



Chairman's Report

Success is a word I would usually use with caution. It opens up a lot of pit falls. However, in writing this report I am looking back over the year and I can use this word freely in the knowledge it has been a good year for the charity and a year of advancement in the treatment and management of Myositis.

The conference was a resounding success made possible by Irene who put together a programme of highly respected speakers who themselves made comment that this had produced a collective enthusiasm that could only bode well for the future. We were also

fortunate that we had the conference recorded on DVD which I now consider the most definitive record on Myositis and will be a useful and a valid source of information to help sufferers for the next few years. The medical content of the meeting was again chaired by Professor David Scott who has a remarkable ability and honesty to make the conference interesting and meaningful. All the medical profession present gave their time freely on a Saturday to help our cause with interesting and enthusiastic presentations about their work and the future for Myositis study. It was particularly rewarding to have Dr Chester Oddis who had travelled from the United States of America to be with us.

Success can also be attributed to the new web site launched in August last year. The teething problems were few and being a genuine luddite it took a few weeks for me to adjust to the new system but once mastered the benefits and speed of operation are a great improvement. I dislike change but we realised this change had to come. Since the launch over 200 people have joined on line in the UK, 99 overseas and over 220 registered on the new community board. When using a search engine to find the charity the MSG is usually the first in the results and always within the first five.

In March of this year the resource, "The Listening Ear" was successfully launched. This is for members who may not wish to use or do not have a computer to talk to fellow members. Members have kindly put themselves as a point of contact for others to get in touch to discuss their Myositis and already resulting in sound friendships being made. Our secretary, Paula, has developed this service that has taken much time and effort for her and she is pleased with the role this service will give to members.

Success has also been achieved in the progress of medical research sponsored by the charity into all forms of Myositis. These projects have taken place or are still in progress at Bath University, Imperial College London, Institute of Child Health, Manchester University and University College London.

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INCLUSION BODY MYOSITIS
JUVENILE DERMATOMYOSITIS

These projects needed to be funded and my appeal last year to members, their family and friends to help raise money was successful. Many responded with all manner of fund raising activities and individuals also played a more private role in helping by personal donations. There were also financial gifts in memory of loved ones to help as well. The Run for Richard Campaign and our London Marathon runners with support of the charity members made a significant impact this year.

The charity has also been fortunate that we have dedicated and extremely hard working Trustees. Our Group coordinator, my dear wife Irene, along with our daughter, Paula who is our general secretary and minute secretary, have put in many long hours covering every facet of charity work associated with the Myositis Support Group that have included several trips to London and other cities. They have been supported at our meetings by trustees, Tony and Sue Hindle and Catherine Risley who are wonderful servants to our cause. Of course holding onto the financial reins which at times can be an onerous task is our honouree treasurer, Jo Goode. As the charity grows her work load grows and yet she still finds time for this role along with coping with a busy family life. My gratitude is also offered to our auditor, Bridget Kalloushi for her service and help she has given freely to the charity.

On a personal issue, how can you say the year has been less than a success when you have been made a Member of the Order of the British Empire. As chairman I am so very proud and grateful to everyone involved in the application and submission for this award.

There is always need for improvement and one of the main issues which we have been trying to address for some time is the updating of our information on all forms of Myositis. Catherine and Paula have been working on this. They have the treatment and Juvenile information almost ready but a major problem has been that medical progress has advanced more quickly than they can work on the information and we now feel it needs to be addressed by perhaps those working at the cutting edge of the diseases. Neither Paula or Catherine have the spare time to do so, especially as Catherine is getting married in August! We are therefore looking into other ways to have the literature updated.

In conclusion our progress over the years has been a steady path of advancement in the understanding and treatment of Myositis. I feel we have much to look forward to in the coming year.

Les Oakley - Chairman

Executive Committee

2007-2008

Chairman

Mr Leslie Oakley

General Secretary

Miss Paula Oakley

Honorary Treasurer

Mrs Joanne Goode

Committee Members

Mr Tony Hindle

Mrs Sue Hindle

Ms Catherine Risley



Trustees with Dr Chester Oddis and Group Co-ordinator Irene Oakley. From L to R; Paula Oakley, Les Oakley, Chester Oddis, Catherine Risley, Irene Oakley, Joanne Goode, Sue Hindle, and Tony Hindle.

Charity Review

New Year's Honours for Chairman

Chairman Les Oakley was awarded an MBE in the New Year's Honours and received his award from Prince Charles in the Ball Room of Buckingham Palace on the 19th March.

The award was in recognition of his service to people with Myositis. Les founded the Support Group with his wife Irene in 1986 initially to put parents of JDM sufferers in touch with each. The Support Group became a Registered Charity in 1987 and since then, with Les and Irene still at the helm and working hard, the Support Group has helped thousands of people, raised a considerable amount of money to fund Myositis research in more than ten institutions and has held yearly meetings and four yearly large conferences. Les has been an active fundraiser too, he has a regular second-hand bookstall outside his business premises, cycled 175 miles in two days from Paris to Hayling Island in 2001 and regularly attends meetings to raise awareness of Myositis.



