

Myositis News



Dear Member,

I trust this latest edition of Myositis News brings you up to date with all our activities and progress. It has been some months now of quite intense work by all the trustees in producing the new website in conjunction with Pinsar Design. The change and promotion of our new charity name has also created much work, but it has been very worthwhile.

The charity will always be small in numbers because of the rareness of the disease in all its forms. However, with the day to day running of the charity continuing to be run from the present office, the trustees have agreed to sponsor and support members

to set up local meetings around the country where needed in the future. This will also be cost effective without the unrealistic and well researched prospect of renting and staffing an office. Our charity funds can therefore be directed where they are increasingly in great demand in medical research. This is showing good progress, particularly at long last in Inclusion Body Myositis.

If any member would like to host a meeting, informally I would suggest being the best option, then please get in touch with the office. We can also notify members in your area of your meeting and invite them to attend. It

can be a general myositis meeting or more specific to a disease type or just for a cup of tea and chat. These can be occasional meetings or regular, held in a home or other cost effective venue and even perhaps within a hospital complex involving a speaker with knowledge of the disease, its management and treatment.

It has always been a difficult task to evaluate how, as a small charity, we can best determine our direction in the future to help and support members and our cause. I consider we have performed reasonably well over the years, particularly when there are many demands and expectations to consider.

Let's Meet Up!



Our treasurer, Jo Goode, has arranged an informal Afternoon Tea for members on Saturday 4th October 2014, 2-3pm at Browns, Barristers' Court Room, St Martins Lane, Covent Garden, London, WC2N 4AG.

Disabled info: Two steps at front entrance, wheelchair access to side, lift to Court Rooms.

To attend please register and RSVP at:
www.meetup.com/MyositisUK/
Or on the Facebook page at: www.facebook.com/MyositisUKMeetup

Discover more at
www.theroomsatbrowns.co.uk/court-rooms-st-martins-lane/



Rheumatology 2014

Irene and I attended this three-day conference in Liverpool. We manned our charity stand in the Arma Village where Arma had kindly allocated us a place. We really enjoy meeting up with all the other associated charities and catch up with their news and progress. This also enabled me to sit in on the talks given at the Myositis Special Interest Group.

Dr Hector Chinoy of the University of Manchester and Dr Patrick Gordon of King's College hospital, London, chaired the meeting. The aim was to provide an update on current issues in myositis and upcoming research/clinical activities relevant to the clinical management of myositis.

Outcome 1: To provide an update on current clinical trial activity in myositis

Outcome 2: To raise awareness of how to diagnose, manage and treat newly defined serotypes in the inflammatory myopathy spectrum

Outcome 3: To discuss a number of challenging myositis cases and to enter a discussion about best practice in the treatments of myositis

Dr Chinoy gave a clinical trials update. Dr Patrick Kiely of St George's hospital, London, gave a talk on challenging myositis cases which produced much discussion. Professor David Isenberg of University College, London, spoke about autoantibodies in clinical practice.

What was most noticeable was even though a larger room had been allocated following last year's overcrowding the numbers attending these presentations again passed expectation and over 230 people occupied every seat with some standing at the back while others sat on the floor. This is great news for myositis patients because the audience was made up completely from the medical profession. An abstract from the meeting is included in this Myositis News.





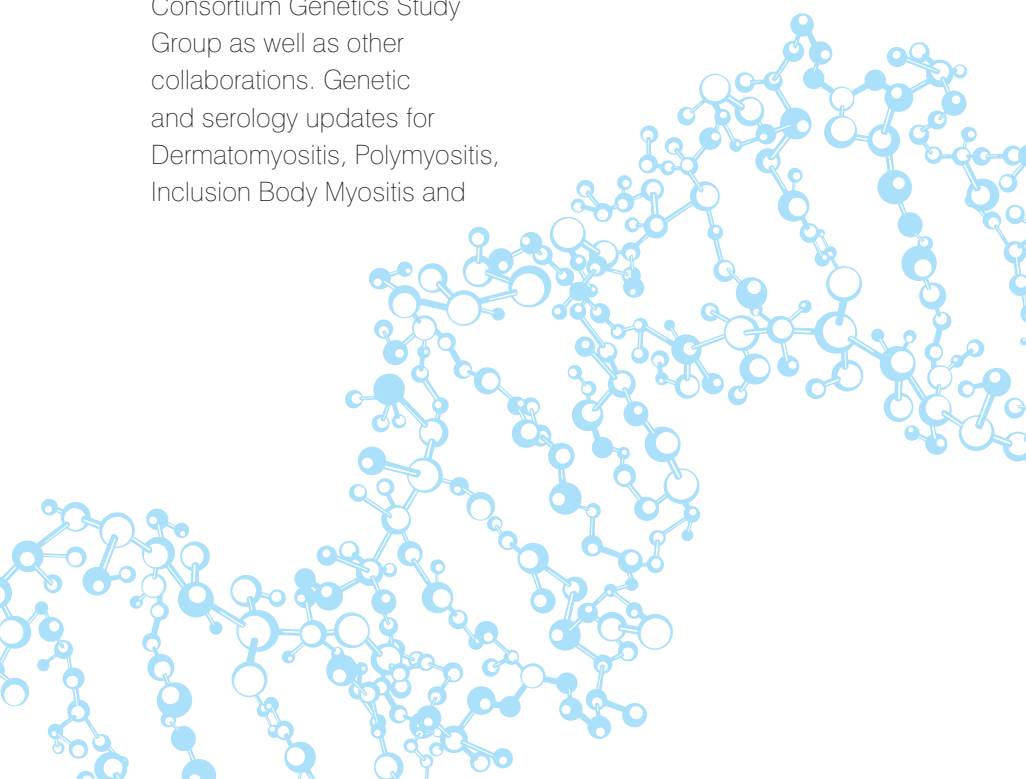
European Science Foundation-Sponsored International Myositis Genetics Workshop

The conference was held in Manchester for two days. This conference, organised by Professor Cooper, attracts experts from all over the world. Much of the work presented was by the International Consortium Genetics Study Group as well as other collaborations. Genetic and serology updates for Dermatomyositis, Polymyositis, Inclusion Body Myositis and

Juvenile Dermatomyositis were presented which were informative and encouraging for the future. Irene and I, with my daughter Paula Jordan, attended, representing the charity.

7th UK Neuromuscular Translational Research Conference

The UK Neuromuscular Translational Research (UK NTR) Conference was held in London for two days. This large conference hosted jointly by the MRC Centre and the Muscular Dystrophy Campaign centres mainly on the Neurology field and Inclusion Body Myositis featured in many talks and poster presentations. Much of the work by Professor Mike Hanna's Queen Square Team was on display, including studies into the effects of aerobic training, physical activity, identification of disease susceptibility genes, international IBM consortium genetic studies, natural history of IBM, Arimoclomol treatment trials, and magnetic resonance imaging. Irene and I attended the conference, manning our charity stall, which was very popular with the delegates who came from all over the world. I am very grateful to Jenny Fenton whose donation of her Myositis books proved very useful, particularly to delegates from countries where myositis is little understood. The next conference will be in 2015.

