It costs you nothing. What more can I say?

## RECLAIM IT

Thank you to everyone who has recycled their printer cartridges and mobile phones. We have received over £60 in payments for them. Please let Irene know if you would like further bags.



## BOOK STALL

Member, Peter Allan writes, "I have enclosed a cheque for £275 raised by my son, David who has organized a book stall at his place of work – the Newcastle upon Tyne Civic Centre and this represents the profit he has generated over the last winter. My wife, Margaret and I had no idea what David was doing and we were both delighted at what he has achieved. I would like the money to go into our research projects."



## GOLDEN WEDDING

Margery Ford writes, "I requested that guests to our Golden Wedding celebration make a small donation to either the Myositis Support Group or the Samaritans rather than a gift. I suffer from Polymyositis and am a former Samaritan." £70 was presented to the Group.



## MARILYN'S CRAFT SHOP

The shop in Cullybackey, Northern Ireland has been busy raising funds for us again. Marilyn's sister, Frances writes, "There have been several women's outings to the shop over the last couple of months and as usual morning coffee, afternoon tea or supper was provided and a donation in lieu of payment. I therefore enclose a cheque for £428." Visitors making this donation possible have included, Portglenone Women's Institute, Mrs Linton with Hydebank Presbyterian Circle of Friends, Ballymena Trefoil Guild, Ahoghill Women's Institute, Wesley Centenary Church Bangor Women's Group, Glenoe Women's Institute, Bangor Art Club and Dundonald Townwomen's Guild plus of course Marilyn's Tea Tin."



## COMPANY GOLF DAY

James Borrett writes, "Please accept this cheque for £575 which represents money raised at my company's golf day. My sister has Dermatomyositis and so I was delighted when work agreed that the Myositis Support Group should be the charity supported by the event. It was a very successful day as not only did I win the competition but more importantly I had the opportunity to give a brief talk about Myositis and publicise the illness to a wider audience."



## EASTLEIGH MASONIC LODGE, HAMPSHIRE

The president, Kelvin Skinner and members kindly presented £500 to the charity. You may recall that the Lodge has been very supportive of our charity in the past. I know many of the members personally and although the charity has benefited from this gift I am so very grateful to them for just knowing they are there. They really are a helpful and benevolent group of people and help many causes. Member, Colin Whitfield suggested to the Lodge that perhaps with all our present ongoing projects we could do with this help.

## DUNWOOD MANOR GOLF CLUB – ROMSEY, HAMPSHIRE

Member of the club, Geoff Skinner invited Irene and me to a cheque presentation for the charity. It was a beautiful Sunday with the weather really warm. During lunch time on the club patio the members all turned out to show their support with several faces of good old friends in the audience. I was given a chance to say a few words about the charity and our work. Afterwards Geoff presented me with a cheque for £720.95 which were part of the funds raised by him during his captaincy. We were then invited to join him and his wife Pam in the club house for a superb Sunday lunch.

Geoff is an old school chum of mine and has helped the charity in the past. He has followed our progress over the years and has been pleased to have been of help. I think it may go back to our playground scraps, "all for one and one for all!"

## JEAN DUNN, FAMILY AND FRIENDS

The Northwich Charity Event held on 28th April raised a grand total £2414.31 – another successful evening enjoyed by all with two excellent local band's, "Beaver" and "Midlife Crisis" who gave an excellent performance and had the crowd up on their feet dancing all evening.

Sisters Jean Dunn and Catherine Sutcliffe (who are sufferers of Myositis) would like to thank family, friends, neighbours, work colleagues for their kind generosity in supporting them in raising the money and the help given to make the evening a success.

Jean writes, "There were many special people we would like to thank for helping out on the evening especially my children Megan & Jordan Dunn and out niece and nephew, Emily and Ryan Flynn. I would also like to thank Tim Randles from Midlife Crisis for being an excellent commentator for the evening, couldn't of done it without him. The rapport he had with the crowd was a job well done.