Les holding his MBE with his mum Rene, wife Irene and daughter Paula in the grounds of Buckingham Palace

"I was delighted to see the announcement of your award in the New Year's Honours List. It is splendid that your achievements have been recognised in this way and the award is well deserved. Many congratulations."

Alan Johnson (Secretary of State for Health)

"Very many congratulations on your award in the New Year's Honours List. I read all the citations so know how much this honour is deserved. I am sure that it will be widely welcomed."

Hugh Taylor (Permanent Secretary, Department of Health)



Listening Ear Telephone Network

The Listening Ear Telephone Network was launched in March. The LETN is a directory of members with Myositis who have volunteered themselves as a point of telephone contact to support others affected by the disease. Details of how to obtain a copy of the LETN feature regularly in the Newsletter and are included in the new member welcome pack and on the "About Us" page of the charity website.

Conference

The four-yearly larger conference was held in July and attendance was over 140 delegates. The conference was chaired by Professor David Scott (Kings College London) and guest speaker was Dr Chester Oddis from Pittsburgh University and a member of the Medical Advisory Board for the Myositis Association (USA). Also presenting were Dr Robert Cooper (Manchester University), Dr Harsha Gunawardena (Bath University), Professor David Isenberg (UCL), Dr Michael Rose (King's College London), Dr Clarissa Pilkington (Great Ormond Street), and Dr Ernest Choy (King's College London). The Iris Hazel Memorial Talk was given by member Anne Ali. Dr Zoe Betteridge (Bath University) and Dr Jo Cambridge (UCL) also attended.

A double DVD of the conference talks was produced. This cost £2399 and sales of the DVD have returned £850. The purpose of the DVD was not to raise money but to obtain a resource for members that gives a definitive record of Myositis including the current and forthcoming research in the medical world.



Doctors conversing at the Conference. From L to R; Dr Pilkington, Dr Cooper, Dr Rose, Dr Choy, Dr Betteridge, and Professor Isenberg.

Fundraising

Group Fundraising

The **London Marathon**, **Grand Summer Draw** and **Christmas Cards** are fundraising activities easy to support. The combined profit generated from them this year was £6369 - an invaluable source of income to the charity so thank you for supporting them.

Frank Littler ran on behalf of the Myositis Support Group in the **Flora London Marathon** in April 2007. He completed the 26-mile run in 3 hours 45 minutes. His effort helped the Support Group raise £2394.

The **Grand Summer Draw** raised a profit of £1164. Draw tickets were sold by members and supporters. Our appreciation once again goes to Draper Tools and other private donators who gave prizes for the draw.

Profit on **Christmas Cards** raised £2811. Thanks to everyone who purchased our Christmas cards and a special thanks to Frances Ferguson who again as in previous years sold a substantial amount of packs.

Other Fundraising, Just Giving and Donations

This year's **Fundraising Activities** by members have again been varied and included a the 26 miles for Richard Campaign, Rotterdam Marathon, May Day Fayre, BBQs, coffee mornings, dress down days, charity golf days, craft demonstrations, Northwich Charity Event, after dinner speeches, sponsored silence, Mind Body and Spirit Festival, cake and produce sales.



justgiving
fundraising made easy

The Support Group is now registered with Just Giving and many fundraisers took advantage of this facility and set up a Just Giving Page for their supporters to sponsor them. Fundraising pages were set up by Bradley Dearnley (coast to coast bike ride), Danni Smith (tamden ride from Big Ben to the Eiffel Tower), Anthony Armstrong (Chest Wax), Lee Adler (MZ5Nutz Drag Race), Catherine Risley (Hydro Active Women's Challenge), Catherine Singfield (Hydro Active Women's Challenge), Andrew Allan (Great North Run), Lynne Nazer (Sponsored Diet), Ruth O'Rourke (Great North Run), and Shelley Egan (Going Blue). Just Giving Pages are an easy way to advertise and ask your friends, family and work colleagues to support you and includes a link to the Myositis Support Group website. All these efforts were greatly appreciated and raised over £5000 which allows the Support Group to continue its work.

We received many **private donations** and were able to claim back £2307 through the **Gift Aid scheme**. The Myositis Support Group would not be able to make the commitments to research projects if it were not for the donations received. We are very appreciative for the many private donations that are sent in with the simple message, 'please put towards funds!' and donations that are sent in lieu of birthday, anniversary and Christmas presents as well as those in memory of a lost loved one.



