



# MYOSITIS

---

## Support Group

### Newsletter 62 May 2007

---

*Dear Member,*

*There is much to report and I trust you find this edition of our newsletter mainly compiled by Paula and Irene an informative and useful read. Our 2007 conference is just months away and the support for it from the doctors and scientists has been excellent. We could do with more members showing a similar enthusiasm making the conference another mile stone day for the charity, well worth the time and effort that has gone into the occasion.*

#### **2007 CONFERENCE**

As Chairman I am very much looking forward to this year's Conference. Irene and the Trustees were making arrangements for the Conference even before our AGM in 2006! This year will be our 5th large Conference so a more central location was chosen. The venue, the Forest of Arden Hotel at Meriden is actually located geographically at the centre of England. In addition it is a beautiful hotel, set in wonderful grounds and close to all major road and rail links.

The Conference is to be held in the Arden Suite and this, the restaurant and rest rooms are all on the ground floor. The chairs have arms and are designed for comfort. There is ample room for wheelchairs and walking frames. Parking at the hotel is complimentary and Birmingham International train station is a short 5km taxi ride away.

I am pleased that all the doctors we invited to attend readily accepted and have put forward very exciting talks. All are giving their time freely to be with us. I look forward to welcoming Dr Chester Oddis who is travelling from the USA. He is professor of medicine in the Division of Rheumatology and Clinical Immunology at the University of Pittsburgh School of Medicine and associate director of the division's fellowship training programme and an association medical board member of the Myositis Association. He is also collaborating with many UK doctors including Professor Isenberg, Dr Cooper and Dr Chinoy.

Along with the Trustees, I am looking forward to the day with great enthusiasm and look forward to seeing you there.

If you wish to attend and have not yet sent back your registration form, please do so as soon as possible. This will allow us time to make all the necessary arrangements. In case you have mislaid your registration form one is enclosed with this newsletter.

All the current Trustees are willing to continue for another year in their respective positions; Les Oakley (Chairman), Paula Oakley (General Secretary), Jo Freestone (Honorary Treasurer), Tony Hindle, Sue Hindle and, Catherine Risley. If no applications to join the Board of Trustees are received by the 14th June 2007 supported by 2 members then the committee can be re-elected on bloc at the AGM. For further details please contact the office.

# Myositis Support Group Conference 2007



## Preliminary Programme

8.45-9.15am	Registration
9.15 am	Welcome & Opening of the Meeting
9.15-9.45am	AGM
9.45-1pm	Morning Session (including 20 minutes break for coffee)
1-2pm	Lunch (to be held in the Broadwater restaurant)
2-4.20pm	Afternoon Session (including 20 minutes break for tea)
4.20-5.20pm	Question & Answer Session
5.20-5.30pm	Formal Acknowledgements & Close

Conference to be chaired by Professor David Scott

## Speakers & Proposed Talks

- Dr Chester Oddis -Myositis in Brief/ Use of the MITAX/ Rationale for Rituximab Trial
- Professor David Isenberg - Autoimmune Diseases/ Update on the MITAX and MYODAM tools
- Dr Robert Cooper - Potential progress on the whole genome scan issue
- Dr Hector Chinoy - Antibodies and Cancer Prediction
- Dr Michael Rose - Inclusion Body Myositis
- Dr Clarissa Pilkington - Juvenile Dermatomyositis/ Muscle Biopsy Consensus
- Dr Ernest Choy - Treatment of Dermatomyositis & Polymyositis
- Ann Ali -Iris Hazel Memorial Talk

## Registration

Attendance at the AGM and Conference is free to members of the Myositis Support Group plus a partner, carer, or parents of a JDM child. To attend please complete and return the Registration Form. On receipt of your Registration Form you will be sent further information including travel directions nearer the time. In brief, leave junction 6 of the M42 and follow the A45 to Coventry. After one mile turn left into Shepherds Lane. The Marriott Forest of Arden Hotel is 1½ miles on the left. Birmingham International Airport and the NEC are four miles away.

*“As parents of a JDM sufferer it was good to talk to many new friends and share experiences, strength and hope.” - AGM 2004*

*“It was a positive day for me.” - AGM 2006*

*“We went home having learnt something and were able to share our own problems and successes” – AGM 2005*

*“Excellent, not only did I learn a lot but I enjoyed it as well.” – AGM 2006*

## Accommodation

Accommodation can be booked directly with the hotel (subject to availability) At present, online prices are £92 (single) and £102 (double/twin) per night including breakfast. Rooms can be booked directly with hotel reservations on 0870 400 7272 and online [www.MarriottForestofArden.co.uk](http://www.MarriottForestofArden.co.uk). If you have any problems please contact Irene on 023 8044 9708. There is also a Premier Travel Inn nearby and many B&Bs.

*“A very enjoyable and informative day and it was lovely to put faces to names and to realise that Myositis is not the end of the world. I came away feeling much more positive.” – AGM 2004*

*“A wonderful day – it was worth getting up early and the journey.” – Conference 2003*

*“My husband and I really found the day informative and useful. I was especially pleased to be able to talk (for the first time) to other people with DM.” – AGM 2006*

## ONLINE DONATING AND SPONSORSHIP

Online donations can be given securely at our just giving online site [www.justgiving.com/myositis](http://www.justgiving.com/myositis). The website does charge a commission so you may prefer to continue sending cheques representative of donations and fundraisers to the charity office.



I'm rather old fashioned myself so this method is still most welcome. The site does have a facility to assist your efforts by allowing you to set up a fundraising page. This is a great way to raise funds as it informs your prospective sponsors what you are doing and keeps track of the funds you've raised. Fundraising pages are typically set up for sponsorship or to receive donations for example in lieu of wedding presents or given in memory of a loved one. Bradley Dearnley has already set up his Fundraising Page for his bike ride (details further in this Newsletter).

## FSB GIVE WITH CONFIDENCE

We have recently become a member of the FSB Scheme and signed a Fundraising Promise which allows us to use the FSB logo. This is a new government initiative to ensure best fundraising practices. The Fundraising Standards Board Fundraising Promise is a promise made by members of the FSB scheme to the public, committing to the highest standards of practice, and ensuring that all activities are open and fair, honest and legal. By signing up to the FSB scheme we've agreed to adhere to the Fundraising Promise when raising funds.



## WEBSITE FACELIFT

As we age some of us will be tempted by a little help, whether it be an extra strength moisturiser or surgical intervention. Well, our website is officially 10 years old and for a while we have been thinking it needed a little extra TLC. Rob Fenton rescued the site a few years ago and introduced the Bulletin Board and Buddies Listing but now with technology moving so fast we had to accept we needed some outside help to update the site. Fortunately, Rob was working with a company called Pinsar Design in connection with his work. He mentioned the charity and its need for help with the website and they kindly offered to help at greatly reduced rates including the initial design for free! Paula and Irene had a meeting with them and they are now making good progress with the new website and it is hoped to be up and running before or in time for the conference in July.



---

## RESEARCH

### DR ROSE IBM MEETING

You may recall from my Newsletters and Chairman's reports that I am fully aware that there are no IBM research projects currently being undertaken in the UK. The Support Group has encouraged speculative IBM projects but none have yet been proposed. Dr Michael Rose is a neurologist at King's College London and we have been in contact with him for many years. He is fully aware of the problems faced by IBM sufferers and he is objective about the viability of performing good research that is relevant to the patient.

Dr Michael Rose organised a meeting at Brookes University Oxford last October and brought together experts to discuss potential exercise-based patient projects for Inclusion Body Myositis and its

practicality. The Myositis Support Group met the costs of the meeting which was attended by Dr David Hilton-Jones (consultant neurologist Oxford), Jane Freebody (physiotherapist Oxford), Dr Helen Dawes (exercise physiologist Oxford), Dr James Miller (consultant neurologist Newcastle), Monica Busse (physiotherapist Cardiff), Jo Reffin (physiotherapist, King's London), Dr Reza Sadjadi (neurologist King's London) and Graham Waltham (patient representative). Also involved but unable to attend the meeting are Professor Mark Wiles (neurologist Cardiff), Dr Bryan Lecky (consultant neurologist Liverpool), Professor Archie Young (gerontologist with expertise in exercise in the elderly Glasgow).