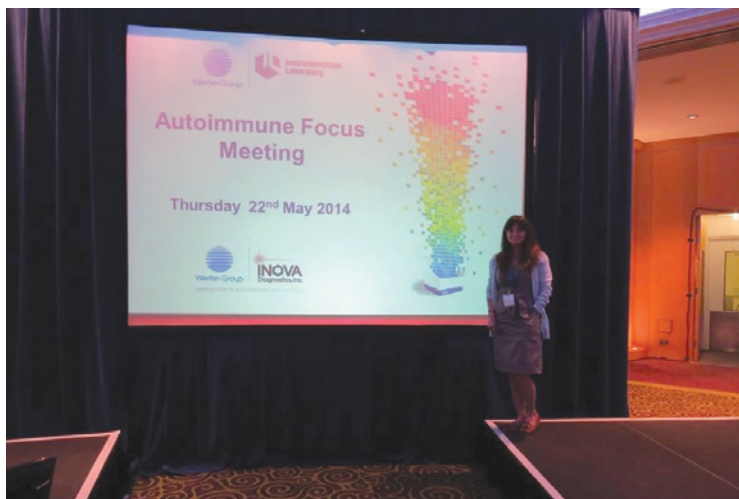


The Juvenile Dermatomyositis Research Group - Myositis UK

The meeting is an annual face-to-face meeting for participating parties to update on their work and to ensure continuation of the working relationship. Professor Lucy Wedderburn and members of the JDRG met with Irene, me, Paula Jordan and Nichola Coleman. An update on the Research Repository, the JDRG network of doctors, and the JDRG website was given, access to Teddy-Bo Book and Bear in clinic was discussed as was future parent fundraising and research projects. The next meeting is planned for October 2014 at the Institute of Child Health, London.

JDRG
Juvenile Dermatomyositis
Research Group

Autoimmune Focus Meeting - Birmingham



Paula writes, "It was a pleasure to talk at the Instrumentation Laboratory Autoimmune Focus Meeting to inform scientists and medics about myositis. I spoke about myositis and its history, the importance of a diagnosis and how in the future serology will play an important part in refining the diagnosis for the benefit of the patient. I was able to show data from the Bath team and I'm thankful to Dr Zoe Betteridge for her updated serology slides. I also spoke about the impact of myositis and I would like to give my thanks to members who gave me permission to show personal photos to make an emotional impact on the audience."

Organiser Karen Lithgo writes, "Dear Paula - a big thank

you for participating in our meeting yesterday. It was a pleasure to meet you and your parents. The content of your presentation was perfect for our audience - with a high level of scientific and clinical detail - together with an insight into what is important to you, and others, living with myositis.

I look forward to maintaining contact and building on a relationship with Myositis UK. As you are aware, as a diagnostic company, we develop diagnostic assays to support the diagnosis and monitoring of autoimmune diseases, such as myositis - so input from you and others associated with your organisation would be of great interest as we continue to look at key serological markers in this area."



UK Myonet Meeting - London



The UK MyoNet meeting organised by Dr Patrick Gordon was held at King's College, London. The meeting was a full day of research update talks and clinical case studies from many research centres. Experts from across the UK MyoNet specialities were present including Professor Isenberg, Professor Cooper, Professor McHugh, Professor Wedderburn, Dr Rose, Dr Chinoy and Dr Betteridge as well as researchers and medical students. Much talk was based on collaboration and how to move research forward into patient

treatment trials. A final talk was given on funding for delivering standards of care within the NHS framework was changing for specialisms and what doctors need to do to ensure they get funding for rare illnesses within their rheumatology department so they can continue or even pursue myositis as specialism. Irene, myself, Joanne Goode and Paula Jordan attended the day to represent Myositis UK. The work of UKMyoNet continues and the next meeting is planned for the end of 2014.

UK MyoNet (UK Myositis Network) is an open group of multidisciplinary physicians (rheumatologists, neurologists, dermatologists, respiratory physicians, and paediatricians), scientists and other interested parties for the advancement in understanding the pathology and management of the idiopathic inflammatory myopathies. UK MyoNet meets twice a year and has links with MyoNet (previously called EUMyoNet) and the IMACs collaborative group for numerous research projects.

Findacure's Workshop "European Commission Funding for Small Patient Groups"

Jo Goode and Bridget Kaloushi attended this meeting on behalf of the charity. The European Commission is providing €30 million in funding for rare disease research as part of its Horizon 2020 programme.

The event was a half-day event from 1:30 to 5:30pm in central London (near Bank station). The day featured an overview of the Horizon 2020 call and its relevance to rare diseases. A successfully funded patient group

then shared their tips about applying to the European Commission, followed by two talks that delved into key aspects of the application process.

Bimagrumab Trial In IBM - Novartis

Novartis have informed us that the Bimagrumab trial is set up and will be recruiting soon so please contact your physician to enquire. At the moment there are three sites in the UK, Manchester, London and Newcastle. There is more information available on the clinical trials website: www.clinicaltrials.gov/ct2/show/study/NCT01925209?term=bimagrumab&rank=1



With Max at Birdworld!

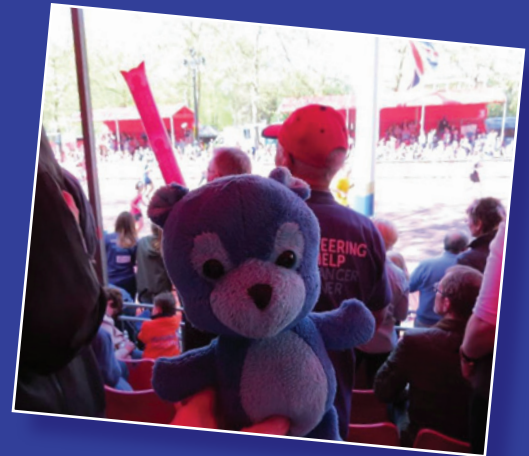
Teddy-Bo, His Friends, Adventures and Juvenile Dermatomyositis



"Selfie"



How cool is Teddy-Bo... here he is at the TT thanks to Helen for taking him on this fabulous trip and snapping the shot!



In the Grandstand at the London Marathon...

Easy Fundraising

Easy Fundraising is a great way of raising funds at no cost to you. If you shop on line through them the charity gets commission on your purchases. It is very easy to do just go to our Easy Fundraising page either through the link on our website or type the web address in your browser. There are over 2,700 top retailers on the site. You purchase directly with the retailer not with Easy Fundraising. www.easyfundraising.org.uk/causes/myositisuk/



...and with Wallace and Gromit!

easyfundraising
.org.uk

Annual General Meeting & Conference 2014

This is to be held on Sunday July 6th at the Oxford Belfry Hotel. This hotel is not in Oxford but just off the M40 at Milton Common, Thame, OX9 2JW.

The start time for the AGM is 10.30am followed by the conference at 11.30am. Registration forms were sent out in May.