Everyclick, BuyAt and Reclaim It



The new initiatives to raise funds, Everyclick, BuyAt and Reclaim-it have been fruitful. "Everyclick" is a search engine that generates funds by registered users using it to search the internet. "BuyAt" is a webshop interface to hundreds of high street stores that offers commission on purchases made through it and "Reclaim-it" is a recycling scheme for used printer cartridges and mobile phones. All these initiatives offer simplicity at no cost to the user. If you are not using any of these and are able to please consider doing so. Details are published regularly in the Newsletter and Reclaim-it recycling bags have been sent out with new member welcome packs and Newsletters.

Research

The Support Group has been central to funding and assisting in Myositis focussed research in the UK. This year, with financial support from the Charity, work in Myositis was undertaken at Manchester University, University College London, Imperial College and the University of Bath. Funding was also given to the Institute of Child Health to update the server and maintain the Juvenile Dermatomyositis Registry and Repository of the UK and Northern Island.



Key to the research this year has been collaboration. Doctors from the University of Bath, the Institute of Child Health, and Manchester University worked together to assess haplotypes and autoantibodies associated with Juvenile Dermatomyositis. Findings from this work were published in the medical journal *Rheumatology* in December 2007 and March 2008.

Dr Chinoy and **Dr Cooper** (Manchester University) of the Adult Myositis Onset Immunogenetic Collaboration (AMOIC), whose work on investigating genetic polymorphisms associated with Polymyositis and/or Dermatomyositis was part-funded by the Support Group, have continued to publish their findings in medical journals this year. These include the journals *Rheumatology* (April 2007 and September 2007) and *Annals of Rheumatic Diseases* (July 2007 and October 2007). Dr Cooper spoke at the Conference about this work, "**What has Genetics taught us so far about Myositis**".

Professor McHugh (University of Bath) was awarded £18,212 for the salary of Dr Betteridge. This grant was awarded using funds held in memory of Letitia Rawson. **Dr Betteridge** became the holder of the, "Letitia Rawson Fellowship" and worked with Dr Gunawardena on the identification of novel autoantibodies in myositis. Their work was published in the journals *Rheumatology* (June 2007), *Arthritis and Rheumatism* (September 2007) and in collaboration with the AMOIC and the JDM Research Group UK. Dr Gunawardena presented their research, "**Autoantibodies in Myositis - New Findings**" at the Conference.

A small equipment grant for £2,025 was awarded last year to **Dr Harari** (Imperial College) to assist in the identification of novel myositis autoantibodies. This work is currently being undertaken by scientist **Peter Charles** and will be completed shortly.

Dr Cooper, **Professor Ollier** and **Dr Lamb** were awarded £35,000 towards a Genome Wide Association Study in Myositis. This project is further development of the genetic research performed at Manchester University and will utilise new "gene chip" technology only recently available. The project aims to scan 650 European cases of myositis, of which the majority will be from the AMOIC Registry and Repository held by Dr Cooper. To ensure a suitable number of samples are scanned to yield good data collaboration has been set up with Sweden, Czech Republic, Hungary and the Netherlands, known as the European Myositis Consortium. Samples will be prepared at Manchester and then sent for analysis in the USA. The total cost of the project is £120,000 and Dr Cooper was able to obtain grants from AutoCure (£75,000) and other sources (£40,000). The purpose of a Genome Wide Association Study in Myositis is to obtain genetic information which may be useful in the future to diagnose a myositis sub-type, identify novel targets for treatment intervention and determine genetic risk factors associated with complications like interstitial lung disease or cancer.

Funding for computerisation of the MITAX and MYODAM indices was completed this year (£20,000 in total). At the conference **Professor Isenberg** spoke on, "**Developing the Tools to Assess People with Myositis**" and **Dr Oddis** spoke on, "**The Birth of Clinical Trials in Myositis: The RIM Study**" for which the computerised tools will be used.

Dr Wedderburn (Institute of Child Health) has been awarded a two year grant from the research charity Action Medical for just over £114,000 to develop further the JDM Muscle Biopsy Study. The JDM Muscle Biopsy Consensus Workshops aimed to develop a muscle biopsy scoring tool were funded by the Support Group (approximately £47,583) and this study was published in the journal Arthritis and Rheumatism (October 2007). It is good to see a larger organisation able to fund the research further.

The year ahead is looking promising for research into Inclusion Body Myositis. Establishment of the MRC Neuromuscular Centre will lead to IBM focussed research. Doctors and researchers with a specific interest in IBM and adult muscle disease will meet in June 2008 to develop ideas for IBM research in the UK. Key to this work will be medical collaboration and establishment of an IBM Registry and Repository. **Professor Hanna** and **Dr Miller** plan to set up the collection of IBM patient samples for laboratory research and potentially a Genome Wide Association Study. **Dr Holton**, **Professor Hanna** and **Professor Sewry** have proposed a study to establish pathological criteria for the diagnosis of IBM. This will be a project similar to that of the JDM Muscle Biopsy Consensus Study Group who defined criteria to establish a muscle biopsy scoring tool for JDM.