Graham Waltham who is a member of the Support Group and IBM sufferer attended the meeting and writes, "I am pleased to say that we had a successful meeting to discuss the IBM Exercise Study in Oxford on 18th October. This is not to say there is not a lot more work to be done."

I know Michael Rose is still working on his proposed project and when I have more details I look forward to reporting on them here in a future Newsletter. Fingers crossed!

## GENETIC WORK PUBLICATIONS

Dr Hector Chinoy and Dr Robert Cooper have been working very hard with their clinical genetics team. They have three new publications from the work that was initially part-funded by the Support Group. I have spoken to them and they will be presenting their exciting work at our conference in July. The scientific abstracts for these works are below if you wish to read them but I will wait for a lay person summary from them for printing in a future Newsletter. You may also note that Dr Chester Oddis is an author on all three of these papers which further emphasises the benefits of international collaborations.



Please remember that you can help their genetic work simply by providing a blood sample and completing a questionnaire and this can be done by your GP. Interested? Please contact Dr Cooper by email via his secretary Jill, [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.

### **Monocyte chemotactic protein-1 single nucleotide polymorphisms do not confer susceptibility for the development of adult onset polymyositis/dermatomyositis in UK Caucasians.**

H Chinoy, F Salway, N Fertig, BD Tait, CV Oddis, WE Ollier, RG Cooper.

*Published in the Journal Rheumatology (Oxford) in April 2007 pages 604-7.*

**OBJECTIVES:** Polymyositis (PM) and dermatomyositis (DM) form part of the idiopathic inflammatory myopathies (IIMs). The chemokine monocyte chemotactic protein-1 (MCP-1) is expressed at sites of the T cell inflammatory response in the IIMs. We thus investigate whether genetic markers in the MCP-1 gene confer disease susceptibility for the development of PM and DM.

**METHODS:** DNA samples were analysed from a group of 195 UK Caucasian IIM patients, comprising 103 PM and 92 DM. Their results were compared with those of 162 ethnically matched controls. The polymorphic positions of three single nucleotide polymorphisms (SNPs) and one insertion-deletion sequence within regions coding for MCP-1 were tested. The SNPs examined were located in intron 1 (rs2857657, C/G), exon 2 (rs4586, A/G) and the 3' untranslated region (rs13900, C/T). The insertion-deletion sequence was located in intron 1 (rs3917887, AGCTCCTCCTTCTC/-). Each SNP was tested for Hardy-Weinberg equilibrium and allelic/genotypic associations. Haplotype frequencies were estimated using the

Expectation/Maximization algorithm.

**RESULTS:** There was strong linkage disequilibrium present between three out of these four markers. The majority of controls were in Hardy Weinberg equilibrium. No allelic, genotypic or haplotypic associations were detected when comparing PM or DM cases to controls, or when PM and DM were compared with each other.

**CONCLUSIONS:** Genetic markers in the MCP-1 gene do not demonstrate significant genetic associations with the IIMs, and do not discriminate PM from DM in a UK Caucasian population.

### **Interferon-Gamma and Interleukin-4 Gene polymorphisms in UK caucasian idiopathic inflammatory myopathy patients.**

H Chinoy, F Salway, S John, N Fertig, BD Tait, CV Oddis, WE Ollier, RG Cooper.

*Published in the Journal Ann Rheum Dis on the 3rd April 2007*

**OBJECTIVES:** To determine whether interferon-gamma (IFN-gamma) and interleukin-4 (IL-4) genes confer susceptibility for the idiopathic inflammatory myopathies (IIMs).

**METHODS:** A large cross-sectional study of UK Caucasian adults with polymyositis (PM, n=101), dermatomyositis (DM, n=94) and myositis overlapping with a connective tissue disease (myositis/CTD-overlap, n=70) was completed. 177 ethnically matched controls were available for comparison. Single nucleotide polymorphisms (SNPs) within intronic regions coding for IL-4, IFN-gamma and a microsatellite marker within intron 1 of the IFN-gamma gene were typed.

**RESULTS:** Strong linkage disequilibrium was present between SNPs in each gene. In the IFN-gamma gene, a weak allelic association was observed in PM vs. controls at rs1861493 (odds ratio [OR] 1.6, 95% confidence interval [CI] 1.03-2.4). The microsatellite IFN-gamma CA(14) allele was associated with risk for IIMs overall (OR 3.3, 95% CI 1.4-7.8), the strongest association being observed within the anti-U1-RNP group (OR 6.0, 95% CI 1.5-23.1), and persisting after adjustment for known myositis HLA class II associations.

**CONCLUSIONS:** Genetic markers in the IFN-gamma gene demonstrate significant allelic associations with the IIMs in a UK Caucasian population. The SNPs tested in this study within the region coding for IL-4 fail to show significant associations to IIM disease susceptibility.

### **The diagnostic utility of myositis autoantibody testing for predicting the risk of cancer-associated myositis.**

H Chinoy, N Fertig, CV Oddis, WE Ollier, RG Cooper.

*Published in the Journal Ann Rheum Dis on the 28th March 2007.*

**OBJECTIVES:** There is a known association between myositis and cancer. The risk is greater in dermatomyositis than polymyositis, although reliable methods to predict cancer risk in specific myositis patients are not presently available. This study was undertaken to determine whether risk of developing cancer in myositis is predictable by antibody profiling.

**METHODS:** A cross-sectional study of UK Caucasian adults with polymyositis (PM, n=109), dermatomyositis (DM, n=103) and connective tissue disease overlap (myositis/CTD-overlap, n=70). Patients were tested for a comprehensive range of myositis-specific/associated autoantibodies (MSA/MAAs). Sensitivity and specificity analyses were performed for optimal identification of cancer risk.

**RESULTS:** Sixteen patients had cancer-associated myositis (CAM) (15 DM, 1 myositis/CTD-overlap). CAM patients were older at disease onset, and patients without MSA/MAAs on 'routine' laboratory testing (negative for anti-Jo-1, -PM-Scl, -U1-RNP, -U3-RNP, -Ku antibodies) had a significantly increased risk of CAM. Possession of the antibody (Ab) against 155kDa and 140kDa protein specificities (anti-155/140 Ab) represented a significant risk factor for CAM, this doublet being found exclusively in DM. A positive anti- 155/140 Ab result proved highly specific, moderately sensitive, with high negative predictive value (NPV) for CAM. A 'negative routine myositis Ab panel' result was highly sensitive, with high NPV for CAM. The combination of these two approaches was 94% sensitive, detecting 15/16 CAM, with 100% sensitivity and NPV in DM.

**CONCLUSIONS:** These results may help clinicians predict which myositis patients are at greater risk of developing cancer, thus identifying those requiring aggressive diagnostic evaluation and intensive cancer surveillance at myositis onset and follow-up.

## GRANTS AWARDED

We have had the pleasure to award three grants. These were to Professor David Isenberg, Dr Lucy Wedderburn, and Dr Olivier Harari.

## MITAX & MYODAM Computerisation

Professor David Isenberg was awarded a further £5,000 to increase the utility of the computerised MITAX and MYODAM indices previously funded by a £15,000 grant from the Support Group. The purpose of the MITAX and MYODAM indices are to develop a consensus in the assessment of disease activity and disease damage to ensure correct treatment and management of the illnesses. Computerisation of the indices enables them to be easily used to assess Myositis in future clinical trials, including a Rituximab Treatment Trial in the USA headed by Dr Chester Oddis.

These indices were established by a world-wide collaboration known as IMACS. The work of IMACS and the MITAX and MYODAM indices are outlined on the IMACS website hosted by the National Institute of Health (NIH) in America. Unfortunately, this website currently fails to recognise the financial support of our Support Group given to develop these indices.

