

21st Annual Conference 2010

Thank you for a lovely day, especially the Birthday Party

Programme content, a good mix, something for everyone

Facilities Brill!

*Good to see people coming together to help each other and make friends and meet some new faces. **Long may it continue!***

I thoroughly enjoyed the experience, will definitely come again.

All the speakers spoke clearly and in layman's terms. Not too technical and very informative.



It was useful knowing that the Experts were available all day to ask questions

Venue ideally situated with good facilities, but didn't like the main course of the meal.

Too many workshops to choose from and time not long enough.

Thank you for all your very hard work in putting together an excellent conference.

July 2010

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Letter from Margaret Bowler National Co-ordinator

I have been invited to attend a family conference of the Myotonic Dystrophy Foundation in August in Minnesota USA.

On the 21st June I attended the Muscular Dystrophy Campaign regional meeting, held in Leicester. Dr Max Damian spoke to the 40 people present about his Myotonic Dystrophy Clinic in Leicester. The clinic enables patients to have ECG's, see a speech and language specialist and other professionals as necessary, saving another visit to a separate clinic.

At the meeting there was a discussion about patients being more active in letting their MP know about their needs as families affected with a neuromuscular condition.

Myotonic Dystrophy Specialist

Clinics - Several areas now have specialist clinics, this is really good news.

The Myotonic Dystrophy Support Group has encouraged consultants to have their DM clinics in the afternoon, to make it easier for families to attend, because of the tiredness associated with Myotonic Dystrophy.

On the 8th October 2010 there is a Royal College of General Practitioners Annual Conference to be held at the Harrogate Conference Centre. MDSG will be having an awareness display with leaflets, and will have the opportunity to talk with the 1000 plus GP's who hope to attend. We are invited to put a leaflet in each of the doctors delegate bags, this will cost £600 but will be well worth it. The display area will cost £490 a good price compared to other doctors Annual Conferences.

Royal College of Anaesthetists meeting will be held in London during November. At this conference we display our leaflets at no extra cost, and talk to doctors.

Meeting of the Scottish Muscle Network will be held in September in Dundee. Plans for a MDSG meeting in Scotland are being made.

Postage stamps - Did you know that MDC collect used postage stamps? The stamps from the letters we receive in the office are sent to MDC for funds. (Stamps that I collect from church are sent to the Leprosy Mission.)

Carers - Did you know that if you visit a Museum, Concert, Zoo or any public place and you pay to go in, state that you are a carer, you could be admitted free. When I took Peter, my son to see Torvill and Dean at the Ice Arena in Nottingham in April for his birthday, I only paid for one ticket of £40. Mike Thornton of Somerset, who was a committee member first explained this to us.

At the Directors meeting on the 19th June, all the Directors were given a file containing Memorandum and Articles, Constitutions and documents connected with the running of the MDSG. All minutes of meetings with us should be kept in the file and brought to each meeting.

Dr Max Damian is asking for information about a very sensitive question. Please would you let Margaret know at the office if you have had a sudden death in the family due to Myotonic Dystrophy.

MDC have said goodbye to their Ex Director Philip Butcher. We wish him well in his future work.

Conference 2011 - Please contact the office to tell us about a subject that you would like included in the 2011 Conference. During the last few years we have covered many different aspects which have included – Congenital DM, Anaesthetics, Sleep, Heart, Workshops ---- included Children's Behaviour, CDM, Transition. We try to put too much in the programme, so would you be interested in a Friday night get together? Is the cost of the Conference too much? £15 this year, £20 last year, the cost includes all refreshments and the lunch. It has been suggested that light refreshments could be offered at the end of our next Conference, as the sandwiches were very welcome when we had the birthday tea.

Jeans for Genes

Jeans for Genes day is Friday 1 October 2010. Jeans for Genes provides funding for the care and support of children with genetic disorders.

Letter from the Editor Elycia Ormandy

Hello Everyone,

Welcome to this Newsletter and Conference 2010 Report.