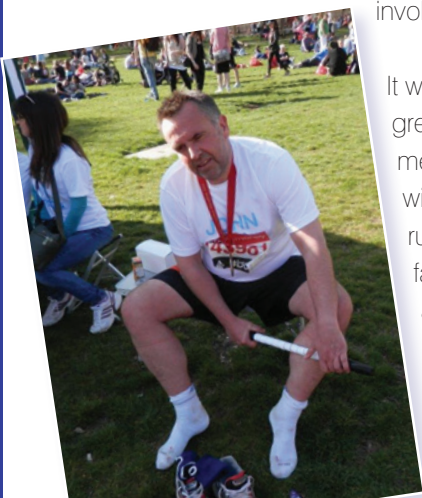
Fundraising: London Marathon 2014

Another wonderful and successful day. All seven members of Team Muscle finished. They all appear to have enjoyed the event because it is an amazing achievement to run over 26 miles! The weather held fine which is just as well because we were up early to get to London with all our charity paraphernalia loaded into the car. My daughter Paula and her husband, Andy, realising that we needed help, travelled from Gloucester to help us unload the car and get all the gear carted off to St James's Park after we had a hearty breakfast. Irene was limited to walking with crutches but still managed to contribute to the effort involved.

It was great to meet up with the runner's families and friends

on a sunny afternoon. It truly is a lovely day and there is so much friendship and goodwill between the masses of people who attend and also relax in the park. I must now be showing my age though for while pulling our trolley up a slope a group of lads offered to give me a hand.

With your kind help in raising sponsors and from the runners own efforts over £10,000 has been raised. Fantastic.



Ruby Wedding

Pat and Clive Willetts write, "Please find enclosed a cheque to the value of £210, being the proceeds of a collection at our recent Ruby Wedding celebrations. With all good wishes for your work in the future."

Susan Hatt

Part of a donation by Susan in support of the charity included £34 from her Tarot reading. Susan has been making regular donations from her readings for many years helping charity funds.

Mr L Bacigalupo

He writes, "I enclose a donation of £25 to add to all other fundraising efforts. Thank you for all your work in this area to help improve the lives of many people."

Garden Open Day

Eileen Pryer writes, "We had an open day and the proceeds from the teas and cake went to you. (My husband has the condition). So, enclosed are cheques for £250. We hope to do the same in August."



Himalayan Kingdom Marathon

James Borrett ran the Himalayan Kingdom Marathon in Paro, Bhutan, on 27th May 2014 to raise money for Myositis UK.

James began running 10 years ago at about the same time as his sister was diagnosed with Myositis. Through running he has lost over 4 stones and has completed a number of marathons including London in 2008 where he raised over £2,000 for Myositis UK. To mark a decade of his sister's illness and his running James decided to choose a more extreme race that would push him to the limit and hopefully help him raise as much money as possible for Myositis UK; hence the marathon in Bhutan.

Having trained on the flat roads of Peterborough and with less than 3 days to acclimatize, running for 26 miles between 7,000 and 8,500 feet on the slopes of the Himalayas was always going to be a challenge. However, all the runners were lifted by running in Bhutan, a country where gross national happiness, a core Buddhist value, is a counterpoint to gross national product; where economic growth is a means to achieving more important ends

such as cultural heritage, health, education, good governance, ecological diversity and individual wellbeing.

An inspiring pre-race talk was given by world champion ultra-runner Lizzie Hawker and following a small but evocative Buddhist ceremony at the start line everyone was ready for the journey ahead. It was certainly an eventful race which included runners falling into streams and paddy fields (including James) much to the amusement of the locals, a participant being bitten by a dog and a number of wrong turnings especially on the isolated tracks high above Paro.

The main goal was just to finish and helped by the friendships and camaraderie built up in the days before the race nearly everyone overcame the mental and physical challenge and managed to reach the end. The resulting feeling of euphoria and accomplishment just reflected what a tough race it had been. Much to James's shock he came 6th out of 23 and won the male over 40 category.

His charity webpage can be found on www.justgiving.com/James-Borrett

Rotary Magna of Southampton

The club donated a share of money raised from their Christmas dinner and gardening talk amounting to £300. The fundraising event was held at Haskins garden centre, Southampton. Irene and I, along with a party of friends, attended the

function which was well supported and a very enjoyable evening. The club have been very kind and helpful to the charity for years now and we are very fortunate to have had this long association with them.

Gardening Group

Mrs Ann Burton writes, "Earlier this year the group held a plant sale, the proceeds of which we donate to charities. It was decided at our last meeting that part of this should go to your charity as one of our members

is also a member of your charity and is suffering at present. I believe what you raise you give to help research this little known group of diseases so I hope this small amount will go towards this."

Northern Powergrid

Field safety manager Simon Keightley writes, "I am pleased to enclose a cheque for £1,250.00. Your charity has been nominated by a group of 46 individuals from Northern Powergrid who have won an award for their contribution to safety. The prize was a

donation to charity of their choosing. Your charity was chosen for all the hard work you do in providing advice and support in Dermatomyositis, Polymyositis, Inclusion Body Myositis and Juvenile Dermatomyositis."

In Memory of Letitia Rawson

Mr and Mrs Rawson write, "Thank you for keeping me up to date again with all the work of the charity – such a lot of hard work by so many people. It is the time of year again when

we realise Letitia would have had another birthday and so we enclose a donation in her memory of £52.00 and hope this small amount will help and encourage all that hard work."

Donations in Memory of Loved Ones

We have received donations in memory of loved ones. On behalf of the charity I thank all these families and friends for thinking of others and in particular this charity at a time of much sadness.

Money Advice Group

Saima Masood put our charity forward for help and we received a cheque for £500 from the company.

Masonic Caerdydd Lodge No. 3959

The Lodge treasurer, Alan Hankins, writes, "Please find enclosed our cheque for £500.00. This donation was arranged by president Phillip McCarthy of the Lodge in respect of his son Jack who was successfully treated."

It is very much appreciated how the Lodge has helped in the past and kept in touch even though Jack is doing well.

Margaret Slater

Margaret writes, "I enclose a cheque for £20 and am delighted to say that my Dermatomyositis has improved greatly over the years (I was diagnosed in 1995). My skin is now normal although I still need to take prednisolone. I'm now eighty years old, am still driving my new automatic car and enjoying holidays in Britain and France. Best wishes to you all at Myositis UK."

Jump Design & Direction

Karen Hall of the award winning company who produce channel brands and programme identities for terrestrial, satellite and corporate television sent a donation of £150.

Myositis Website

It took much time and anguish to get the new site up and running. However, I was talking in passing to a gentleman, who I had never met before, about the charity last Christmas and I referred him to view our website which at that time was the former site. He was very impressed and kindly made a donation of £2,000! Amazing and somewhat confusing.

The Foster Wood Foundation

Trustee Mrs Margaret Lodge writes, "At their recent meeting, the trustees of the Foundation requested me to forward the enclosed cheque for £10,000. They would like the money to be used where you feel it is most needed. The decision has been made to wind up the Foundation during 2014 so this cheque, I'm afraid, will be the last."

The Foster Wood Foundation has been so very kind and helpful to us and have played a major role in enabling us to sponsor research grants. I have written to the Foundation, but again through these columns, I wish them every happiness. I will always be grateful for their trust in how we have managed and placed their donations and the contribution they have made to help people with Myositis.