Thank you to companies who contributed a donation for the raffle and the Halifax PLC for their kind donation. Companies who supported the Charity Event were Asda, Roberts Bakery Northwich, Tesco Stores, Tomlinson's Flowers Northwich, Quality Inn Northwich, Marks & Spencer, Mercedes Benz, Sue Percival, Oakland's Hotel Northwich, Brewster's Northwich, The Lowry Manchester, The Curious Orange Restaurant Northwich, Chester Zoo, and Morrison Super Market."

## SPONSORED SILENCE

Catherine Sutcliffe & Jean Dunn would like to thank their niece Emily Flynn whom stayed silent for a whole day to raise money for the Support Group and anyone who knows Emily would know that was an achievement in itself! Hesitant to say, Emily's teacher from her school in Poole, Dorset sponsored her for £5 – "that says it all Emily and well done for raising £30."

## MIND, BODY AND SPIRIT

Dawn Allmark who is a good friend of Jean Dunn organised a mind body and spirit festival for the Support Group. The event held at the Winnington Rec on the 3rd June raised a fantastic £466.

## ROTTERDAM MARATHON

It was a true battlefield, but I really enjoyed it! by Marjolein van Kralingen.

Running my first marathon last April in Rotterdam, The Netherlands was a very special experience. I was very lucky that I was even allowed to finish, because due to the weather conditions the organisation had to make the decision to stop the race; there were too many people having serious health problems. By the time they decided to cut off the second loop of the course they had already had to resuscitate three people! In the end about 20 people ended up in hospital.



The temperatures were really devastating; it was between 26 and 32 degrees celsius. After a few miles it became quite clear that this had nothing to do with aiming for a particular time, it was much more about surviving.

Certainly after the half marathon distance people were dropping out all the time, walking and lying next to the course. Fortunately by that time I could really make the switch from aiming for a particular time to just enjoying the experience, so that's what I did. After that I felt great and had a fantastic time. I just enjoyed the atmosphere and saw everybody who I knew would be there to cheer and support me.

We had to walk certain parts of the route, but every time when I could or was allowed to I just started running again. So I finished in 4.23.41 net time. From the 20,000-ish participants only 4,334 finished (or were allowed to finish). I'm really happy that I could make that mental switch, because I'm not disappointed at all, I made the best of it and could really enjoy it! In total, with help from Jean Dunn I raised £773.68 for the Myositis Support Group!



## COAST TO COAST BIKE RIDE

In the last newsletter we reported that Bradley Dearnley and his dad Mark were taking part in the Coast to Coast bike ride from Whitehaven to Sunderland which thankfully they successfully completed and raised £1,401.15.



## TANDEM FROM BIG BEN TO THE EIFFEL TOWER

Another event that was in the last newsletter was the tandem ride. I am pleased to say that Danni Smith and Simon James along with their friend and pursuit rider David Spiers successfully completed the ride and in the process raised over £500.



## 5KM RUN IN HYDE PARK – LONDON

Trustee Catherine Risley completed her run in the 5km in Hyde Park along with member, Cathy Singfield. Unfortunately, we did not meet up with Cathy on the day but we managed to find Catherine and her family at the designated meeting point in the park after she finished her run.

Catherine wrote on the Just Giving page on our web site, “It seemed like a good idea at the time to run 5km in Hyde Park on September 16th along with several thousand other people. Well, it was. I made it round the course in 32 minutes 56 seconds so a bit slower than I had hoped mainly due to the volume of people! It was a great atmosphere and if you have ever wondered about taking part in something similar, then go for it. Thank you to all my sponsors I really never thought I would raise this much money but believe me it really spurred me on! This site will stay live until November so any more donations will of course be gratefully received.”



To date Catherine has raised £371.

Cathy Singfield hoped to raise £200 from the run but she has passed this sum and to date has raised £230! She ran the 5km because her daughter suffered from Juvenile Dermatomyositis.

Well done to both ladies for this wonderful effort to help the charity.