Research Grants

The Myositis Support Group paid out over £68,200 this year to Myositis research projects.

Paid out	Professor David Isenberg University College London	The Final £10,000 (of a grant of £20,000) for the design of a computer programme to implement the MITAX and MYODAM indices developed by the IMOACG. 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.
Awarded & Paid Out	Dr. Robert Cooper Professor Ollier Dr Lamb University of Manchester	£35,000 to undertake a collaborative Genome Wide Association Scan in Idiopathic Inflammatory Myositis.
Paid Out	Dr. Lucy Wedderburn Institute of Child Health	£5000 for a replacement server for the JMD National Registry and Repository of UK and Ireland.
Awarded & Paid Out	Professor Neil McHugh University of Bath	The Letitia Rawson Fellowship. £18,212 bridging salary for Dr. Zoe Betteridge to undertake research into the Clinical and Immunogenetic Associations of Anti SAE Auto antibodies in patients with Dermatomyositis. Further funding will be awarded in the next financial year.

Financial Report

The income of the Myositis Support Group for the year ending 31 March 2008 was £64,935 and resulted from fundraising and donations (84%), reclaimed money on donations through the Gift Aid scheme (4%) and bank interest (11%). The income for Gift Aid reclaim appears lower than last year because this figure does not take into account money automatically reclaimed on donations made through the Just Giving website. Overall income was £13,000 more than last year.

No income was received from the government, pharmaceutical industries or national lottery. A legacy of £1000 and monies in memoriam contributed to 15% of the charity's income. Donating by Standing Orders and Pay As You Earn Schemes have been promoted this year through the welcome pack sent to all new members on joining. Income from donations was £8464 (30% of total income) and non-group fundraising was £11,233 (17% of income). Income from both donations and fundraising were increased on last year. Group fundraising (London Marathon, Grand Summer Draw, and Christmas Cards) raised £10,301 (16% of income), this is comparable to last year's £10,970. These events continue to provide a steady income to the charity but unfortunately have not increased proportionally to that of the increase in membership over the year. Much of the membership growth has been through people joining online. We are ensuring all Group fundraising events are promoted to these members as well as to postal members.

The Support Group will endeavour to maintain our financial strength. However, a significant amount of money has been committed to funding Myositis projects over the next year. Membership to the charity (United Kingdom residents) will remain free of charge.

Statement of Income & Expenditure for the Year Ended 31st March 2008

2007	INCOME	2008
8,464	Donations/Give as You Earn	19,689
6,014	Fundraising	11,233
9,368	Funeral Donations	8,986
0	Legacies	1,000
5,184	Christmas Cards	5,821
3,537	London Marathon	2,394
5,240	Bookstall	2,040
2,249	Summer Draw	2,086
4,556	Gift Aid	2,307
1,244	Conference/AGM Donations	800
0	DVD Sales	850
534	Miscellaneous	430
5,410	Bank Interest	7,299
51,800	TOTAL INCOME FOR THE YEAR	64,935
35,039	TOTAL EXPENDITURE FOR THE YEAR	102,634
16,761	DEFICIT FOR THE YEAR	£(37,699)

2007	EXPENDITURE	2008
12,207	Research Costs	68,211
2,382	AGM/Conference	11,026
5,028	Office Salary	5,208
5,945	Printing & Stationery	4,533
3,304	Christmas Cards	3,010
1,707	Postage	3,119
1,058	Telephone/Internet	789
922	Summer Draw	922
352	London Marathon Silver Bond	0
0	DVD Costs	2,399
350	Website	1,895
1,188	Office Equipment	335
2	Bank Charges	3
594	Miscellaneous Expenses	1,184
35,039	TOTAL EXPENDITURE FOR THE YEAR	£102,634

2007	APPROPRIATION ACCOUNT	2008
126,531	Accumulated Surplus at April 2007	143,292
16,761	Excess of Expenditure Over Income For The Year Ended 31st March 2008	(37699)
143,292	Balance Sheet at 31st March 2008	£105,593

2007	CURRENT ASSETS	2008
2,824	Sundry Debtors	1,841
800	Cash in Hand	800
131,566	CAF Gold Account	86,115
4,743	CAF High Interest Cheque Account	15,509
3,359	Lloyds Cheque Account	1,328
143,292	Total Assets	£105,593
143,292	Represented By:	
	Income & Expenditure Account/General Fund	£105,593

Bankers:

CAF Bank Limited

Kings Hill, West Malling, Kent, ME19 4TA.

Lloyds TSB

PO Box 112, Canons House,
Canons Way, Bristol, BS99 7LB.

Independent Financial Examiner:

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