George Mackie

George writes, "Dear All, I am delighted to enclose cheques to the value of £270 for Myositis UK. My brother ran the Cardiff half marathon and raised £120. When I was thanking all who supported on Facebook the total went up to £270 within twenty-four hours. I am so grateful to all my supporters. I have been suffering from Inclusion Body Myositis for just over a year now and joined Myositis UK earlier this year. When I was diagnosed, I was totally ignorant of this disease, but my family and friends and my church

were incredibly supportive. Once the initial shock and prospects became public I felt able to cope. Reality kicked in when I discovered I could no longer work or drive my car. I was encouraged by the information on your website and follow it constantly. I am slowly coming to terms with this illness but fear for the future as I know this is a progressive disease. If my small contribution can help with research into all forms of Myositis then I could not be happier in contributing."

Head Shave - Olivia Bassett

When Olivia's sister-in-law (and best friend) Kate became ill over a year ago, hospitalized to intensive care and a diagnosis of Dermatomyositis, she decided to raise money to help. Part of Kate's treatment involved medicines that caused her to lose her hair so in a drastic comradeship she chose to shave her head. Olivia had beautiful long hair, it has been her pride and

joy and a safety blanket for a long time. Friends and family sponsored this fundraiser and £2,625 was raised.

Olivia says, "This is an awesome charity, which supports people like Kate and those around them. Dermatomyositis is very rare, making Kate truly one in a million!"



Snowdonia Marathon - Howard Booth

When Howard's niece Niamh was recently diagnosed with JDM he wanted to show his support by completing the Snowdonia Marathon to raise funds for research and he raised over £600.

Howard says, "Juvenile Dermatomyositis is a disease with no cure and affects 3 in a million children and Myositis UK and the JDMRG have been invaluable to my sister. Despite being one of the toughest marathons I should still get around Snowdonia quicker than one of Niamh's hospital trips!"

Otmoor Challenge - Andy Galway

Andy writes,
"I'm running The
Otmoor Challenge
Half Marathon for Myositis

UK because research is needed for Inclusion Body Myositis. At present there is no effective treatment for this disease which is why research is so

desperately needed. I'm aiming for a sub 2hr half marathon, the training is in the bank so now I just have to do it! Thank you in advance for your support." To date Andy has raised over £400. Her Just Giving page is www.justgiving.com/Andy-Galway

Jodie Szwedzinski

Jodie writes, "Forevermore Tattoo Parlour presents Friday 13th Noir, a charity event for Rob Szwedzinski and research into the treatment and prevention of Inclusion Body Myositis. We are doing Friday 13th tattoos and holding a Friday 13th art exhibition in the Defectors Weld (next to the Forevermore Tattoo London).

A number of tattoo artists who work at Forevermore or are part of the wider Forevermore family have kindly donated artwork for the exhibition. The Moonshine Stalkers will also be playing a swing Jazz set for us on the exhibition night followed by some Motown, northern soul, disco and rock 'n' roll by DJ Trailer Trish." The event raised over £430 for the charity.

Bath Half- Marathon

Stefanie Patrick gave herself just 3 months to train for the Bath Half Marathon. With a back injury she completed her challenge and raised £190.

Stefanie says, "The charity is not very well known as Myositis is a very rare muscle condition, however it is very close to mine and my family's hearts. My mum was diagnosed with Dermatomyositis which is an auto immune disease and I've seen how much this charity has helped and supported her over the years."

Simon Marr - Major Series South

Simon quotes, "I'm getting Muddy for Myositis UK because I'M AFRAID OF IT." The major series South is the UK's most fun and friendly obstacle race. The course is littered with all kinds of obstacles, hills, mud and water! Simon took part and raised over £340 for the charity.

Published Research

▶ Genotyping of immune-related genetic variants identifies TYK2 as a novel associated locus for idiopathic inflammatory myopathies.

M Jani, J Massey, LR Wedderburn, J Vencovsky, K Danko, IE Lundberg, L Padyukov, A Selva-O'Callaghan, T Radstak, H Platt, RB Warren, CE Griffiths, A Lee, PK Gregersen, FW Miller, WE Ollier, RG Cooper, H Chinoy, JA Lamb; and EUMYONET.

Published in the journal *Annals of Rheumatic Disease* in May 2014.

▶ Entering a new phase of immunogenetics in the idiopathic inflammatory myopathies.

S Rothwell, RG Cooper, JA Lamb, H Chinoy.

Published in the journal *Current Opinion in Rheumatology* in November 2013

Abstract

PURPOSE OF REVIEW: To review the progress that has been made in understanding the genetics of the idiopathic inflammatory myopathies (IIMs) in the past 2 years, with particular focus on polymyositis, dermatomyositis and inclusion body myositis.

RECENT FINDINGS: Candidate gene studies in the Japanese population have implicated signal transducer and activator of transcription 4 as a risk locus for IIM, and HLA-DRB1 as a risk locus for anti-melanoma

differentiation-associated gene 5-positive dermatomyositis. Evidence for gene-environment interactions has been found between HLA-DRB1*03 and smoking as a risk factor for the development of anti-histidyl tRNA synthetase antibodies, and HLA-DRB1*11:01 and statins for the development of anti-hydroxymethyl glutaryl-coenzyme A reductase-positive statin-induced myopathy. The HLA-DRB1*03:01/*01:01 genotype confers the highest disease risk in inclusion body myositis. A recent genome-wide association study has been performed in dermatomyositis. The most significant

signals were in the major histocompatibility complex region, with other loci suggesting evidence of genetic overlap with different autoimmune diseases.

SUMMARY: Recent association and gene-environment interaction studies have increased our knowledge of genetic risk factors for the IIMs. Ongoing international collaborations will facilitate larger and more meaningful genetic studies revealing much about the genetic architecture of these complex diseases.

▶ Editorial: collaborative international research leads to new biomarkers for diagnosis and prediction of outcome in the idiopathic inflammatory myopathy spectrum.

H Chinoy and RG Cooper.

Published in the journal *Current Opinion in Rheumatology* in November 2013

▶ Genome-wide association study of dermatomyositis reveals genetic overlap with other autoimmune disorders.

FW Miller, RG Cooper, J Vencovsky, LG Rider, K Danko, LR Wedderburn, IE Lundberg, LM Pachman, AM Reed, SR Ytterberg, L Padyukov, A Selva-O'Callaghan, TR Radstake, DA Isenberg, H Chinoy, WE Ollier, TP O'Hanlon, B Peng, A Lee, JA Lamb, W Chen, CI Amos, PK Gregersen; Myositis Genetics Consortium. And 128 collaborators.

Published in *Arthritis & Rheumatism* December 2013.

Abstract

OBJECTIVE: To identify new genetic associations with juvenile and adult dermatomyositis (DM).

METHODS: We performed a genome-wide association study (GWAS) of adult and juvenile DM patients of European ancestry (n = 1,178) and controls (n = 4,724). To assess genetic overlap with other autoimmune disorders, we examined whether 141 single-nucleotide polymorphisms (SNPs) outside the major histocompatibility complex (MHC) locus, and previously associated with

autoimmune diseases, predispose to DM.