In April 2000 Irene and I were invited and attended an IMACS workshop in Oxford, to represent patients and the Support Group. Following from this meeting the Support Group funded two "live patient" studies (May 2001 and March 2002). The initial work of this collaborative group resulted in publication of the preliminary indices in the Rheumatology Journal with acknowledgement to the Support Group. Professor Isenberg has written many articles for our Newsletter updating the work of IMACS and has accredited much of the success of the project to the Support Group for its financial support. Professor Isenberg wrote, "It is a realistic goal that reliable and validated indices for assessing the degree of disease activity and damage in patients with Myositis will have been devised and shown to be reliable valid tools. This will truly be a major leap in our attempts to improve serious inflammatory muscle disease. The Myositis Support Group has been invaluable in funding 'live patient' studies to try out these indices."

To validate and evaluate the indices the Support Group part-funded the salary of Dr Shabina Sultan who travelled across the UK and Europe to medical centres using the indices. It is from her work that the MITAX and MYODAM indices were further refined prior to computerisation. This work was commented on by Dr Robert Cooper who is a member of the collaboration group. He said, "Hopefully we will soon know whether the tools (IMACS indices) are the 'business' or not. If they

are it is once again down to the Myositis Support Group who have funded the necessary international meetings and Dr Shabina Sultan.”

The coordinators of IMACS are Professor David Isenberg, Dr Fred Miller, and Dr Lisa Rider. We are currently in communication with them to have the Myositis Support Group listed as a Sponsor of the IMACS work. The Support Group has been pleased to and will continue to support the work of IMACS in the UK and computerisation of the indices for use in Dr Oddis’s Rituximab trial as this collaborative group is fundamental to improving the lives of persons with Myositis.

The IMACS website can be found at

<https://dir-apps.niehs.nih.gov/imacs/index.cfm?action=home.main>

## **Vital Software/Hardware Equipment for JDM Registry**

A grant of £5000 was awarded to Dr Lucy Wedderburn for replacement of vital equipment for the JDM National Registry and Repository of UK and Ireland. This Registry and Repository was established in 2000, with the aim of collecting high quality data and samples from children with Myositis from across the UK and Ireland, in order to facilitate research and collaborations, and to improve the management and outcomes of this serious disease for children with Myositis and their families. The JDM Registry and Repository has been highly successful. It holds data and samples collected from over 220 children with Myositis. The knowledge and database within the Registry and Repository is internationally recognised as a major achievement, and has already led to several publications about JDM and developments which should improve the treatment of JDM. The resource of the JDM Registry and Repository has facilitated three major collaborations of research into JDM. One on genetics (in collaboration with a Dr Hector Chinoy and Dr Robert Cooper in Manchester, supported by the Myositis Support Group), a second on auto-antibodies in JDM, and the third, a highly successful project on JDM Biopsy measurement and scoring (also supported by the Myositis Support Group) involving international biopsy experts. All three of these projects have been written into publications, which are currently under review.

To date the funding for this Registry has been provided by the Cathal Hayes Research Trust, with pump priming originally for 2000 – 2005, with a further year extension of funding in 2005 – 2006. This funding included support for a data manager, a laboratory technician to store samples and also money with which to maintain the database, which is held on a dedicated server, and is regularly security checked in order to be compliant with the Data Protection Act and security requirements of storing sensitive data. This server has now reached the end of its functional life (it has been in use for over 6 years and a typical useful life for this type of server is 4 – 5 years). Dr Wedderburn and her team were advised by their IT experts to replace this equipment and the Support Group were pleased to financially help cover the costs of a new server with safe and secure transfer of the data to the new server as this is an invaluable and indispensable collection of data.

## **Research Equipment**

A grant of £2,025 was award to Dr Olivier Harari for equipment to assist his group’s work looking into identifying novel auto antibodies in Myositis. Dr Harari is a rheumatologist at Hammersmith Hospital (Imperial College London). He is working with colleagues at the Kennedy Institute of Rheumatology and plans to initiate a clinical research programme in Myositis. Dr Harari writes, “We believe that there are Myositis-associated auto antibodies yet to be discovered, and we are designing an experimental strategy to find these.” This project is in its conception phase and we have provided funding to cover the cost of laboratory consumables associated with the preliminary phase of this work.

## CLINICAL NURSE SPECIALISTS

Last November, Irene and Paula attended a Myositis Patient Evening at Queen Alexandra Hospital, Portsmouth.

The evening was organised by Colin Beevor who is matron and clinical nurse specialist in the department of trauma orthopaedics and rheumatology. Myositis patients who attend the hospital were invited and also members of the Myositis Support Group local to the area. The purpose of the evening was to introduce and tour the new rheumatology building, provide an overview of the rheumatology services in Portsmouth, to gain an understanding of what patients want from a rheumatology service and to introduce the Myositis Support Group.

Irene and Paula both found the meeting very informative and were pleased to see some Group members had travelled to attend for the evening. From letters, emails and telephone calls I have received from you over the years, my view of local hospitals for the diagnosis, treatment and management of Myositis was not held with high esteem. Over the years we have concluded that maybe patient care would be best served at specialised academic centres. However, following discussion with Colin and the other attendees at the meeting, Irene and Paula were most enthused by the understanding of Myositis, not just the initial care but also the long-term outlook and advocacy of patient support groups by Colin and his team. I personally believe that central to a good department especially within primary care trusts are specialist nurses. Unfortunately, not many departments have specialist nurses and funding for those that do is often under threat.

I would be interested to hear from you to see if you have been assigned to a specialist nurse for your Myositis. I would like at a future date to contact as many of these specialist nurses to inform them of the Myositis Support Group and equip them with our literature so that as soon as a patient is diagnosed with Myositis they have access to support if they so wish. I know many of you were not aware of the Support Group until many months or even years after your diagnosis.

---

## YOUR NEWS

### EXERCISE

Abigail Goodman writes, "I was diagnosed with Juvenile Dermatomyositis in 1979, aged three. My treatment and recovery – of which I have little memory – was successful and bar a sense of being permanently exhausted by modern life (which may, of course, have absolutely nothing at all to do with JDM!) I am very healthy.

Growing up, I did not factor JDM into my sense of self in a real and articulate way. I was always last at sports day and hated PE, and knew that JDM was the likely reason. But it wasn't until a few years ago that I stopped to consider my emotional relationship with my own body. When I did it was a shock to discover that my body and my mind didn't get on very well together. It wasn't that I disliked the way I looked; more that my mind didn't trust my body. Somehow I felt that my body had let me down and was still letting me down. I didn't have the stamina and flexibility of my friends because my body was a bit rubbish; not quite up to the job.

This all changed a couple of years ago when I discovered, for the very first time, the joy of physical exercise. A pressured working environment led to stress-related chest pains and sent me hurrying to the gym with the intention of burning off as much negative energy as possible. In a matter of weeks I realised that technique, whether it was on the rowing machine or in a yoga class, was as important as strength, speed and flexibility; and it was something I had as good a chance of

developing as anyone else. I stopped looking at exercise as an unpleasant continuation of dimly-remembered physiotherapy sessions and began to view it in a more positive light.

I finally fell in love with my body. Through a regular exercise programme I developed a real sense of my own body, what it can do now and what it might be able to do with patience, perseverance and a little kindness. I also discovered that exercise really does make you feel better emotionally too. Most of the time I don't want to go to the swimming pool, for a run or to yoga, but I'm nearly always glad I did. It cheers me up, helps me think more clearly, more positively and more creatively.

Ending the internal competition and opening up a real conversation with my body through regular exercise has been one of the most positive things I have ever done. I hope sharing my experience will encourage more of you to take the plunge and see what it can do for you.”