It was great that so many of you were able to be a part of the Conference this year. I hope that you will enjoy this 'snapshot view' of the Day. The fact that we had a high number of first time delegates this year is really encouraging. It shows us that patients and carers alike really do want this day for access to excellent information from the experts in the field of DM. Again we had a strong message from the delegates about the importance of meeting together and sharing with one another. The Birthday Tea was such a successful opportunity for this, and the specially commissioned birthday cake was scrumptious. Elsa, many thanks.

Because of other commitments during the Conference, (see inside), I had to 'catch up' later with the use of the Conference Day DVD, (thank you Michael Moore and Robert). If you were unable to be with us or even if you were there but found that it was difficult to 'take it all in', I strongly recommend that you try to have a copy of the DVD. It is sensitively and professionally produced and deals almost exclusively with the presentations by the main speakers.

Contact MDSG office for DVD ordering details please.

A few weeks ago the press informed us that we, that is all of us, really do benefit from being outdoors. Research indicates that even a few minutes spent outside and alongside Nature, enhances our well-being. After the long winter months, we really do need to enjoy the great outdoors! Even those of us who find access to parks or open countryside difficult or impossible could consider sitting by an open window or even having a chair by an open door for a short while each day. Perhaps you are reading this outdoors already! Read on, and thanks to all our contributors for this issue. **Elycia**

Research money for Professor David Brook

The MDSG has donated £5000, which is to part fund the research work currently being carried out by Professor David Brook and his team at Nottingham University.

Fundraising for Research

Always on the look out for new ways of spreading awareness of D.M., whilst also raising funds for research, Sue Kelly approached Boden, the mail order company with casual men's, women's and children's clothes, hoping they might let her host a Boden Party. When they knew it would be in support of such a worthy cause, Boden could not have been more helpful. January 28th was the date, Damerham Village Hall the venue, John and Sue printed and circulated 2000 fliers around schools, village shops, surgeries, notice boards and friends then, somewhat apprehensively, they awaited delivery of the collection. Good friends offered to help with the party and Cathy Partridge ran the complimentary teas, coffees and biscuits with great success. Boden kindly offered a Voucher which, when raffled, covered the expenses of the day - and delighted the lucky winner! Over £15,000 worth of orders were taken which, after the 3 months period necessary for returns was taken into account, we have received £1,348.53 plus £300 in donations. Just wonderful, and Sue is planning to host another Boden Party on January 27th 2011!



Apology

In the last issue of the Newsletter, we had a page 1 report about a Rare Disease Day event and Presentation of a cheque in memory of David Roberts to Prof. David Brook for his ongoing research at Nottingham University. Apologies to Enid Roberts and family for the incorrect spelling of David's name. It should have read, Mr David Ogwen Roberts

Mini Fair

For the fifth consecutive year and Pat Ratcliffe, kindly opened days for a 'Mini Fair' in again 'Good Going' (casual way from North Yorkshire and and reversible cotton sari fabric Heaven' (organic beauty course, were the attractions to were readily available total of well over £1000 was Research. Our sincere thanks



friends of John and Sue Kelly; Nick their home in April on 2 successive Breamore, near Fordingbridge. Once clothes and shoes) travelled all the 'Ab Fab' (beautiful costume jewellery jackets), plus 'Rhodes to products), and Sue's Servealls of tempt visitors. Coffee and biscuits throughout the event and a fantastic raised for Myotonic Dystrophy are due to everyone concerned.

Triathlon

When my brother James, or Jim as he prefers, told me in February that he was going to do a triathlon and intended to raise money for the Myotonic Dystrophy Support Group I was overwhelmed. My little boy, who is aged 8 has Congenital Myotonic Dystrophy and James was going to call his race "My race for Daniel". I adopted Daniel when he was 17 months old. I had read as much as I could about Congenital Myotonic Dystrophy but I had fallen in love with his photo and nothing could deter me from wanting to care for this beautiful little boy. There are so many worthwhile cause that James could have picked but as he said this one is close to his heart.

For the past year James has trained very hard. He gave up smoking and drinking completely and took up healthy eating and did some form of training every single day. How he managed to do all that as well as working full time, writing a sports column for our local newspaper and numerous other activities he has going on, I do not know.