## GREAT NORTH RUN 2007

### ANDREW ALLAN - 20 YEARS ON!

Andrew wrote, “On Sunday 30th September 2007 I ran in the Great North Run twenty years after I completed it last time! Why, you may ask? Well after watching it on television last year I decided that it was now or never! After discussing it with a few friends over a few drinks I submitted an application to the public ballot which surprisingly was accepted! Now all I needed to do was train and to choose a charity to run for (the easy bit!). However, I felt I didn’t need to look far from home. My father, Peter, after a long illness, was diagnosed in 2000 with a sub type of Polymyositis called a Necrotising Myopathy.” Andrew set up a fundraising page on line at [www.justgiving.com](http://www.justgiving.com) and to date he has raised £1,100. His page runs until the 14th February 2008 so there is still time to support him!



### RUTH O’ROURKE

Ruth also set up a fundraising page on the Just Giving site and wrote, “The aches gained by running 13.1 miles will be all the more bearable if I can raise a bit of money for charity. I’ve chosen Myositis Support Group in memory of Dr Vanessa Knights, a colleague and inspiration from Newcastle Uni’s School of Modern Languages who sadly passed away last year. Please donate whatever you can. Every little helps! A MASSIVE thanks!”

Ruth has raised £300 to date and her page runs until 2nd January 2008.

## MZ5Nutz CHARITY DRAG RACE

Lee Adler from the MX5Nutz community writes,

“MX5Nutz is a community primarily for MX5 drivers across the UK and the world and we get together and chat about cars, life and everything. We have people from all walks of life and ages from young whippersnappers to golden oldies that just should know better!



Over the years the forum has been running we have really become more than a community and are a big family. Everyone knows everyone and we hold many meets across the country just to hang out and chat. We have celebrated births, weddings, birthdays and good fortune together and have been there for people when they have experienced tragedy or misfortune.

One of our members (in fact a forum moderator) has the condition called Dermatomyositis a condition that would really effect peoples' lives - but not Will. He is one of the most strong willed people that I know and has a great zest for life!

Recently our good friend was hospitalised for a problem with his kidneys thought to be caused by the Dermatomyositis, which has really effected him, his fiancée and all of us that know and love him. The sheer amount of support for him has been astounding and has brought the condition to the forefront of mine and others thoughts. So, we have decided as a community to do something to support research into this condition and of course build it into a fun event that will hopefully raise awareness and for the event to be remembered for a long time to come!”

On Sunday the 28th October the MX5Nutz community held a ‘Run what you Brung’ event at Santa Pod Dragstrip in Poddington and setup a fundraising page on the Just Giving website raising to date over £430.

## WALKER(S) WANTED

Just Walk is a charity walk for anyone who is keen to get their walking boots on and wanting to fundraise for the charity of their choice. The date for next years Just Walk Open Charity Event organised by Across the Divide has been announced as the 10 May 2008 and details on how to join-up will soon be on the Just Walk website [www.just-walk.co.uk](http://www.just-walk.co.uk) . We are looking for volunteers who would like to take part and fundraise for the Myositis Support Group.



This charity walk is designed to offer enthusiastic walkers the chance to experience a breathtaking walk over the picturesque South Downs and generate funds for their chosen charity. You, and possibly your friends, can choose to participate in a gentle 15km walk or a whopping 60km. On registration, you are required to pay a fee of £45 per walker for the 15km walk and £65 for the 60km walk. All the money you raise will go to your chosen charity. So, whether you raise £10 or £10,000, your charity will get it ALL. There are no hidden overheads. Your registration fee covers full event plans and support, T-Shirt, safety staff and pampering people, training and fundraising advice, drinks and snacks at stations along the walk, clearly marked route with free views and a celebratory BBQ at the finish.

On the walk you will be joined by walkers representing loads of different charities all walking for very different reasons. If you want to raise funds for us and get the name of the Myositis Support Group out there, then join up now.