## **JDM GOOD NEWS**

Simon Millyard writes,

“About eight years ago, we were a settled and happy young family with four children ranging from 4 to 14 years, illness and disabilities were something that other people had and not something that we had experienced. Then it happened, our 13 year old son developed diabetes followed three weeks later by our 4 year old daughter. We struggled to pick ourselves up from this but “got stuck in” because realistically you have no choice. However, young Emily got worse and worse with great red blotches all over her skin and a complete loss of strength. She could only walk a few paces and was choosing to just lie on the floor, listless. The local hospital care in Suffolk was very good and her paediatrician (having seen it before) quickly diagnosed Juvenile Dermatomyositis. Thrown into depression by reading about mortality rates on the internet, we were rushed off to Great Ormond Street Hospital. I cannot praise enough the care and support that we and Emily have received over the years from GOSH, I think if I had been Bill Gates, young Emily could not have had better care and attention. To cut a long story short, after many years, numerous hospital visits and stays and many steroid and immunosuppressant regimes, Emily has developed into a healthy and active 12 year old. It took a long time to wean her off all the medicines (apart from insulin) after an initial stabilising period on steroids and supplements but the predictions from the GOSH doctors proved true. We hope and pray that she has grown out of it for good and look forward optimistically to the future. A work colleague with SLE put me in touch with the Myositis Support Group and it is a help to know that you are not alone.”

---

## **FUNDRAISING**

### **COAST TO COAST BIKE RIDE**

Bradley Dearnley, between the 6th to the 9th July, will be participating in a Coast to Coast bike ride from Whitehaven to Sunderland which is about 140 miles. Bradley's dad Mark is helping him and he is a bit concerned that they may get lost on the Pennines! Just as well I'm not leading the way or they will be!



This is a remarkable effort as Bradley was a sufferer of Juvenile Dermatomyositis. Bradley says, “At school I was very ill and could barely walk at that time. Thankfully I am now fully recovered and I would like to make a difference to the charity and give hope to people suffering from the condition

today by showing them that I can now complete this challenge.” Bradley aims to raise £1000 and you can sponsor him online at, [www.justgiving.com/bradleydearnley](http://www.justgiving.com/bradleydearnley)

## TANDEM FROM BIG BEN TO THE EIFFEL TOWER

Danni Smith and friend Simon James are cycling on a Tandem from Big Ben to the Eiffel Tower along with another friend David Spiers in hot pursuit on a single cycle. This will involve cycling 100 miles a day for three days commencing on Friday 25th May 2007. Danni’s mother, Zanna Goddard died on 25th July last year aged 60, having fought valiantly for 10 years with a combination of Dermatomyositis, Scleroderma, Sjögrens and Raynaud’s. Danni says, “This ride is in memory of her courage, spirit and general bloody mindedness and to raise money for her chosen charity.”



## SPONSORED DIET

Member, Lynne Nazer, is doing a sponsored diet from 8th January until 17th December and she hopes to lose 5 stone! She has had her weight verified by her Weight Watchers leader and one of her sponsors is so confident she will meet her target that they have already sent £70!



## 26 MILES FOR RICHARD

Maice Sanders and her friends and colleague are running a campaign for their friend and colleague, Richard Armitage, who sadly lost his battle with Dermatomyositis in 2005. The “26 Miles for Richard” campaign will run between November 2006 and 22nd April 2007. They have a number of events scheduled such as training walks, a wine tasting evening, cake stalls, charity fitness classes and their 26 mile sponsored walk.

## LONDON MARATHON

Thank you to all of you who have supported Frank Littler in the London Marathon this year. He completed the marathon in just over 4 hours (4:02:22) and his overall finishing position was 9685 but for his age group it was 109. With temperatures in London topping 21°C this was a fantastic run. We have raised to date over £1100. Our sincere thanks go to Frank for running on behalf of the Support Group again this year.



## PROJECT SEVEN

Christine Boggis writes, “I was presented with a cheque for £500 at the evening presentation of Project Seven. All through the summer I have been helping them with their BBQ and craft fairs. So my little bit of help has raised more money for charities. Next year I will help Project Seven to raise more money for good causes and for the Myositis Support Group.”

## MARGARET DULIEU

Margaret and her husband Harry have been fundraising for the group for many years by making and selling gifts at craft fairs. Unfortunately, they are no longer able to help this way, so Margaret decided to ask some of her family to make a donation to the Group instead of Christmas presents and has sent a cheque for £200.



## DRESS DOWN DAY

Sarah Edwards, writes, "Further to my recent email, I am pleased to enclose a cheque for £285.44 the sum raised by the Dress Down Day held in aid of the Myositis Support Group at Southern Water's Falmer (Brighton) office on Friday, 15th December. Once a month Southern Water gives staff based at its four main regional offices the opportunity to nominate a charity to benefit from the proceeds of its Dress Down Days. The days are always well supported and staff are invited to make a minimum contribution of £1 for the privilege of dressing down. As my father has suffered from Polymyositis for a number of years now, I wanted to make a small contribution to the invaluable work undertaken by the Myositis Support Group and I hope the enclosed cheque will help you to continue your good work."



Sarah has also sent a cheque for £50 which was donated by Southern Water.

## HAND MADE CARDS

Edna Rutherford writes, "My family have been thinking of ways to raise money to aid research into the diseases highlighted by the Support Group. My friend and I have been making hand made cards and have been very busy selling them to friends and family as well as neighbours and anyone else we can think of really. We are also collecting orders for Christmas cards from the people around us. We hope that in this way we can help the much needed research that will help people like myself who suffer from this degenerative disease. I enclose a cheque for £20."

## GRANDCHILDREN HELP

Not only has Edna Rutherford been busy but her two grandchildren have also been supporting the Group.

Edna writes, "My grandchildren have been very busy raising money to help research into the disease and have had lots of fun thinking of new ideas and ways to raise money. My grandson, Sam, was granted



*Kathryn in silence*

*Sam - the purple*

permission from his head to dye his

hair on the last day of term. He asked his friends, family and teachers to sponsor him and as no one believed he would go ahead with it he got lots of sponsors! So, on the last day of term, he had purple hair! My granddaughter, Kathryn, is a chatterbox so when she suggested that she would do a sponsored silence we thought that this was NOT the way to make money! However, she kept to her decision and was silent for twenty hours, If you knew Kathryn you would know that this was a tremendous act as she sings and chatters from morning to night. So, I enclose a cheque for the £172.80 and hope that you will put their details in the next newsletter. It may encourage others with some ideas or create new ways of raising money."

## OPEN UNIVERSITY

Lorenzo Bacigalupo, writes, "My wife Vivien works at the Open University Curriculum and Awards office. After hearing about my Dermatomyositis condition, this donation was recently collected by her colleagues. I am grateful to everyone who contributed and it gives me great pleasure to enclose a cheque for £81 to help support the work of the MSG."

## TAROT READING

Suzanne Hatt has been busy with her Tarot Reading on behalf of the Group and sent a donation of £26.

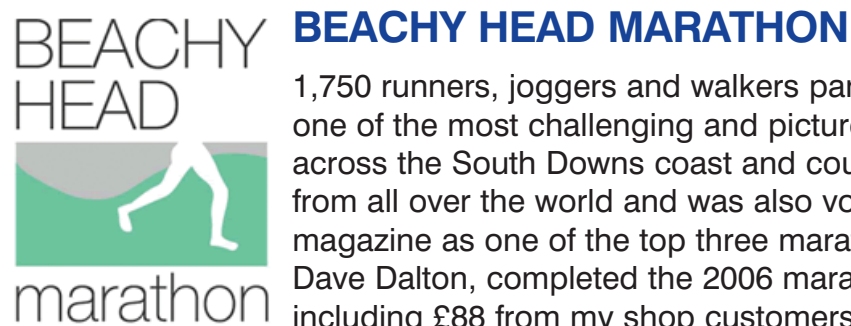
## 50TH BIRTHDAY CELEBRATIONS

Mr and Mrs Dawes celebrated their 50th birthdays by having a party to raise funds for the Support Group. They raised £316 on the evening. Their daughter had a jar of sweets and for a donation you had to guess the number of sweets and she raised £86. They also sold pin badges and raised another £46. They held an auction for a micro desk top radio/CD player and this sold for £65. A raffle was held on the night and raised a further £119. The Dawes would like to give a special mention and their sincere thanks to Sandra who donated a lot of the prizes for the raffle and also the radio/CD player for the auction.