We watched as month by month the weight dropped off him and after six months he lost four and half stone and turned into a "lean, mean fighting machine". He would cycle for miles before he went into work, he swam and ran and got in plenty of practice. All the time he was raising sponsor money as well.

The day finally came. I think I was more nervous than he was as I read on the triathlon website that the dock he would be swimming in was infested with jellyfish but "not to worry they don't sting"! *It was a roasting hot day* and I worried he would be dehydrated. We watched him swim in the cold dock then run off to get changed for the bike ride. We did not see him then until he arrived at the finishing line, 1 hour 44 minutes after setting off for the swim. Not bad for a 41 year old doing his first triathlon. I felt so emotional seeing him cross that line!

I am so proud of him and so grateful that he has raised money for this very cruel disease. He is hoping to reach a target of £2000 and is almost there. I would also like to thank Margaret and Peter for travelling all that way to cheer James on. This gave him a fantastic boost.

Regards, **Alison Davies**



Coffee Morning

(This article is reproduced from the Haltwhistle Partnership newsletter and written by one of our members Margaret Forrest)

I have recently had a coffee morning in memory of my husband, Roland, to raise funds for Myotonic Dystrophy.

It is a genetic complaint and has been discovered to be gene number 19. Some of the effects apart from muscle wasting can be heart related. Roland needed a pacemaker. It can also affect the muscles in the face making chewing difficult and the throat muscle can go into spasm. Caution with anaesthetics has to be highlighted. The support group give red cards for those affected to carry with them, and big red notices to put on hospital lockers. Through research and the work of the support group the medical profession are now more aware of the condition-now doctors wanting to work with anaesthetics frequently find questions about Myotonic Dystrophy in their exams.

I don't know all the effects it can have as every case is different. One thing I do know is how hurtful some people can be if a disabled person falls.

If you would like to find out more about Myotonic Dystrophy and how the work of the support group helps those affected by the condition and their families look at www.myotonicdystrophysupportgroup.co.uk

We raised nearly £612 and, after deducting the cost of the hall, a cheque has gone to Myotonic Dystrophy-£50 for the Support Group who do a fantastic job, a lot of it on a voluntary basis, and the rest for research.

Thank you for your support. My family and I do appreciate it very much and hope the effort will result in a cure eventually.

I would also like to add in a huge thank you to all those who helped on the day. I was not able to be there myself as I was not well, and a group of friends rallied round to make sure that the coffee morning could still go ahead and raise these much needed funds. You know who you are and how grateful I am.

Margaret Forrest

St Martin's Outlookers

Margaret Bowler attended the Annual Charity Lunch on 21 April at St Martins of Tours in Ruislip, Middlesex. One of our members Colin Neville, musical director at his church had nominated Myotonic Dystrophy Support Group as one of two charities for them to support. A cheque for £1000 was presented for the work of MDSG. A big thank you to Colin and his church.



Recital

The renowned local classical pianist and good friend of John and Sue Kelly, Frances Dodd, invites you to a recital, duration approx 1 hour, followed by a home-made cream tea at her home in Gorley, near Fordingbridge on Tuesday 3 August at 2.30pm for 3pm. Tickets @£12.50 each from Sue Kelly, Tel 01725 519233 or email bennettscottage@gmail.com
ALL proceeds to MDSG Research

*Remember
the water
flume at the
local baths?
over many
years
Margaret
Forrest has
worked
tirelessly
and held
many
fundraising
events for
DM*

Seeking Advice

We are delighted when our supporters decide to run, cycle or walk etc for MDSG, but your safety is paramount. We would urge you to train sensibly and seek proper advice and guidance if you are new to the sport or embarking on a rigorous training package. There are plenty of websites and other sources of information and guidance to help you train safely and responsibly, including what equipment to buy, training regimes and injury prevention. If you are in any doubt as to your level of fitness, or have any concerns, we would suggest you seek professional advice. A personal thought from Dr Mark Rogers, one of our medical Advisors is, 'strenuous exercise is generally not recommended, but even here we would not wish to discourage otherwise very mildly or asymptomatic individuals who happen to carry the DM1 triplet repeat from exercising. However there is undoubtedly a greatly increased risk of developing a cardiac rhythm disturbance. We do know that DM is associated with cardiac dysrhythmia and that a number of people with DM will show involvement of the cardiac conduction tissue. Vigorous exercise is more likely to induce a rhythm disturbance if the individual is prone. Certainly I would recommend an ECG and cardiac check-up before even considering long distance running but better still to have an exercise stress test organised by a cardiologist'.