If you have any further questions then do not hesitate to contact the Just Walk team: Julie Thomas, Gemma Philips or Tony Ford @ [justwalk@acrossthedivide.com](mailto:justwalk@acrossthedivide.com) Tel: 01460 30456.

## BUY AT

Don't forget to use our webshop for your internet shopping especially over the Christmas shopping period! [www.buy.at/myositis](http://www.buy.at/myositis) is home to over 100 retailers including; Marks & Spencer, John Lewis, Amazon, HMV, Goldsmiths, Superdrug, Tesco, Littlewoods, Mothercare, and Thorntons. Christmas can be a financially difficult time for many of us but by shopping through our webshop you will find great offers and the Myositis Support Group will benefit from all your Christmas shopping indulgences, does that make you feel better?



## Christmas shop at our Webshop!

Do your Christmas shopping at [www.buy.at/myositis](http://www.buy.at/myositis)

It's stress free, quick, easy, and value for money.

With over 100 retailers ranging from well known high street stores to ethical shops we are certain you will find the perfect gifts for all your shopping needs.

Every time you use our webshop to go to a retailer's web site and subsequently buy something, you'll automatically earn money for us! You don't pay anything extra by using our webshop, so please try to use it whenever you can.

Thank you.



## DISPLAY SCREEN FOR PATIENT INFORMATION

Colin Beevor Matron and Clinical Nurse Specialist writes,

"We have a new screen display for patients' in the Rheumatology outpatient department waiting room in at Queen Alexandra Hospital. Details of the Myositis Support Group are included on its show real."

This is an excellent way to raise the profile of the Support Group to people who may need it most.



## EVENING FOR PATIENTS

Colin Beevor Matron and Clinical Nurse Specialist at the Queen Alexandra Hospital in Portsmouth has kindly offered to host an evening for patients at the Rheumatology outpatients department in the evening on Wednesday 13th February 2008. A consultant will speak on "Myositis - an overview" and Colin will talk on managing fatigue. Invitations will be sent out in the new year to members in the local area but if you are interested in attending please contact Irene at the office.



## BMA GLOSSARY

The BMA's Patient Liaison Group has developed a glossary to help patients and carers understand the roles of healthcare professionals - doctors, nurses and allied healthcare professionals - who work in the NHS. The glossary of over 100 different healthcare professionals can be accessed through an alphabetical list or by type of healthcare professional. A brief description of the healthcare professional is given along with an outline of the training needed by that professional. Information on regulatory and professional bodies is also given. Any suggestions or amendments regarding the content are welcomed and can be made by e-mailing [info.science@bma.org.uk](mailto:info.science@bma.org.uk) <http://www.bma.org.uk/ap.nsf/Content/Hubwhoswhoinhealthcare>



## 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](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.



## FINANCIAL SUPPORT GUIDES

Useful guides on the types of financial support for disabled people can be found on the Directgov website. These guides provide information on the range of benefits, tax credits and other disability-related financial support you may be able to get. Included are details on Disability Living Allowance (if you need help getting around and/or looking after yourself because you are ill, disabled or terminally ill. You must claim before you reach age 65), Attendance Allowance (a tax-free benefit for people aged 65 or over who have an illness or disability and need help with personal care) and Incapacity Benefit (if you can't work because of illness or disability. It is paid in three weekly rates depending on how long you've been unable to work). [http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG\\_10020535](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10020535)



Also on this website is up to date information for carers on support programmes and services, money matters (including Carer's Allowance), employment (leaving and getting back to work), and Carer's Rights. Visit <http://www.direct.gov.uk/en/CaringForSomeone/index.htm>

## MEDICINE SHEET FOR CHILDREN

In conjunction with their awareness week in November 2007 ASK About Medicines (campaign to increase people's involvement in decisions about their use of medicines) have produced a "My Medicine" sheet which can be downloaded free from their website. The My Medicines sheet is a fun and easy to use sheet for parents and health professional to fill in with children to help them understand more about the medicine they have been prescribed. Visit [www.askaboutmedicines.org](http://www.askaboutmedicines.org)