Mr and Mrs Dawes, writes, “We would like to say to parents who have children with Dermatomyositis and Adults who have Polymyositis there is a light at the end of the tunnel and we hope the photo of our daughter will prove to them that its true. Eilish had Juvenile Dermatomyositis at the age of 4 years. She is nearly 13 and has only come off all her medication in February this year. Eilish will have check ups at Manchester Children’s hospital for a while yet. Keep well Eilish!”

“My sister in law has recently found out she had Polymyositis and is very poorly with it. We all wish her well and hope she makes a full recovery. Thanks everyone for a great party to remember especially to Elizabeth and Philip (Royals).”



## BEACHY HEAD MARATHON

1,750 runners, joggers and walkers participate in this annual event which offers one of the most challenging and picturesque routes in the country, winding across the South Downs coast and countryside. The event attracts participants from all over the world and was also voted by readers of Runners World magazine as one of the top three marathons in the UK. One of my customers, Dave Dalton, completed the 2006 marathon and raised £204.50 for the Group including £88 from my shop customers!

## GLAXOSMITHKLINE CHARITIES ASSOCIATION

Elizabeth Kerr writes, “I am pleased to enclose a donation for £500 towards the Myositis Support Group on behalf of GlaxoSmithKline Charities associations chaired by Elaine Cowan.



This donation came about through my son’s girlfriend’s mother, Elaine Kerr, who is an employee of GSK. They have a charities project and unknown to me, Elaine had nominated the Group this year for a donation. I was pleasantly surprised to receive this donation as the Charities Association normally only donate to local groups and donations from GSK are normally only around the £100 mark. However, due to fewer meetings and nominations I was overwhelmed when I received the cheque for £500.”

## MONEY BOXES

Well those pennies are certainly taking care of themselves! Thank you to all who have been using and reusing your money box. A special mention goes to young Tom Yaldren who frequently pops into my place of work with a full box. I am amazed at how much is collected in them. Those little boxes are a bit like a Tardis! If your box is starting to look a bit tired please let us know and we will send a new one. A good sticky plaster usually holds it together as well!



## YARBOROUGH MASONIC LODGE

Mr Creswick writes, "At the recent meeting, when we discussed making donations to charities the name of your Group was brought to our attention. One of our members, Malcolm Jackson, our former secretary, is affected by this condition and we felt that we should give you our support. On behalf of the Worshipful Master and Lodge I therefore have pleasure in enclosing a cheque for £250 which we hope will be of some assistance and we wish you every success in the work that you are doing."

## FRANCES FERGUSON

Frances writes, "I am enclosing cheques for £625.30 and £8.10 for sale of this year's Christmas Cards, in total £633.40. As well as selling the cards in Marilyn's craft shop, my other sister, Doreen, sells a big percentage of them and another friend, Yvonne, sells some for me every year. I also enclose another cheque for £154.50 from donations in the tea tin in Marilyn's craft shop."

## JULIE DEARNLEY

Julie writes, "Our son was diagnosed with Dermatomyositis six years ago when he was only just 4. He had four to five years on steroid treatment and daily physio and has been 'clear' for the last two years. This year my husband and I both had our 40th birthdays and decided to donate some money to a worthwhile cause rather than presents for ourselves. Please find enclosed a cheque for £161 for your charity to put into research of a very rare condition."



## HYDRO ACTIVE WOMEN'S CHALLENGE 2006

We have received £5 from the Hydro Active Women's challenge 2006. We do not know who nominated the Support Group to receive the £5 from the entry fee but thank you!



## BOOKSTALL

The Myositis Support Group Bookstall has raised over £5000 this financial year! Many thanks to all who have donated books.

## WEBSHOP [www.buy.at/myositis](http://www.buy.at/myositis)

Sales through our webshop have generated almost £140 in commission helped by the Christmas shopping period. It is now home to over 100 retailers including; Marks & Spencer, John Lewis, Amazon, HMV, Tesco, and Littlewoods. You can help raise awareness of the webshop by letting your family, friends and work colleagues know of it. We can supply posters, leaflets and template email advert. Just drop us a line and we will get these mailed out to you.



## EVERYCLICK

Everyclick.com works just like any other search engine but it also enables you to raise money for the Myositis Support Group every time you search the web. It's a great way to give everyday and it doesn't cost you a penny! Visit [www.everyclick.com](http://www.everyclick.com) to register and select Myositis Support Group as the charity to benefit from your internet searches and that's it!



**Please give it a go and if you like it as much as we do  
- pass the message on!**

To date the search engine has raised £75 and we have 35 registered users and their comments are:

*"I have joined Everyclick and find it as good as Google, so thanks for this tip." - Simon Millyard*

*"From the day Everyclick was first mentioned, I have used it and I find it as good and as fast as Google." - Otto*

*"I registered and I have had a week of really odd searches and it comes up with an answer every time. If you require verification from Google then put Google as a search on Everyclick and then use the Google.com result. This way Myositis [Support Group] still gets money." - Paul*


*"I also have just started to use Everyclick. I have found it very good - equally as good as Google and if it earns something for the Myositis Group all to the good. I sincerely hope many others do the same and make some funds to help support this excellent website." - Shelia*

## RECYCLING SCHEME



Please find enclosed with this Newsletter a prepaid envelope for the recycling of used printer cartridges and mobile phones. Just follow the instructions on the envelope and funds will be generated for the Support Group (the charity name is encrypted in the bar code). If you work in a large office with many printers you may wish to have one of our larger collection boxes. For further details and more prepaid envelopes please contact Irene in the office or email [irene@myositis.org.uk](mailto:irene@myositis.org.uk).

## RAISE FUNDS SELLING ON EBAY

Supporting the Myositis Support Group while selling on eBay is easy. Not only can you make a difference by donating between 10% and 100% of your items final selling price. You also benefit from your listing really standing out. Your listing will be marked with the special blue and yellow ribbon. 

Buyers can also easily search for charity items both on the main site and on the eBay for charity hub page. Often this can mean more bids and even more selling success! After your item sells, your donation will be paid directly into the Myositis Support Group bank account, along with Gift Aid (if you've ticked the box) and an eBay fee donation.



The really good news is that, although it will require a little leg-work up front to get you up and running, once you're registered it requires little extra effort. You just tick the charity box when you're listing, choose the percentage of your final sale price you want to donate and choose the Myositis Support Group as the charity. The rest is taken care of for you. Selling for charity is like selling anything on eBay but with one additional twist. You need to register with MissionFish, the UK charity partnered to eBay. MissionFish does all the back-end work to make sure your donation

reaches the Myositis Support Group. Once your item sells, you're then able to pay your donation directly through your MissionFish account, or if you prefer, MissionFish can take it directly from your credit card. Selling through eBay and MissionFish is like doing a car boot sale at your leisure!



## LISTENING EAR TELEPHONE NETWORK

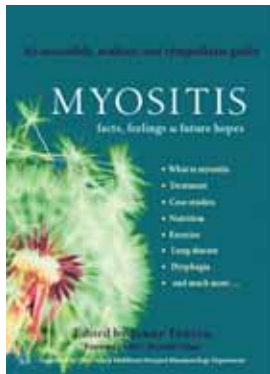
The Listening Ear Telephone Network will be a self-help resource for Myositis Support Group members. The network will be made up of Myositis Support Group members who have volunteered themselves as a point of telephone contact to others.

Paula writes, "I hope to have the directory ready for launch at the meeting in July and send out to members soon after. I have discussed with the Trustees the best format for this resource. To enable the Listening Ear Telephone Network to be readily updated the resource will be a binder rather than a booklet. This opened up a whole new world to me - the world of binders! With my principal prerequisite of minimal cost I journeyed into the world of 'paper over board', 'polypropylene', 'screen print', 'lithoprint', 'D rings' and 'round rings'. As the Listening Ear Telephone Network will constitute as a binder this will allow the addition of volunteers to the network in the future.