RESULTS: Compared to controls, patients with DM had a strong signal in the MHC region consisting of GWAS-level significance ($P < 5 \times 10^{-8}$) at 80 genotyped SNPs. An analysis of 141 non-MHC SNPs previously associated with autoimmune diseases showed that 3 SNPs linked with 3 genes were associated with DM, with a false discovery rate (FDR) of <0.05 . These genes were phospholipase C-like 1 (PLCL1; rs6738825, FDR = 0.00089), B lymphoid tyrosine kinase (BLK; rs2736340, FDR = 0.0031), and chemokine (C-C motif) ligand

21 (CCL21; rs951005, FDR = 0.0076). None of these genes was previously reported to be associated with DM.

CONCLUSION: Our findings confirm the MHC as the major genetic region associated with DM and indicate that DM shares non-MHC genetic features with other autoimmune diseases, suggesting the presence of additional novel risk loci. This first identification of autoimmune disease genetic predispositions shared with DM may lead to enhanced understanding of pathogenesis and novel diagnostic and therapeutic approaches.

► **Arthritis in idiopathic inflammatory myopathy: clinical features and autoantibody associations.**

M Klein, H Mann, L Pleštilová L, Z Betteridge, N McHugh, M Remáková, P Novota, J Vencovský.

Published in the Journal of Rheumatology in June 2014.

Abstract

OBJECTIVE: To determine the prevalence, distribution, and clinical manifestations of arthritis in a cohort of patients with idiopathic inflammatory myopathies (IIM). Associations with autoantibody status and HLA genetic background were also explored.

METHODS: Consecutive patients with IIM treated in a single center were included in this cross-sectional study (n = 106). History of arthritis, 68-joint and 66-joint tender and swollen joint index, clinical features of IIM, and autoantibody profiles were obtained by clinical examination, personal interview, and review of patient records. High-resolution genotyping

in HLA-DRB1 and HLA-DQB1 loci was performed in 71 and 73 patients, respectively.

RESULTS: A combination of patients' medical history and cross-sectional physical examination revealed that arthritis at any time during the disease course had occurred in 56 patients (53%). It was present at the beginning of the disease in 39 patients (37%) including 23 cases (22%) with arthritis preceding the onset of muscle weakness. On physical examination, 29% of patients had at least 1 swollen joint. The most frequently affected areas were wrists, and metacarpophalangeal and proximal interphalangeal joints. Twenty-seven out of the 29 anti-Jo1-positive

patients had arthritis at any time during the course of their illness; this prevalence was significantly higher compared to patients without the anti-Jo1 autoantibody ($p < 0.0001$). No association of arthritis with individual HLA alleles was found.

CONCLUSION: Our data suggest that arthritis is a common feature of myositis. It is frequently present at the onset of disease and it may even precede muscular manifestations of IIM. The most common presentation is a symmetrical, nonerosive polyarthritis affecting particularly the wrists, shoulders, and small joints of the hands. We have confirmed a strong association of arthritis with the presence of the anti-Jo1 antibody.

► **The diagnostic utility of autoantibodies in adult and juvenile myositis.**

SL Tansley, ZE Betteridge, NJ McHugh.

Published in the journal Current Opinion in Rheumatology in November 2013.

Abstract

PURPOSE OF REVIEW: The purpose of this study is to review recent advances in the diagnostic utility of autoantibodies in dermatomyositis.

RECENT FINDINGS: Alternative nonspecialist testing methods have been developed for anti-transcription

intermediary factor 1 gamma, anti-MDA5 and anti-nuclear matrix protein 2, which are potentially exploitable by any hospital laboratory. Although these have yet to be validated for diagnostic use, it is likely that testing for myositis-specific antibodies will soon become readily available.

SUMMARY: The identification of myositis-

specific autoantibodies provides both diagnostic and prognostic information and offers a unique opportunity to adopt a stratified approach to treatment. Their identification, in many cases, should prevent the need for invasive diagnostic tests such as muscle biopsy.

► New insights into the benefits of exercise for muscle health in patients with idiopathic inflammatory myositis.

L Alemo Munters, H Alexanderson, LJ Crofford, IE Lundberg.

To be published in the journal Current Rheumatology Reports in July 2014

Abstract

With recommended treatment, a majority with idiopathic inflammatory myopathy (IIM) develop muscle impairment and poor health. Beneficial effects of exercise have been reported on muscle performance, aerobic capacity and health in chronic polymyositis and dermatomyositis and to some extent in active disease and inclusion body myositis (IBM). Importantly,

randomized controlled trials (RCTs) indicate that improved health and decreased clinical disease activity could be mediated through increased aerobic capacity. Recently, reports seeking mechanisms underlying effects of exercise in skeletal muscle indicate increased aerobic capacity (i.e. increased mitochondrial capacity and capillary density, reduced lactate levels), activation of genes in

aerobic phenotype and muscle growth programs, and down regulation in genes related to inflammation. Altogether, exercise contributes to both systemic and within-muscle adaptations demonstrating that exercise is fundamental to improve muscle performance and health in IIM. There is a need for RCTs to study effects of exercise in active disease and IBM.

► Resistive Home Exercise in Patients with Recent-onset Polymyositis and Dermatomyositis - A Randomized Controlled Single-blinded Study with a 2-year Follow-up.

H Alexanderson, LA Munters, M Dastmalchi, I Loell, M Heimbürger, CH Opava, IE Lundberg.

Published in the Journal of Rheumatology in June 2014.

Abstract

OBJECTIVE: To evaluate the outcome of resistive home exercise and its possible longterm influence on health, disability, and disease activity in patients with active polymyositis (PM) or dermatomyositis (DM).

METHODS: Nineteen patients with recent-onset PM/DM were included after introduction of high-dose prednisolone. They were assessed by independent assessors as to perceived health, muscle performance, aerobic capacity, and serum creatine phosphokinase (CPK) at baseline and after 24 weeks, including repeated muscle biopsies at 24 weeks (single-blinded randomized controlled study), and in an open-label followup at

52, 78, and 104 weeks. Patients were randomized to 12 weeks, 5 days/week resistive home exercise with telephone support and encouragement for another 12 weeks of twice-a-week home or gym exercise (EG, n = 10) or to 24 weeks, 5 days/week range of motion exercise (CG, n = 9). Patients in the CG group without inflammatory infiltrates in muscle biopsies at 24 weeks were invited to the 12-week resistive home exercises.

RESULTS: At baseline, the EG had poorer perceived health, but otherwise the groups were comparable. At 24 weeks, both groups improved in muscle performance and aerobic capacity (p < 0.001 to < 0.05) with no signs of increased

inflammation assessed by CPK levels or muscle biopsies. Both groups improved in muscle performance and aerobic capacity up to 52 weeks (p < 0.05) lasting to 104 weeks in the EG (p < 0.05) and presented minor improvements in perceived health.

CONCLUSION: Our study supports the safety of resistive exercise in patients with active PM/DM but did not reveal any between-group differences in exercise effects. An individually adapted physical therapist-supervised home exercise program might be recommended in early active PM/DM, with regular evaluation of muscle performance and health.