## CHANGES TO BLUE BADGE SCHEME

The government has announced further changes to the Blue Badge Scheme, extending its reach and increasing security. In October 2002 the Disabled Persons Transport Advisory Committee (DPTAC), began its review of the scheme, which culminated in 47 recommendations for improvement. The recommendations were aimed at overcoming problems such as widespread badge fraud and theft, abuse of blue badge spaces, and councils without proper databases of blue badge holders. Implementation of these recommendations has been slow and many of the recommendations are still in consultation. Last year powers to inspect blue badges were given to police officers, traffic wardens and parking attendants but more needs to be done to stamp out fraud and misuse. Helen Smith, director of policy and campaigns at Mobilise said, "The blue badge system has almost got out of control. It's something we definitely need to have and parking concessions are invaluable, but we need to stamp out the fraud."



These latest changes which came into place on the 15th October extending the scheme to children under two who need to travel with bulky medical equipment, and to people with impairments in both arms who drive non-adapted vehicles but have difficulty using parking meters. In the prevention against fraud Blue Badges will now exhibit a hologram and will include a gender specific serial number to aid parking enforcement and clearer information about the use and abuse of the scheme directly on the badge. The words: "Front – display this side up", will be added to the badge to help prevent people being fined for displaying their badge incorrectly. Such changes may prevent fake Blue Badges but misuse often arises from those stolen from cars. You can prevent theft of your Blue Badge with a Blue Badge Protector. It is a simple, visible deterrent, in which the Badge is locked into a steel case and protected by 5mm of thick clear plastic. The device is then locked with a flexible steel cable, which attaches to the steering wheel.

The Blue Badge Protector is available in two options: at £19.99 for the Double Blue Badge Protector which can hold two disabled badges, or one badge and a time of arrival parking disc; or the Single Blue Badge Protector costs £15.99. These are available from Gowrings Mobility Ltd FREEPOST, Bone Lane, Newbury, Berkshire, RG14 5ZW. Tel Lo-call 0845 608 8020 or visit their website [www.independentliving.co.uk/gowrings/mobility.html](http://www.independentliving.co.uk/gowrings/mobility.html)

The DPTAC is due to publish its "Comprehensive Blue Badge Strategy" next April and will incorporate research into the introduction of a national blue badge database, the scrapping of exemptions from

the scheme held by some central London boroughs and extending the scheme to other groups of disabled people. Rosie Winterton (Transport Minister) said about the Strategy “[This] which will help us continue to improve the scheme, making it fairer, more consistently administered and easier to understand.”



For further information about the Blue Badge Parking Scheme visit the following websites:

[www.dft.gov.uk/transportforyou/access/bluebadge/pubs/general/thebluebadgeschemeexplainer5983](http://www.dft.gov.uk/transportforyou/access/bluebadge/pubs/general/thebluebadgeschemeexplainer5983)

[www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/DG\\_4001061](http://www.direct.gov.uk/en/DisabledPeople/MotoringAndTransport/DG_4001061)

[www.disabilitynow.org.uk/news/news\\_oct\\_2007\\_006.htm](http://www.disabilitynow.org.uk/news/news_oct_2007_006.htm)

## BAYWATCH CAMPAIGN

The Baywatch Campaign spearheaded by Disability Now, Mobilise, the British Polio Fellowship and partnered with Scopes Time to Get Equal campaign (human rights initiative for the UK's 10 million disabled people) continues to make efforts in trying to stop the abuse of blue parking bays by the general public and enforcing leading supermarkets to take action. Sir Bert Massie, chairman of the DRC, said: “Supermarkets need to understand that their duties under the Disability Discrimination Act are considerably more than just painting some lines and a wheelchair symbol in the car park. [They] are legally bound to make their services accessible. If they don't take steps to stop non-disabled people parking in these spaces they could be breaking the law.”