If you would like to volunteer to be part of this unique self-help resource please get in touch for further information. Please email [paula@myositis.org.uk](mailto:paula@myositis.org.uk) or call Irene in the office and we will be happy to send you further details."

## A BOOK WORTH READING



# Myositis

## Facts, feeling and future hopes

### An accessible, realistic and sympathetic guide

Edited by Jenny Fenton

£14 including postage and packaging

Thoughtful Publications, PO Box 46214, Ealing, London W5 1YF

## MEDIA ARTICLES AND NEWS CLIPS

The Myositis Association (TMA USA) contacted us to let us know of a programme being shown on the Retirement Living Channel (USA aired) which can also be viewed on the Internet. The programme titled, Adult Forms of Myositis, was broadcasted on the Retirement Living Channel on the 26th January 2007 and was viewable at

<http://www.rl.tv/OurShow/ShowClips.aspx?scid=144&channel=5>

Also in America on the 12th March 2007 a programme titled, "A Disease that is Being Misdiagnosed All Over the Country" was broadcasted on ABC 7 News and can be viewed on the Internet at <http://news.wjla.com/news/stories/0307/404903.html>. On the 29th March 2007 a broadcast on Good Morning America titled, "Medical Mystery: Immune Disorder Often

Misdiagnosed” was aired and this too can be viewed online at <http://abcnews.go.com/GMA/OnCall/story?id=2980054&page=1>.

A written article titled, “An Elusive Diagnosis, and One That Comes With a Risk of Cancer” was published in the NY Times online on 27th March 2007. Due to high copyright costs we cannot reprint the article here but it can be viewed on the internet at <http://tinyurl.com/23f6dt>.

Thanks to our members and website visitors who posted on the Bulletin Board to tell us of these clips and articles.

## DISABLED LIVING FOUNDATION

The Disabled Living Foundation has a new national helpline. Members of the public can now leave messages on the helpline's voicemail in order for an advisor to call them back with the advice they need. Using its extensive database of equipment (DLF Data), the DLF Helpline responded to over 21,000 calls in 2006 and expects to reach more people in 2007 thanks to the new telephone system. The Helpline is open 10am-4pm, Monday to Friday, Tel: 0845 130 9177 (textphone 020 7432 8009) e-mail: [advice@dlf.org.uk](mailto:advice@dlf.org.uk).



The Disabled Living Foundation provides free, impartial advice about all types of disability products and disabled equipment for older and disabled people, their carers and families. From stair lifts to walk-in baths, jar openers to tap turners, bath seats to walking sticks, wheelchairs to scooters, hoists to beds, the DLF can help you find disabled equipment solutions that enable you to stay active and independent.

## NHS DIRECT ONLINE

The NHS's main health advice and information website for patients and the public was re-launched on 31 October 2006 with a fresh look and new features such as a mind and body magazine containing news on current health issues and interactive health tools. [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)



## CARERS UK NEW ONLINE FORUM

Carers UK is an organisation offering advice and support to carers. In February, Carers UK launched a new online forum for carers to communicate with each other and share experiences. For more information about Carers UK and to use this forum visit [www.carersuk.org](http://www.carersuk.org).

**CARERS UK**  
the voice of carers

## PREMIA MOBILITY INSURANCE

The Good Access Guides has informed us of a new insurance provider, Premia Mobility.



“Premia Mobility is the new name in motor, home and travel insurance for people with disabilities or specific lifestyle requirements. So, if you need personal insurance policies that suit your style of living, they promise to take a fresh look with you. You may have found that non-specialist insurance companies or high street brokers can't offer you what you're specifically looking for. At Premia Mobility their aim is to offer you a service and a range of products that suits you personally with staff specially trained to help you get the right policy and cover for your specific needs. Premia Mobility's product range is designed to offer you flexible protection including some of those harder-to-find requirements, like; motor insurance that replaces vehicle modifications on a new-for-old basis, and provides extra cover for wheelchairs; Home Insurance that, should you need alternative accommodation provides you with extra facilities and automatically includes liability cover for stair lifts; Travel Insurance for pre-existing medical conditions.

By working in partnership with people like the "Good Access Guide", their staff are specially trained to help you get the right policy and cover for your specific needs."



For a quotation contact Premia Mobility on 0870 907 9617, 8.00am-8.00pm Monday to Friday, email [info@premiamobility.co.uk](mailto:info@premiamobility.co.uk) or visit [www.premiamobility.co.uk](http://www.premiamobility.co.uk). Premia Mobility is a trading name of the Towergate Underwriting Group Limited, authorised and regulated by the Financial Services Authority.

## HAND WARMERS

My daughter, Paula, never ceases to amaze me! Along with her JDM she has suffered with Raynaud's overlap and her hands and feet are often blue with cold. Sat next to me at the football ground I noticed she was not shivering in her usual manner. When we go to the football she wraps up in many layers and ski socks but she still feels the cold. However, on that day she didn't look cold at all. I then noticed these tea bag like things in her gloves which apparently heat up to 70°C when you activate them. She then proceeded to show me similar heat bags inside her shoes and a larger one which she had under her coat. She was a walking heater.



Paula explained to me that despite all the other heated gadgets she has used over the years to keep warm these are her favourite. These tea bags are actually called Mycoal warmers and are readily available through many ski and golfing shops. Paula was impressed with these warmers as they get very hot and last for many hours. The only downside is that they can only be used once.

Mycoal hand warmers cost £1.20 per pair and Mycoal foot warmers £1.50 per pair and can be purchased online at [www.newitts.com](http://www.newitts.com). A tester pack (pair hand warmers, pair foot warmers and a body warmer) £3.95 can be purchased direct from the Mycoal manufacturers [www.mycoal.co.uk](http://www.mycoal.co.uk). If you do not have internet access you should be able to get hold of these through most golf and ski outlets. Alternatively, please contact us here at the office as we have postal order forms for Mycoal Warm Packs Ltd.

## DISABLED ACCESS HOLIDAYS

Michael Davis writes,

"Disabled Access Holidays Ltd owns and operates accessible self catering holiday accommodation to rent in Puerto Pollensa, Majorca, Balearic Islands, Spain that has been designed and adapted to meet the needs of the disabled traveller. They have two and three bedroom apartments available which have been built with extra wide doors and turning circles to allow easy access throughout for wheelchair users. They can provide hoists, shower chairs, bedsides, four wheel walkers, electric scooters and changing tables for users with more complex needs. All of their apartments have spacious bathrooms with grab rails and walk-in/wheel-in shower areas.

The apartments are in the centre of Puerto Pollensa close to the town square. The central location means restaurants and shops are close by and are easily accessible by wheelchair. The beach and pine walk area are less than 50 metres away. A swimming pool which has a hoist is available for disabled swimmers. The apartments are air-conditioned and have fully equipped kitchens including washing machine, dish washer, fridge-freezer, oven/hob and utility area. The appropriate turning

circles for wheelchairs ensures the apartments are accessible for all our holiday their guests.

Disabled Access Holidays has now completed its first season in Puerto Pollensa. Many people with varying disabilities have stayed in their accessible two and three bedroom apartments and they are delighted to report that feedback has been very positive and that a great time has been had by all! Please have a look at their "Customer Reviews Section" on their website to read what their customers have to say about their stay with them in Puerto Pollensa. They will have two additional apartments with an accessible pool available from May 2007."

For further information visit [www.dah-europe.com](http://www.dah-europe.com), telephone 0141 270 7577 (9am-5pm Monday to Friday), or write to Disabled Access Holidays Limited, 9 Newton Place, Charing Cross, Glasgow, G3 7PR.



## SCOUT HOLIDAY HOMES TRUST

The Scout Holiday Homes Trust is a registered charity, and provides self-catering holiday accommodation in a welcoming family environment for any family or group who has a member with special needs, families with elderly or frail members, people with any special needs with their carers, single parent families, and low income families - in fact any family in which the quality of life is diminished by a physical or mental disability, infirmity or misfortune.