► Progress report on the development of new classification criteria for adult and juvenile idiopathic inflammatory myopathies.

C Pilkington, A Tjärnlund, M Bottai, LG Rider, VP Werth, M Visser, L Alfredsson, AA Amato, RJ Barohn, MH Liang, JA Singh, FW Miller, IE Lundberg; members of the IMCCP International Myositis Classification Criteria Project.

Published in Arthritis & Rheumatology in March 2014.

Abstract

BACKGROUND/PURPOSE: Inadequate classification criteria for IIM are a fundamental limitation in clinical studies. An international, multidisciplinary collaboration, the International Myositis Classification Criteria Project (IMCCP), supported by ACR and EULAR, was established to address this problem.

METHODS: Identification and definition of potential criterion Candidate variables to be included in classification criteria were assembled from published criteria and inclusion criteria in controlled trials of myositis and refined using Nominal Group Technique. Comparator groups confused with IIM were defined.

DATA COLLECTION: Within this retrospective case control study, clinical and laboratory data from IIM and comparator patients were collected from 47 rheumatology, dermatology, neurology and pediatrics clinics worldwide from 2008-2011.

ANALYSIS: Crude pair-wise associations among all variables measured and between each variable and clinician's diagnosis were assessed. Three approaches for derivation of classification criteria were explored: Traditional: case defined by specified number of items from a set Risk score: patient assigned a probability risk score by summing score-points associated with the variables (Probability model 1 and 2) Classification tree: case defined by a decision tree A random forest algorithm explored the most important variables. Results obtained with each approach were utilized to improve others iteratively.

VALIDATION: Internal validation using bootstrap methods was performed. External validation using extracted data from the Euromyositis register and an UK juvenile myositis register was performed.

RESULTS: Data from 973 IIM patients (74% adults; 26% children), representing subgroups of IIM (245 polymyositis, 239 dermatomyositis, 176 inclusion body

myositis and 246 juvenile dermatomyositis cases) and 629 comparators (81% adults; 19% children) were obtained. The comparators include other myopathies and systemic rheumatic diseases. Two probability score models were developed (Table): Model 1 comprised clinical variables on muscles, skin, and laboratory measures; Model 2 additionally comprised muscle biopsy variables. Model 1 performed nearly as well as Model 2 and both models performed as well as and often better than, the classification tree that was developed and published criteria. External validation using data on 2363 myositis patients in the Euromyositis register resulted in >99% sensitivity, and using 332 juvenile myositis cases resulted in 100% sensitivity for both probability models. [Table: see text] [Table: see text]

CONCLUSION: New classification criteria for IIM with readily clinically assessable measurements and symptoms have been developed. They generally show superior performance compared with existing criteria.

► Non volitional assessment of muscle endurance in Idiopathic Inflammatory Myopathies (IIM): There is no relationship between patient reported fatigue and muscle fatigability.

R Campbell, P Gordon, K Ward, C Reilly, DL Scott, G Rafferty.

Published in Muscle & Nerve in December 2013.

Abstract

Introduction: We investigated whether muscle endurance differs between IIM patients and controls and if a relationship exists between perceived fatigue and poor muscle endurance.

Methods: Quadriceps contractility, measured using femoral nerve stimulation (TwQ), and strength, measured using maximal voluntary contraction (MVCQ),

were assessed in 20 IIM patients and matched controls. Quadriceps endurance was assessed using repetitive electrical stimulation (3 minutes). Time for force to fall to 70% initial force was determined (T70). Reported fatigue was measured using FACIT-F / fatigue severity scales.

Results: TwQ and MVCQ were lower and perceived fatigue greater for patients. There was no difference in T70 between groups. No relationships were observed between

perceived fatigue and endurance (T70).

Discussion: IIM patients reported more fatigue and were weaker than controls, but there was no difference in muscle endurance. Endurance and strength were unrelated to reported fatigue measures. Mechanisms driving perceived IIM fatigue are likely to be multi-factorial.

► Classifying idiopathic inflammatory myopathies: comparing the performance of six existing criteria.

H Linklater, N Pipitone, MR Rose, F Norwood, R Campbell, C Salvarani, DL Scott, P Gordon.

Published in *Clinical Experiment Rheumatology* in June 2013.

Abstract

OBJECTIVES: Various criteria have been proposed to classify the inflammatory myositides (IIMs) polymyositis (PM) and dermatomyositis (DM). However, none have received universal acceptance. Our aim was to assess the performance of the main criteria used to classify IIM. Specialist consultant diagnosis was considered the gold standard.

METHODS: Patients attending King's College Hospital (KCH) or Reggio Emilia Hospital (REH) since 1990 with a diagnosis of IIM or non-inflammatory myopathy were identified, and their records and

laboratory investigations retrospectively reviewed. Where the complete data required for the classification criteria or a final physician diagnosis was unavailable, patients were excluded. 52 patients with a specialist diagnosis of PM, DM, inclusion body myositis (IBM) or non-inflammatory myopathy were included. Agreement between specialist consultant diagnosis and classification criteria was measured using Cohen's kappa (κ) statistics. Sensitivity and specificity were also calculated.

RESULTS: The Dalakas (2003) criteria demonstrated substantial agreement with

specialist diagnosis: $\kappa=0.69$, sensitivity 77%, specificity 99%. The European Neuromuscular Centre criteria (ENMC) demonstrated fair agreement: $\kappa=0.49$, sensitivity 71%, specificity 82%. Other criteria performed less well. In particular, the Bohan and Peter criteria demonstrated a specificity of only 29%.

CONCLUSIONS: The criteria of Dalakas (2003) agreed best with specialist consultant diagnosis. The criteria of Bohan and Peter demonstrated very poor specificity. Prospective studies are required to develop improved classification criteria.

► A retrospective cohort study identifying the principal pathological features useful in the diagnosis of inclusion body myositis.

S Brady, W Squier, C Sewry, M Hanna, D Hilton-Jones, JL Holton.

Published in *BMJ Open* in April 2014.

Abstract

OBJECTIVE: The current pathological diagnostic criteria for sporadic inclusion body myositis (IBM) lack sensitivity. Using immunohistochemical techniques abnormal protein aggregates have been identified in IBM, including some associated with neurodegenerative disorders. Our objective was to investigate the diagnostic utility of a number of markers of protein aggregates together with mitochondrial and inflammatory changes in IBM.

DESIGN: Retrospective cohort study. The sensitivity of pathological features was evaluated in cases of Griggs definite IBM. The diagnostic potential of the most reliable features was then assessed in clinically typical IBM with rimmed vacuoles (n=15), clinically typical IBM without rimmed

vacuoles (n=9) and IBM mimics—protein accumulation myopathies containing rimmed vacuoles (n=7) and steroid-responsive inflammatory myopathies (n=11).

SETTING: Specialist muscle services at the John Radcliffe Hospital, Oxford and the National Hospital for Neurology and Neurosurgery, London.