The result of the fifth Baywatch Survey (performed in July this year) found that leading supermarkets continued to fail at tackling the abuse of accessible parking bays. More than one in five accessible bays were being used by people without blue badges, the same levels of abuse as the last survey in 2005. For both ASDA and TESCO, more than 23 per cent of their accessible bays were being abused, higher than in 2005. For Sainsbury's, abuse remained at nearly 19 per cent and while

Morrisons cut abuse from more than 19 per cent in 2005 to less than 13 per cent. In the prevention of abuse of blue bays, Morrisons remain committed, Sainsbury's hope to move towards enforcing

accessible bays across all its car parks and ASDA have announced a trial of fining customers (£60) who park in its store's disabled bays without blue badges and their car park in Seaford has installed a number-plate recognition system so that that a barrier to disabled bays only opens for regular disabled visitors. Unfortunately, TESCO have no plans to introduce stricter enforcement.



### Baywatch Campaign Comments

*“The continuing failure of supermarkets to tackle abuse of blue badge bays is an on-going disgrace. I'm amazed that people like the CEOs of Tesco and Asda aren't squirming with embarrassment and thinking about whether this represents a failure on their part to meet their responsibilities both to disabled customers and under the DDA.” - Ian Macrae, Disability Now editor*

*“Morrison's have done it, so why can't the other supermarkets? We have been campaigning on this for more than six years now. It is time for the supermarkets to take this issue seriously.” - Graham Ball chief executive of the British Polio Fellowship*

*“When there is no accessible bay free, disabled people are often unable to do their shopping. This kind of abuse makes life so much harder than it needs to be for disabled people. Those who abuse accessible parking bays, whether outside supermarkets or anywhere else, are lazy, ignorant and selfish.” Helen Smith Mobilise's director of policy and campaigns*

For more details on this report visit <http://www.baywatchcampaign.co.uk> and for further to voice your views on this and other campaigns (Baywatch, Cannabis, Flight Rights, Winter Fuel) visit the Disability Now Forums

<http://disabilitynow.infopop.cc/eve/ubb.x?a=cfm&s=485103811&f=377103811>

## INSPECTION POWERS ARTICLE

**disabilitynow**

An interesting article on the Disability Now website about how a parking attendant on the streets of Cambridge is implementing the year-old inspection powers is worth a read. The article also highlights the difficulties disabled people have in accessing

designated parking bays and how not to use your Blue Badge.

## MOBILITY ASSISTANCE LOUNGE

Victoria Coach Station has opened a new 'Mobility Assistance Lounge' for disabled passengers. It is located opposite Gate 21 in the east departures terminal and caters for up to 25 people. The lounge has toilet facilities and is free of charge for passengers using the Mobility Assistance Service whilst at Victoria Coach Station. This is not a luggage service and passengers are requested to use the licensed luggage porters at the Coach Station. The service is free but passengers with impaired mobility must pre-book (minimum of 24 hours before your coach is due to depart Victoria Coach Station) by calling 020 7824 0000 or completing an online request form at <http://www.tfl.gov.uk/tfl/gettingaround/vcs-mobilityassistance>.



## NEW EU LEGISLATION – AIRPORTS

New European Union legislation which will require airport managing bodies to organise services for disabled people to board, disembark and change planes will come in July 2008. British airports say they will be ready; Birmingham International Airport has invested over £1million in new assistance areas and wheelchairs. Help points are now available in their car parks and the transport interchange at Birmingham International rail station. Manchester, Bournemouth, East Midlands, Humberside, Stanstead, Heathrow, Tees Valley, Doncaster and Liverpool, Glasgow, Edinburgh and Aberdeen airports are working through tendering process to find a contractor to provide its service. By July 2008 a robust complaints procedure will be in place and if airports do not comply with the legislation they may face a penalty. For more on this story visit the Disability Now website