All the Trust's caravans and chalets are wheelchair accessible. They have a purpose-built ramp, and the unit doors - inside as well as the outside - are wide enough to allow access for all standard-size manual wheelchairs. There is sufficient room inside the accommodation to allow for a wheelchair to get alongside the bed, the toilet, the meal table, the shower, and to be able to move freely in most areas. The Trust now has one caravan with a wheel-in shower.

The Trust has units in Northumberland, Yorkshire, Norfolk, Essex, Sussex, Hampshire, Dorset, Devon, Cornwall, Somerset and North and South Wales - all on fully commercial holiday parks such as British Holidays and Haven (both now owned by Bourne Leisure) and Hoburne. These parks have superb facilities, as well as daytime and evening entertainment - at the very least all their holiday parks have a grocery shop, take-away, restaurant, bar, swimming pool, children's playground, and launderette.

The Trust aims to provide a family holiday that can be enjoyed by every single member of the family or group. The Scout Holiday Homes Trust was founded on the basis that, often, the carer needs the break as much as the cared for and the holiday is all the more beneficial when enjoyed within the bounds of the whole family. The self-catering ensures that everyone can get up and go to bed, have meals and enjoy the surroundings at any time and in any way the holidaymaker chooses. And when there is someone in the family with a special need, it may even be essential.

Everyone should be able to benefit from a break from the normal routine, and none more so than a family or a group in need, or with a frail relative to care for, or perhaps a parent struggling alone to provide a good home and upbringing for the children. Families like these can have difficulty in finding somewhere welcoming for a holiday at an affordable price. The Scout Holiday Homes Trust gives its holidaymakers the freedom and opportunity to get away from everyday pressures and enjoy a wide range of on-the-spot facilities.

For a colour brochure and more information contact, The Scout Holiday Homes Trust, Gilwell Park,

Chingford, London, E4 7QW, telephone 0208 433 7290, email [scout.holiday.homes@scout.org.uk](mailto:scout.holiday.homes@scout.org.uk) or visit [www.scoutbase.org.uk/hq/holhomes](http://www.scoutbase.org.uk/hq/holhomes).

## ACTIVE MOBILITY

Active Mobility are suppliers of disabled and mobility equipment. A wide range of products are available from walking sticks, to wheelchairs and scooters. A selection of their products can be viewed and ordered through the Active Mobility Equipment Shop online at [www.activemobility.co.uk](http://www.activemobility.co.uk). Many of the products are VAT exempt for persons who are chronically sick or disabled providing they are being used for their own personal use. Finance can also be offered on many of their products. Active Mobility offer expert help and advice and an after sales service. If you cannot find what you are looking for in their extensive catalogue they can be contacted on 01642 805050 or [enq@activemobility.co.uk](mailto:enq@activemobility.co.uk). Active Mobility has four disability equipment showrooms in the North East of the UK and visitors are welcome.



## IVG LIVING MAGAZINE

Intravenous immunoglobulins are used in the treatment of many illness and have been of benefit to some Myositis sufferers. IVG Living is a magazine dedicated to patients who use immune globulin products and to their care providers. The magazine was launched last year and is published bimonthly in the USA. The magazine features include, product and manufacturer news, resources for healthy living, immune globulin treatment options, and clinical trials. The IVG Living magazine is available free on the internet and free subscriptions to the print edition are offered to USA residents. For further details visit [www.igliving.com](http://www.igliving.com).



## MOTABILITY SCHEME DVD

A new DVD was released in February to help raise awareness about the Motability Scheme. The DVD, aims to inform health professionals, advisory groups, social services and other charities and organisations about the help that is available through Motability, for disabled people and their families.



Motability enables disabled people who receive the Higher Rate Mobility Component of the Disability Living Allowance or the War Pensioners' Mobility Supplement to obtain a new car, powered wheelchair or scooter. Some 450,000 customers have chosen to join Motability and 97% of them would recommend the Scheme to their friends. Yet another 1.3 million disabled people are eligible to join but haven't taken advantage of doing so. The DVD has been produced to reveal the benefits to those who think they can't afford a Motability vehicle or are unaware of the Scheme.

The DVD explains how the Motability Scheme works, from how to join to actually getting on the road. The presenter on the DVD says: "There are too many people out there that could be enjoying the freedom that their own transport would give them. But, chances are they don't know how easy and affordable it is. The Motability Scheme isn't meant to be a secret but not enough people seem to know about it. And, that is definitely something that needs to change."

The DVD includes options for viewing with subtitles, British Sign Language and in alternative languages. To order copies please visit the 'Marketing Literature' section of their website at [www.motability.co.uk](http://www.motability.co.uk) located within 'Contact Us' or telephone their Brochure Hotline on 01279 632067.

For general enquiries about the Motability Scheme call their Customer Helpline on 0845 456 4566.

## GET MOTORING – FREE GUIDE

How many of your disabled friends don't drive or don't own a car? Is it because they're unsure about how to get started? They're not alone. The good news is that there is a new guide available that can help to get them on the road.



The Royal Association for Disability and Rehabilitation (RADAR), with the support of Motability, has produced Get Motoring, a guide to the ins and outs of getting on the road. Released to coincide with the International Day of Disabled People on 1st December 2006, Get Motoring was written for disabled drivers, by a disabled driver and is available free from RADAR.

The guide addresses everything from driving lessons to fuel economy and includes additional information specific to disabled motorists such as adaptations, VAT-exemption and, of course, the Motability Scheme. Copies of the guide can be downloaded from RADAR at <http://www.radar.org.uk>. For further details about RADAR, email [radar@radar.org.uk](mailto:radar@radar.org.uk), telephone 020 7250 3222 or write to RADAR, 12 City Forum, 250 City Road, London, EC1V 8AF.

## MOBILITY ROAD SHOW 2007

The Mobility Road Show is the annual national motor show for disabled people, plus a showcase of a vast variety of products and services to aid an independent lifestyle. The Mobility Road Show aims to give anyone with a mobility problem - drivers, passengers, adults or children - the chance to assess what is available to help solve that problem and most importantly to try out and evaluate the options in a 'no pressure' environment.



The Mobility Road Show is a free event and takes place between 19th-21st July 2007 at Kemble Airfield near Cirencester, Gloucestershire. Open Thursday & Friday 10am- 5pm, Saturday 10am-4pm. For further information call 0845 2410390 or visit [www.mobilityroadshow.co.uk](http://www.mobilityroadshow.co.uk).

## REAL PEOPLE MAGAZINE

Contact a Family writes,

"Every week Real People magazine runs a short piece on a child with a rare condition or disorder. It is a popular magazine, and the headlines can be a bit sensationalist, but the information given on the rare disorder is usually quite straightforward. The piece involves a brief interview with the child's parent, and a paragraph from a medical specialist. Parents would also need to supply photographs which are returned after publication. With a circulation of around 350,000 people, this could be a real opportunity to raise awareness of your child's condition, and help other parents. If you are interested, please contact Clare Swatman, Health Editor at Real People. It's best to email her at e-mail: [clare.swatman@acp-natmag.co.uk](mailto:clare.swatman@acp-natmag.co.uk), as she only works Thursdays, or you can Tel: 020 7339 4591."



## EUDRAPARM PUBLIC DATABASE

The European Medicines Agency (EMA) has launched a new public database, EudraPharm, designed to facilitate access to information about medicines available in the EU. Medicines included on the database include those for cancers, AIDS/HIV, diabetes, neurodegenerative disorders and rare conditions. For more information visit [www.emea.eu.int](http://www.emea.eu.int).

## PRESCRIPTION & NHS CHARGES

The Government has issued a response to the Health Committee's report on NHS charges and in response to one recommendation, has asked officials to review the current exemptions for prescription charges and put forward options that would cost nothing. The outcome of this review will be reported to Parliament before the 2007 summer recess. To read in detail the '**Government Response to the Health Committee's Report on NHS Charges**' visit <http://www.official-documents.gov.uk/document/cm69/6922/6922.pdf> for the full 23 page document.