RESULTS: Individual pathological features, in isolation, lacked sensitivity and specificity. However, the morphology and distribution of p62 aggregates in IBM were characteristic and in a myopathy with rimmed vacuoles, the combination of characteristic p62 aggregates and increased sarcolemmal and internal major histocompatibility complex class I expression or endomysial T cells were

diagnostic for IBM with a sensitivity of 93% and specificity of 100%. In an inflammatory myopathy lacking rimmed vacuoles, the presence of mitochondrial changes was 100% sensitive and 73% specific for IBM; characteristic p62 aggregates were specific (91%), but lacked sensitivity (44%).

CONCLUSIONS: We propose an easily applied diagnostic algorithm for the pathological diagnosis of IBM. Additionally our findings support the hypothesis that many of the pathological features considered typical of IBM develop later in the disease, explaining their poor sensitivity at disease presentation and emphasising the need for revised pathological criteria to supplement the clinical criteria in the diagnosis of IBM.

► Widespread RNA metabolism impairment in sporadic inclusion body myositis TDP43-proteinopathy.

A Cortese, V Plagnol, S Brady, R Simone, T Lashley, A Acevedo-Arozena, R de Silva, L Greensmith, J Holton, MG Hanna, EM Fisher, P Fratta.

Published in the journal *Neurobiology of Aging* in June 2014.

Abstract

TDP43 protein mislocalization is a hallmark of the neurodegenerative diseases amyotrophic lateral sclerosis and frontotemporal dementia, and mutations in the gene encoding TDP43 cause both disorders, further highlighting its role in disease pathogenesis. TDP43 is a heterogenous ribonucleoprotein, therefore suggesting that alterations in RNA metabolism play a role in these disorders, although direct evidence in patients is lacking. Sporadic inclusion body myositis (sIBM) is the most common acquired myopathy occurring in adults

aged older than 50 years and abnormal cytoplasmic accumulations of TDP43 have been consistently described in sIBM myofibers. Here, we exploit high quality RNA from frozen sIBM muscle biopsies for transcriptomic studies on TDP43-proteinopathy patient tissue. Surprisingly, we found widespread sIBM-specific changes in the RNA metabolism pathways themselves. Consistent with this finding, we describe novel RNA binding proteins to mislocalize in the cytoplasm of sIBM myofibers and splicing changes in MAPT, a gene previously shown to play a role in sIBM.

Our data indicate widespread alterations of RNA metabolism are a novel aspect of disease pathogenesis in sIBM. These findings also document an association, in TDP43-proteinopathy patients, between heterogenous ribonucleoprotein pathology and RNA metabolism alterations and carry importance for neurodegenerative diseases, such as amyotrophic lateral sclerosis and frontotemporal dementia. Full online paper accessible online <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3988933/>

► 188th ENMC International Workshop: Inclusion Body Myositis, 2-4 December 2011, Naarden, The Netherlands.

M R Rose; ENMC IBM Working Group (26 Collaborators).

Published in the journal *Neuromuscular Disorders* in December 2013.

► Update in inclusion body myositis.

P Machado, S Brady, M G Hanna.

Published in the journal *Current Opinions in Rheumatology* in November 2013.

Abstract

PURPOSE OF REVIEW: The purpose of this study is to review recent scientific advances relating to the natural history, cause, treatment and serum and imaging biomarkers of inclusion body myositis (IBM).

RECENT FINDINGS: Several theories regarding the aetiopathogenesis of IBM are being explored and new therapeutic approaches are being investigated. New diagnostic criteria have been proposed, reflecting the knowledge that the

diagnostic pathological findings may be absent in patients with clinically typical IBM. The role of MRI in IBM is expanding and knowledge about pathological biomarkers is increasing. The recent description of autoantibodies to cytosolic 5' nucleotidase 1A in patients with IBM is a potentially important advance that may aid early diagnosis and provides new evidence regarding the role of autoimmunity in IBM.

SUMMARY: IBM remains an enigmatic and often misdiagnosed disease. The

pathogenesis of the disease is still not fully understood. To date, pharmacological treatment trials have failed to show clear efficacy. Future research should continue to focus on improving understanding of the pathophysiological mechanisms of the disease and on the identification of reliable and sensitive outcome measures for clinical trials. IBM is a rare disease and international multicentre collaboration for trials is important to translate research advances into improved patient outcomes.

► Frequency and circumstances of falls in people with inclusion body myositis: a questionnaire survey to explore falls management and physiotherapy provision.

A Hiscock, L Dewar, M Parton, P Machado, M Hanna, G Ramdhary.

Published in *Physiotherapy* in March 2014.

Abstract

OBJECTIVES: To survey the incidence and circumstances of falls for people with inclusion body myositis (IBM) in the UK, and to investigate the provision of physiotherapy and falls management.

DESIGN: Postal questionnaire survey.

SETTING: Participants completed questionnaires at home.

PARTICIPANTS: Ninety-four people diagnosed with IBM were screened against the inclusion criteria. Seventy-two potential participants were sent a questionnaire, and 62 were completed and returned. Invited participants were sent an adapted Falls Event Questionnaire

pertaining to falls, perceived causes of falls and the provision of physiotherapy. Questionnaires were returned anonymously.

MAIN OUTCOME MEASURES: The proportions of respondents who reported a fall or a near fall, along with the frequencies of falls and near falls were calculated. Descriptive data of falls were collected pertaining to location and cause. Data analysis was performed to investigate provision of physiotherapy services.

RESULTS: The response rate was 86% [62/72, mean (standard deviation) age 68 (8) years]. Falls were reported by 98% (61/62) of respondents, with 60% (37/62) falling frequently. In this study, age

was not found to be an indicator of falls risk or frequency. Twenty-one percent (13/62) of respondents had not seen a physiotherapist in relation to their IBM symptoms, and of those that had, 31% (15/49) had not seen a physiotherapist until more than 12 months after IBM was diagnosed. Only 18% (11/61) of fallers reported that they had received falls management input.

CONCLUSIONS: Falls are a common occurrence for people with IBM, independent of age and years since symptoms first presented, and are poorly addressed by appropriate physiotherapy management. National falls guidelines are not being followed, and referral rates to physiotherapy need to improve.

Useful Websites

Disability Now

The Disability Now website is a useful resource for information. It recently had an article by Helen Dolphin warning of a blue badge online application scam. The fee to apply for a blue badge (returned to unsuccessful applicants) is £10 in England, £20 in Scotland and £2 in Northern Ireland and free of charge in Wales. Some online applications to the person's local authority were being re-routed to an unauthorised website and charging £49, the difference was being pocketed by the scammers. The scam came about when applications could be made online via gov.uk rather than directly applying with the local authority. Applications made online at gov.uk are secure but the problem arose when people searched online terms "blue badge application". The scamming companies took advantage and appeared as a result for the

search term and people used the website and paid the overpriced fee without realising.

The article advises "To ensure that you are using the right website either go to GOV.UK or go directly to your own local authority website. You should also be alarmed if you are charged more than the maximum amount for your country."