[http://www.disabilitynow.org.uk/news/news\\_oct\\_2007\\_009.htm](http://www.disabilitynow.org.uk/news/news_oct_2007_009.htm) and a PDF by the Consumer Protection Group on EC Regulation No 1107/2006 can be downloaded from [http://www.caa.co.uk/docs/33/CAA\\_CPG\\_PRM.pdf](http://www.caa.co.uk/docs/33/CAA_CPG_PRM.pdf)



## COMMISSION CHANGES

The Disability Rights Commission (DRC) closed on the 28th September and the Commission for Equalities and Human Rights (CEHR) took over as the government body promoting all equalities issues on the 1st October. The change in commission reflects the expansion of the DRC. Since its establishment in 2000 the DRC lobbied on many issues important to disabled people and passed into law the Disability Discrimination Act. The CEHR has appointed to its committee persons from the public, private and voluntary sectors who have an understanding and experience of the key issues and challenges facing people with a disability. We hope that disability issues and policy continues to receive high priority within the CEHR as it did in the DRC. To read more on this visit

<http://www.equalityhumanrights.com/pages/eocdrccre.aspx> and the Disability Now news article [http://www.disabilitynow.org.uk/news/news\\_oct\\_2007\\_004.htm](http://www.disabilitynow.org.uk/news/news_oct_2007_004.htm)

## Forthcoming Awareness Events

For details on these and many more events visit [www.countmeincalendar.info](http://www.countmeincalendar.info)



### International Day of Disabled Persons 3rd December 2007

The annual observance of the Day aims to increase awareness and understanding of disability issues and trends, and to mobilise support for practical action at all levels, by, with and for persons with disabilities. Visit [www.countmeincalendar.info/show\\_campaign.php?calid=7&campaignid=753&categoryid=&banner\\_area=3&camp\\_dates=03%20Dec%202007](http://www.countmeincalendar.info/show_campaign.php?calid=7&campaignid=753&categoryid=&banner_area=3&camp_dates=03%20Dec%202007)



### Carers' Rights Day 7th December 2007

Between 40 - 60% of disability benefits go unclaimed, and with many carers unaware of how to access practical help, this campaign is designed to make carers more aware of their entitlements.

Visit [www.carersuk.org/Newsandcampaigns/CarersRightsDay](http://www.carersuk.org/Newsandcampaigns/CarersRightsDay) or telephone 020 7490 8818.

## GOOD NEWS

### BACHELOR OF ARTS

Mr and Mrs Paull write,

"We thought you would be interested to read that Suzanne who had Dermatomyositis in the early days was awarded a degree of Bachelor of Arts in fine painting at the University of Southampton on June 29th 2007 at the age of 35 years. We are very proud of her. She also got married on the 24th August to Bob Wilson from Bentley. They got married in Wales with all the family and friends and had a big party at Bentley the following night followed by a honeymoon in Egypt. We thought this would give hope to others who have Dermatomyositis and not to give up."



### WEDDING

Ken Radford who has remained a member of the Group since losing his wife Anne in 2002 has remarried in August this year. When Ken and Dorothy married they asked for donations instead of wedding presents as Dorothy had lost her husband in similar circumstances. They donated £500 of their "wedding gifts" to the Group in memory of Anne and Frank and donated similar amounts to the Guide Dogs and their Church.

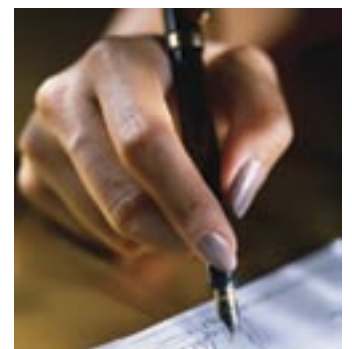


On behalf of the Group we have sent our good wishes to Ken and Dorothy for their future happiness together - Les