Genetic Interest Group

The Genetic Interest Group is a well-established national charity working with patient groups, charities, individuals and families affected by genetic conditions. GIG has over 130 member organisations of which MDSG is one, representing rare genetic conditions. From 1 June 2010 its name has changed to **Genetic Alliance UK**. In recent years they have grown significantly to become involved in an increasingly diverse range of activities and feel the new name and branding provides a better insight into the voices they represent and the wide range of work they now do.

Retirement

Myotonic Dystrophy Support Group would like to wish Dr Jane Fenton-May a long and happy retirement. Jane has been very supportive of MDSG and been to many, many Conferences, chairing the day, holding workshops, giving talks and this year giving help and advice on a one to one basis with many delegates. We wish you well, Jane



Jane Fenton-May at our recent Conference enjoying the birthday tea.

Scottish Muscle Network

The Scottish Muscle Network 11th Annual Conference is taking place in West Park Conference Centre, Dundee on Thursday 23 September. This is a multi-disciplinary meeting open to all professionals with an interest in neuromuscular disorders and for those who work with patients affected by the huge range of disorders covered by the term "neuromuscular disorders". For further information email laura.craig@ggc.scot.nhs.uk The Scottish Muscle Network has also produced a leaflet for professionals entitled 'Management of Adults with Myotonic Dystrophy'

MDSG 21st Annual Conference

A View From Two First Timers

Unfortunately we missed the previous twenty conferences, but we did go to this one. Rachel was diagnosed with DM during 2009, though she had been having symptoms for many years without knowing the cause. We decided to travel down to the conference in Nottingham after reading the MDSG Newsletter. Our journey from Northumberland took around three hours, and the East Midlands Conference Centre was quite easy to find. We arrived just in time to register and were shown to the conference room by the first of many friendly faces. If only we could remember everybody's name.

The first two talks were really interesting. Professor David Brook's quest for new DM drugs from established drug libraries sounded promising. It was also interesting to hear the views of genetic counsellor Keri Oliver. After the break, Dr Mark Roberts presented another interesting talk on gastro-intestinal problems. Many of the problems we could relate to, unfortunately early satiety is not one of them.

After the AGM it was lunchtime. Thoughts of steatorrhoea were left behind in the conference hall and we enjoyed our meals (chicken hotpot and treacle sponge, if you were wondering). This was the first time to really chat to other people. We were lucky enough to chat to two other families whose good humour and positive outlook were encouraging.



Margaret with Victoria cutting the Birthday cake

After buying two pens with handy built-in torches for our 5-year old and 2-year old sons, and ordering a copy of the book "The Magical Journeys of a Cat Called Swankypants", we set off back to the hall to hear, from Dr Chris Turner, about the many effects of DM on the brain. Rachel then attended the Orthotics workshop which she found useful, while Adam continued to learn about genetic research at Professor David Brook's workshop.

After hearing about the UK Research Database and the election results it was time for us to head off. Unfortunately we couldn't stay for the afternoon tea. If anyone saved any of the birthday cake we'd love to have a taste. All-in-all a very interesting day meeting lots of interesting people. Many thanks to all involved in organising the event. It must have taken a lot of time and effort to get it just right.

Rachel and Adam Ward

Conference DVD

If you missed the Conference, a DVD of all the speakers talks is available at a cost of £10 plus postage and packing. Contact the office for a copy.

Delegates letters

Dear Margaret and Elycia
Just a word of thanks to you both, the office staff, the committee and all the volunteers who helped to make the AGM go so well. Once again the information we gleaned, and the speakers we had were excellent. We learn more and more each year, and it is quite hopeful that one day there will be a cure for this condition. Victoria too enjoyed the day very much and proudly brought the flower arrangements home for her friends. We thought too that the venue was very good and the food and drinks were very tasty and went down well.