You can read the article in full and other interesting articles on their website www.disabilitynow.org.uk

disabilitynow

our voice, our lives

Arthritis Research UK

Arthritis Research UK produce many leaflets and you may find these in your clinic. Of interest are the leaflets on Pain and Fatigue. All the ARUK leaflets can be found on their website www.arthritisresearchuk.org



Do you suffer from fatigue?

Fatigue is a feeling of extreme physical or mental tiredness, or both. Most of us feel tired after a long day, but if you have a long-term medical condition such as arthritis you may experience a tiredness that's quite different in quality and intensity and which doesn't always improve after rest.

Many people also report mental fatigue, when they can't think straight and lose their concentration or motivation. Some patients refer to this as "brain fog". Read more about fatigue on their website <http://www.arthritisresearchuk.org/arthritis-information/arthritis-information-search-results.aspx?keywords=fatigue>

What are your tips that help you battle fatigue?



Living with long-term pain: a guide to self-management

Pain is one of the main symptoms of arthritis and musculoskeletal conditions. For some people, the pain is long-lasting and interferes with their daily life, stopping them doing the things they enjoy.

We've produced a self-management guide for people with long-term pain. It includes information on different approaches to pain relief,

who you can ask for support and self-help tips. It also includes activities for you to complete to help you record and assess your experiences.

See more at:

www.arthritisresearchuk.org/arthritis-information/arthritis-and-daily-life/pain-and-arthritis/pain-report.aspx

NHS Second Opinion

If you are wishing for a second opinion the NHS Choices website provides the following information. www.nhs.uk/choq/Pages/910.aspx

You can ask your GP or another healthcare professional for a second or further opinion (an opinion about your health condition from a different doctor). Although you do not have a legal right to a second opinion, a healthcare professional will rarely refuse to refer you for one.

Do you need a second opinion?

Before asking for a second opinion, it's worth asking your GP or consultant to go over your diagnosis and explain anything you don't understand. If you're unhappy with your diagnosis or would like to consider a different course of treatment, discuss this with them. Your GP or consultant will be happy to explain things and in many cases there may be no need for a second opinion.

Can anyone else ask for a second opinion?

Your family or carer can also ask

for a second opinion on your behalf, but only with your consent. If someone requests a second opinion on your behalf, they should have all the information about your illness or condition, and check they understand it thoroughly. Sometimes a GP or consultant may ask a colleague to provide a second opinion. For example, doctors may ask their colleagues about a complicated case.

Second opinion from a different GP

If you would like a second opinion after receiving advice from your GP, you can ask them to refer you to another GP. Alternatively, you may consider asking to see a different GP at your surgery, if you're registered at a surgery with more than one GP, or changing to a different GP surgery.

Second opinion from a different consultant

If you would like a second opinion after seeing a consultant (a senior medical doctor who specialises in a particular field of medicine),

you need to go back to your GP and ask them to refer you again. If your GP agrees to refer you to a new consultant, the consultant will be told that this is your second opinion. They will also be sent any relevant test results or X-rays previously carried out. This does not mean that the new consultant will automatically take over your care. If you want to be treated by the new consultant, this will need to be arranged with the doctors and hospital.

How long will I have to wait for a second opinion?

People who ask for a second opinion have already seen a doctor, so they may have to wait. A second opinion with a different consultant will also usually be at a different hospital, which may involve some travelling. Getting a second opinion may therefore delay any treatment that you need. If you have a serious medical condition, you should take this into account when deciding to ask for a second opinion. Ask your doctor whether a delay in starting treatment could be harmful.

The Prescription Charges Coalition

Myositis UK has joined The Prescription Charges Coalition. It's a group that brings together 30 organisations calling on the Government to extend exemption from prescription charges to all

those with long-term medical conditions in England. Please visit the website, sign the online petition & email your MP if you would like to support the campaign. www.prescriptionchargescoalition.org.uk/

Future Events



British 10K

This takes place on Sunday 13th July 2014. Do you wish to run or have family and friends who would like to take part in this fantastic and probably the best 10k in Britain? We still have 2 places available! Sightseeing London by road without a motor vehicle to run you down! I have done this run and it really is an occasion with a wow factor. Please get in touch with the office if you are interested or for more information.

London Marathon 2015

If you know of anyone who would like to take part in the London Marathon next year and would like one of our Gold Bond places please contact the office for an application form. Places will be allocated at the trustee meeting in September. Runners are required to raise a minimum of £1,000.

Social Media

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

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

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

Team Muscle Facebook page is for anyone fundraising or supporting fundraising for Myositis UK. It is a great way to promote your event, share your Just Giving Page, upload photos or updates and for supporters to see your event. Initially set-up for our Gold Bond London Marathon runners this

Page is now for all fundraisers whatever your activities are.

Paula Jordan and Jo Good administer this Page.

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

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

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

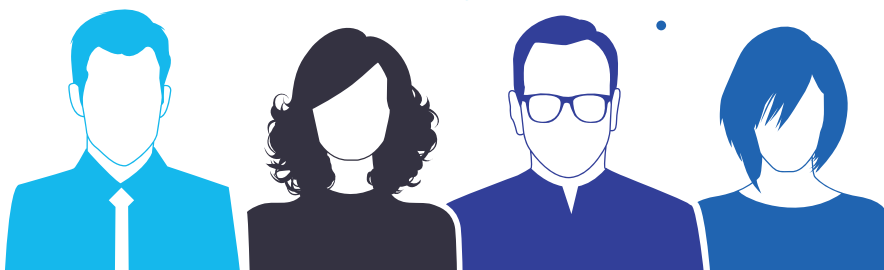
Dermatomyositis-JDM/95955942990

Teddy-Bo his friends, adventures and juvenile dermatomyositis Facebook Page

is administered by Paula Jordan and Nikki Coleman.

This Page allows anyone to follow Teddy-Bo on his adventures as he meets his friends and raises awareness of the inflammatory muscle disease. A distinct Page set-up to allow followers to just follow Teddy-Bo. The Page is for your photos and stories so wherever you and Teddy-Bo are, snap it and post on the Page.

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



● *Christmas Cards & Christmas Draw*

The trustees have decided to hold the annual draw at Christmas again this year. Christmas Card order forms and draw tickets will be send out to all members.

If you have any contacts for draw prizes please let us know!

● *Welfare Advice*

Janet Horton can be contacted at, 1 Fellstone Vale, Withnell, Chorley, Lancs, PR6 8UE. She will be pleased to help Myositis UK 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 UK 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.

● *Myositis Book*

Jenny Fenton has kindly donated copies of her book to the Group. If you would like a copy please send £5 to cover the cost of

postage and packaging to the office. This is a saving of £9 on the original price.

Postscript

I would like to thank everyone who has emailed or written in to the office offering words of kindness and support during a very busy period. I would also like to thank members, their families and friends for their private donations in support of the charity's work. I would like to express my gratitude

to Irene, my wife and charity coordinator, for seemingly tireless energy and enthusiasm even though in recent years she has had to cope and recover from serious personal health issues and very taxing mobility problems.

Les Oakley MBE
Chairman



146 Newtown Road, Woolston, Southampton, SO19 9HR
t 023 8044 9708 e office@myositis.org.uk www.myositis.org.uk

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