### PEN FRIENDS

Joan and Bob Slynn write,

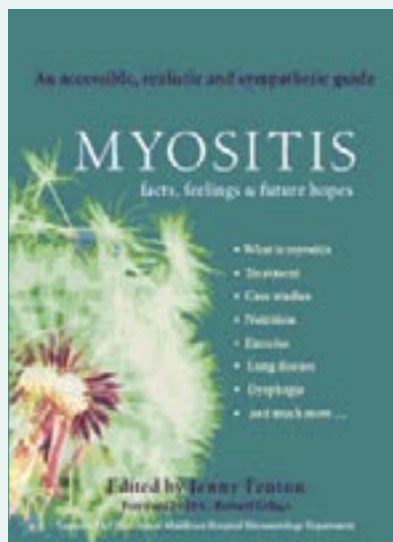
"Please congratulate and thank Paula and Irene for their continuing efforts and the presentation of a very comprehensive newsletter. Through the newsletter we still communicate with an IBM sufferer in Canada, she is called Norma Roop of Aylesford, Nova Scotia. I am not sure if she still receives a newsletter but if she does, please could you include our friendship which has developed over the years in a future edition. She would be pleased!"



## 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](mailto: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.

## A BOOK WORTH READING



### Myositis

**Facts, feeling and future hopes**  
**An accessible, realistic and sympathetic guide**

**Edited by Jenny Fenton**  
**£14 including postage and packing**

Thoughtful Publications  
PO Box 46214  
Ealing  
London  
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## 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.

## AGM AND MINI CONFERENCE 2008

Arrangements are underway for next year's meeting! The date is Sunday 13th July at the Holiday Inn, Eastleigh near Southampton. We have negotiated a special rate of £85 per room B&B per night. To book a room you need to telephone the hotel reservations on 0870 400 9075 and quote reference MSG. As in previous years the meeting will start at 10 am.

## POST SCRIPT

The interest in Myositis research is growing creating more requests for funding projects. All your fund raising efforts and donations are very much appreciated. Please keep up the good work so that we can continue to fund research and be one step nearer to finding a cure for Myositis.

### Les Oakley - 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.*

## LIST OF PRIZE WINNERS FOR THE SUMMER DRAW 2007

PRIZE No	PRIZE	TICKET No	NAME	ADDRESS
1	£500	6874	Maureen Harper	Liverpool
2	£100	2830	Jean Harwood	Bolton
3	£100	6133	Ted Wright	Chandlers Ford
4	£20 Gift Voucher	1038	M Cooke	Norfolk
5	£20 Gift Voucher	6092	Julie Hunter	Troon
6	£20 Gift Voucher	5212	Tina Hughes	Leicester
7	£20 Gift Voucher	815	Barry Bendall	Southampton
8	£20 Gift Voucher	3471	Mrs M Smith	Broseley
9	Multi-tool Set	5137	R Holt	Banbury
10	Rice Cooker	3111	S Macfarlane	Edinburgh
11	CD Radio	1834	Miss G Gower	Romford
12	Slow Cooker	4588	Mrs G Green	Dunstable
13	Britta Kit	2131	K Cook	Yeovil
14	Pro Chef	5570	Trevor Cowie	Peebles
15	OptiBlender and Mill	2451	D Yetton	Southwick
16	Toaster	1378	Maggie Hall	Shaftsbury
17	Cricket Set	568	Neil Middleton	Bristol
18	Princess Enchanted Garden	5479	P Levett	Wisborough Green
19	Deli Pro	1203	Mrs M Mabbott	Eastbourne
20	Karate Chop Challenge	3873	Nr and Mrs George	Spalding
21	Walkie Talkie	2977	B Lord	Carnforth
22	Pen and Letter Opener Set	6187	J Miller	Cambridge
23	Clock	1063	A and J Oakley	Hurstpeirpoint
24	Torch	841	Mr D Cull	Wareham
25	Lazer Level	1250	Irene Wakeman	Market Rasen
26	Mastermind Game	1369	D Williams	Gwynedd
27	Downfall Game	7397	Rita Hollyoake	Southampton
28	Grab Mat	7447	Rawcliffe	Isle of Man



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