Veronica, John and Victoria Ward



Shona with our youngest delegate, her son Dexter

Dear Margaret,
A brief note to say thank you very much for a delightful celebration of your 21st year during which time you have done so much to help many people. Congratulations and thank you on behalf of us all. **Ron Daly**

A couple of years ago my son was diagnosed with Myotonic Dystrophy. He was 35 then, I had heard of it as Margaret Bowler and I sit together at church, so I was fortunate enough to get first hand knowledge. I saw that this year's conference was to be held in Nottingham on May 8th, so I booked a day off work and signed up to go. When I saw the agenda I thought, what have I let myself in for, I thought I'd be bored and most of it would go over my head.

It was totally opposite. I learned such a lot of information, the talks were informative and the speakers made them interesting. The venue was ideal, food delicious, but mainly I met some lovely people. Some parents like me, and some people with DM, but everyone was happy and cheerful.

I came away from my first conference on a high. Hopefully next year I can take my son along too. **Anne Gamble**

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Dear Margaret,  
Forgot to fill in my evaluation sheet—thought I would do it at home where I can think 'carefully' about it. Andy and I really enjoyed our day on Saturday at Nottingham. It was a lovely day (I was rather unsure how I would feel 'emotionally', but managed fairly O.K.) Thank you for your support also Elycia's very much appreciated. It was my first time back after 3 years. I am always amazed at all the planning, organisation etc that you all are prepared to do to make it such a successful day. Many thanks to all concerned. We also loved the 21st party surprise at the end—it was so nice and finished off the day superbly.

**Karen and Andy Northwood**

## Conference Report

We were delighted that we could bring together a Conference Programme that clearly hit the right note and balance for most of our delegates. Thank you to those people who were able to let us know their thoughts about the day either by completing the evaluation sheets or by writing to us afterwards.

Your comments are carefully noted and help us towards planning for next time. Having been greeted by

**Margaret Bowler,**



*Margaret in party mode*

then welcomed to the EMCC by our Chairperson for the day,  
**Dr Margaret Phillips,**

the first talk was the Patron's Address by  
**Prof David Brook.**

This, almost by tradition now, began with a simplified introduction to Genetics with the familiar 'Fried Egg' illustration of simple cell, (egg yolk = the nucleus, egg white = cytoplasm)

We were told about the changes that occur to the cell's metabolism when a genetic mutation, causing Myotonic Dystrophy, occurs.

Prof. Brook shared with us how new equipment in his department is enabling the researchers to screen a huge range of compounds looking for the breakthrough that could potentially lead to a treatment for DM. This work is being done in collaboration with others to enable access to known approved compounds. The largest library of these is in America. We saw pictures of cells with 'trapped' RNA accumulated as 'spots' in the nucleus, and how these responded to different compounds.

**Keri Oliver** spoke about her work as a Genetic Counsellor. She explained her role and how the Dept of Genetics at the City Hospital, Nottingham can offer help, information and reassurance for families with genetic conditions. Genetic Counsellors follow the core principles of counselling having had specific training. They help individuals and families to understand what is going on. We were reassured that even when dealing with individuals within the same family, there is no problem with confidentiality between patients. The strict rules of confidentiality always apply.

*Enjoying the Birthday tea*



**Dr Mark Roberts** from Manchester gave us some insight into DM as a multi-system disorder. He spoke about the Gastro-intestinal Tract, from mouth to anus, telling us that all the many parts that make up this tract can be affected by DM. He detailed under-reporting, by patients, of intestinal problems, probably, he suggested, because doctors don't always ask enough questions about it and because patients are often too embarrassed to talk about incontinence, diarrhoea, constipation and related gut problems such as pain. It was clearly a topic of interest to many of the delegates, and Dr Roberts highlighted the fact that gut involvement is very common in DM. Too often it is mis-diagnosed as a completely separate disorder, e.g. Irritable Bowel Syndrome, yet it is recognised as a core feature of DM. All gastrointestinal problems get worse as the disorder progresses, and it is uniquely complicated. Hormonal involvement, aspiration, bile secretions, bacterial overgrowth and breath tests to determine this, brain mechanisms that drive the gut all make this topic an area that requires very careful and detailed assessment, preferably by a Neuro gastroenterologist. Even in one individual there may be multiple mechanisms that are relevant to the presenting symptoms. Another problem highlighted was early

mortality, recognised over the last ten years. The importance of monitoring lung function and heart function was stressed. Even when manifesting only minor weakness, some patients do have abnormalities that need careful monitoring. A strong recommendation to all patients is to have at least one ECG a year, with further investigation if symptoms indicate this.