## PRESCRIPTION CHARGES SCRAPPED – WALES

Free prescriptions were introduced in Wales on Sunday, 1 April 2007. The Welsh Assembly Government has gradually been lowering prescription charges down to £3 before they became free in April. In England prescription charges have been increasing and now stand at £7.20.



Health Minister for the Welsh Assembly Dr Brian Gibbons said. "The main reason for providing free prescriptions was to ensure people are not put off getting medication they need due to cost. This will therefore enable those people who need medication to get it to improve their health and ultimately their quality of life. While this will benefit everyone who currently pays for prescriptions in Wales, it should particularly benefit those people on modest incomes or who have chronic illnesses, who may not have previously been eligible for free prescriptions under the complicated exemption system. This is the simplest and most effective way of resolving health inequalities and those inconsistencies in prescribing. The move removes all the unfairness surrounding the present outdated 1968 exemption system where, for example, a diabetes patient automatically gets all prescriptions free but a cystic fibrosis sufferer doesn't." To read more visit [www.wales.nhs.uk](http://www.wales.nhs.uk).

This seems unfair to Myositis sufferers here in England. Is Myositis less chronic in English people? Entitlement to free prescriptions applies to people registered with a Welsh GP or Welsh patients who have an English GP with an accompanying entitlement card who get their prescriptions from a Welsh pharmacist. If you live in England but close to the Welsh boarder you may want to pop across there for your medications!

As this is such a 'hot topic' and many charities are expressing concerns I'd like to open up a Voice Box for this topic for the next Newsletter for your comments. Unfortunately, I do not have the time to pursue the issue but if any member(s) would like to develop this further we would be happy to work with you and I can forward you some useful resources.

## EVERY DISABLED CHILD MATTERS CAMPAIGN

Every Disabled Child Matters (EDCM) is a campaign by four organisations working with disabled children and their families: Contact a Family, Council for Disabled Children, Mencap and the Special Educational

Consortium. The EDCM campaign aims to ensure the Every Child Matters policy is inclusive of disabled children. EDCM is focused on England, reflecting devolution, but will be supporting campaigning activity in the other UK nations, as well as campaigning on non-devolved issues such as benefits.



The government says that Every Child Matters but only 1 in 13 families get support from social services. Disabled children are 13 times more likely to be excluded from school, 8 out of 10 families

with disabled children say that they are at breaking point. Disabled children, young people and their families have been left out for too long. Every Disabled Child Matters (EDCM) is the campaign to put this right. The campaign aims to challenge politicians and policy-makers to make good on the Government's commitment. The EDCM wants; families with disabled children to have ordinary lives, disabled children to matter as much as all other children, disabled children and their families to be fully included in society, all disabled children and their families to get the right services and support – no matter where they live, poverty amongst disabled children and their families to be cut by 50% by 2010 and eliminated by 2020, an education system that meets the needs of each child and enables them to reach their full potential, and disabled children and their families to shape the way that services are planned, commissioned and delivered.

The EDCM campaign seeks 25,000 supporters but July. You can voice your support by signing the form online at [www.edcm.org.uk](http://www.edcm.org.uk)

## **QALYity PROJECT**

Alexandra Wyke (CEO of PatientView) and Simon Williams (Together4Health) write,

“Do you believe that doctors and the NHS should do more to improve the quality of life of patients and people with a disability? If you do, one problem is that the medical profession, managers, civil servants and politicians cannot always be expected to know what you (and everyone else) mean when you use the phrase ‘quality of life’.

To help overcome this problem, we would like to invite the members of your organisation to give their viewpoints on the subject of their quality of life to a study taking place in England and Wales.





The QALYity Project (an alliance of prestigious patient groups, medical professionals, academics, and journalists) is conducting the study in order to develop an index that can measure how effective each individual medical treatment or form of care/ support is at improving the quality of life of people with a long-term medical condition (or a disability)—as determined by the individuals themselves, not by clinicians. The results of the survey, and the tools that emerge from it, will be made publicly available, will be submitted for peer review, and will also be presented to the National Institute of Health and Clinical Excellence (NICE), the government-funded body that decides which treatments and care should be paid for by the NHS.

A December 2006 QALYity Project survey collected the views of over 270 patient/disability/carer organisations throughout England and Wales. These groups have kindly provided a wealth of potential definitions of the phrase ‘quality of life’ (results of the December 2006 quality-of-life survey can be read online at <http://www.patient-view.com/qalyity.htm>). But people are different, and not all of the December 2006 definitions are likely to apply to everyone. This second questionnaire aimed at your members should allow these individual differences to be collated.

We would be most grateful if you could give your members a chance to input their opinions to this survey on their quality of life (the short questionnaire “Quality of life survey for patients” can be filled out online at <http://www.surveymonkey.com/s.asp?u=723883484804>.”

For general enquiries about this study, please contact Dr Wyke at: Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, Wales. Email: [info@patient-view.com](mailto:info@patient-view.com) or visit [www.patient-view.com](http://www.patient-view.com) for more information.

## FORTHCOMING EVENTS

	Date	Hosted By	Further Details
National Men's Health Week	11-17 June 2007	Run by the Men's Health Forum, will focus on men and boys and long-term conditions.	Matthew Maycock Tel 020 7388 4449 Email: mhw@menshealthforum.org.uk www.menshealthforum.org.uk
 	Carers Week 11-17 June 2007	<p>Carers UK</p> <p>My life as a carer is the theme for Carers Week 2007, during which we will be promoting and highlighting various aspects of caring, including:</p> <ul style="list-style-type: none"> <li>• Financial – including financial planning for carers, publicising carers allowance, direct payments, other benefits, where to get advice etc.</li> <li>• Career – flexible working hours, job prospects, earnings, pension entitlement, promotion prospects, getting back into the job market.</li> <li>• Social life / relationships -changing experience, limitations as a result of 24/7; time, energy, lack of focus on self.</li> <li>• Health – look after yourself, health checks for carers.</li> </ul>	Carers Week website www.carersweek.org
	UK Fibromyalgia Awareness Week 9-16 Sept 2007	Fibromyalgia Association UK	Helpline: 0870 220 1232 (Mon-Fri 10am-4pm) Email: fmaukoffice@aol.com www.fmauk.org
Lupus Awareness Month	1-31 Oct 2007	LUPUS UK	Tel: 01708 731251 Email: headoffice@lupusuk.org.uk www.lupusuk.org.uk
	World Osteoporosis Day 20 Oct 2007	National Osteoporosis Society	Helpline: 0845 450 0230 Email: info@nos.org.uk www.nos.org.uk
	Scleroderma Awareness Week 5-11 Nov 2007	Raynaud's & Scleroderma Association	Helpline: 0800 917 2494 Email: info@scleroderma.org.uk www.scleroderma.org.uk
	International Day of Disabled Persons 3 Dec 2007	United Nations	www.un.org

## 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.

## WANTED: Your News, Feedback and Recommendation

For future newsletters we would like to hear of your good news. 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 [newsletter@myositis.org.uk](mailto:newsletter@myositis.org.uk) and if you wish to include a photo that would be great. For it is this information that makes the newsletter interesting reading.

Also, have you been or are you involved in any of the projects/campaigns mentioned in this and previous Newsletters? If yes, I would like to hear your views for printing in a future Newsletter. In addition are you using any of the services? And what are your experiences of these? Do you use any useful aids that make day to day living easier and may be of use to other members. If so, drop me a line either by email or post. Lets get sharing!

## POSTSCRIPT

One piece of final news our treasurer, Jo Goode and her husband Michael, have just adopted a eighteen month old baby boy. I am sure you will all join me in wishing them every happiness for the future and I can't think of a kinder couple who could be better parents.

May I take this opportunity of thanking folk for their kind donations to help the charity and in particular to those donations sent and recorded in memory of loved ones.

## 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.*



146 Newtown Road, Woolston, Southampton, SO19 9HR  
**Telephone:** 023 8044 9708 **Fax:** 023 8039 6402  
**E-mail:** [msg@myositis.org.uk](mailto:msg@myositis.org.uk) **Website:** [myositis.org.uk](http://myositis.org.uk)