A presentation by **Dr Chris Turner**, London, was about the brain and how it affects the life of people with Myotonic Dystrophy. He told us that before his talk people had asked him why he had chosen this topic. He responded by saying that this was an area often forgotten, and only recently has the brain been studied. Indeed, samples of relevant tissue are few and difficult to access because of ethical issues. It is important to know about the changes in the brain because this could have implications as genetic treatments are developed.

We had a fascinating 'whistle stop tour' of the structure of the brain, learned that there are 3 ways to study brain function. Neuropsychology, (memory tests and complex thoughts), Neuroradiology, (scans), and Neuropathy, (in terms of DM there is very little known), and had a fun time when the talk became 'interactive'.

Recent research studies have shown that new techniques can illustrate a reduction of blood flow and changes to white matter in the brain, yet compared to other symptoms of DM we really know very little about the effect of DM on the brain. More research is needed. It is recognised that DM does affect the brain yet there is nothing to treat the primary problem. On a more positive note we do know that we can:

- Treat sleep related breathing disorder
- Treat depression
- Treat swallowing problems/weight loss
- Treat infection early

In adult onset DM, both spatial and executive function can be affected, also motivation and apathy. The bigger the genetic mutation, the more problems with 'thinking' occur. Recent studies in education have shown that a disproportionate number of students with DM fail to complete their education or go on to college and university.

At the MRC Neuromuscular Centre, Queen Square, London, where Dr Turner sees many patients with DM, there is ongoing research into these and other under-recognised problems.

**Dr Mark Rogers** from Cardiff gave us some insight into the development

of a National Register of Patients with Myotonic Dystrophy. The Register will be of great importance in the future for all patients with DM. It will enable researchers to access valuable information when data is required for early trials.

**Dr Jane Fenton-May**, Cardiff, was available throughout the day by appointment, allowing delegates to discuss issues and concerns with her on a one to one basis. The delegates were really appreciative of this opportunity.

We do appreciate all the time and effort that our Chairperson, Dr Margaret Phillips, Derby, the Speakers and other invited Guests put into making our Conference Day informative, educational, enlightening and so positive. We are indeed fortunate to be able to bring them together to give us a programme that is of such interest and diversity.

**Thank you all.**

It is an impossible task to give more than outline here, but suffice it to say that at the end of a day full of information gathering, delegates were happy to share a time of relaxation and enjoy a Birthday Tea with Entertainment by the Acappella Choir, and soloists from Carlton, Nottingham. Thank you all. The music made a lovely ending to a busy day.



*Acappella choir entertaining the delegates at tea time*

## Young Adults

The young adults who joined together after listening to the Patron's Address at the start of the day were a group of 'old hands' and welcome new faces. The activities on offer were themed 'Lets Celebrate'. It was, after all, the 21st Birthday of the MDSG!

*Young adults creative contribution- favour boxes for the tables*

Katherine and Lynne had done the advance preparation involving card cut-outs that were to be transformed by folding, decorative stickers and curled ribbons into 'favours' boxes, each to hold an individual chocolate. With a little help from some visitors to the room, but largely by a huge effort by the young people, each box was duly decorated and filled.

In between times everyone had a go at flower arranging to create individual and artistic floral centrepieces for the birthday tea. The little pass the parcel items were wrapped up and gave us a time for cooperation and exchange of either companionable quiet or conversation, as together we cut and stuck.

We had a great time going outside to meet the Crew Manager, Nick and

Firefighters from Highfields Blue Watch, Beeston. We took turns to sit in the fire engine, tried on the helmets, looked around the controls and asked questions.

*Checking out the fire engine*



By the end of the sessions we gathered everything we had made onto trolleys and carefully steered them towards the dining area where they were proudly placed onto the tables. They looked splendid and made a colourful addition to arrive from the main auditorium. I was so sorry that we did not even have time to come back to share the end of the day with everyone else.

It is always a great thrill to see a group of young adults get together and identify with a group that is new to them. Their courage and determination is an inspiration to us all. We made the room our base for the day, with no commitment to stay if the alternative seemed better or more appropriate. In a very unassuming way everyone had learned to seek help, offer assistance, befriend, talk and communicate together. Not only did we learn new skills, but we achieved our goals and had these recognised as a worthy contribution to the day.

I'd like to thank the 'visitors' who popped into the room to say hello, and were persuaded to make a box before they left. We all discovered new things about ourselves and others!

There were many highlights of the day; getting to know you, learning new ways to communicate, using our skills to produce a worthy result, spending quality time together, accepting one another 'just as we are', but most of all for making where we were, a happy place to be.

Thank you Seb, Peter, Chantelle, Jackie, Susie, Victoria, Hannah, Ellie-Beth, Rachel, Lynne, Katherine. A special thank you to Ellie-Beth's mum and dad, Lynne (physio) and Steve (First Aid), and Jenny (Carer) who 'held the fort' for me when I had to nip out for the AGM, voting etc.

It was a privilege and joy to spend time with these young adults, and I want to say a huge thank you to them for sharing the day with me. I'm hoping that the plans we have for next year will be as well supported and as much fun. (No little boxes to decorate and no flowers to arrange, I promise!). **Elycia**

*Taking the floral arrangements to the birthday tea*

## 21st Annual General meeting of Myotonic Dystrophy Support Group on Saturday 8 May 2010 held at the East Midlands Conference Centre Nottingham

### Agenda

- 1 To read the notice convening the meeting
- 2 Apologies for absence
- 3 Chairman's welcome to the delegates
- 4 Minutes of the meeting held on Saturday 16<sup>th</sup> May 2009
- 5 Matters arising from the minutes
- 6 Appoint Director's by ballot
- 7 Receive the annual Director's Report
- 8 To consider the accounts and Auditor's Report
- 9 To appoint the auditor
- 10 To transact any other business
- 11 Inform membership of Company Limited by Guarantee

*Next years conference is likely to be 18 June BUT watch this space!*

Professor David Brook, chaired the meeting and welcomed the 200 delegates. The meeting followed the agenda and discussion about the membership subscription was interesting. Some people were willing to pay more, one suggestion was that people living alone should pay less than a family membership. This will be discussed at a future Committee meeting.

### **The Director's for 2010**

Voting took place as there were 12 candidates and 10 places available. Following 3 counts, the following people were elected as Directors.

**Chris Bruce-Jones**  
**Samantha Cook**  
**Ken Ford**  
**John Kelly**  
**Elycia Ormandy**

**Dr Margaret Phillips**  
**Eileen Tedman**  
**Mike Walker**  
**Margaret Bowler**  
**Dafydd Williams**

The meeting thanked **Cynthia Ford** for 17 years service, and **Sue Kelly** for 3 years service, who were not successful in being re-elected. Their contribution to the Committee had been invaluable.

## MYOTONIC DYSTROPHY SUPPORT GROUP

STATEMENT OF FINANCIAL ACTIVITIES  
FOR THE YEAR ENDED 31ST DECEMBER 2009

|                                                                            | NOTES | Unrestricted<br>Funds<br>£ | Restricted<br>Funds<br>£ | Total Funds<br>2009<br>£ | Total Funds<br>2008<br>£ |
|----------------------------------------------------------------------------|-------|----------------------------|--------------------------|--------------------------|--------------------------|
| <b>Incoming Resources</b>                                                  |       |                            |                          |                          |                          |
| Grants & Donations                                                         | 2     | 37,784                     | 30,590                   | 68,375                   | 66,543                   |
| Subscriptions                                                              |       | 5,580                      | -                        | 5,580                    | 6,340                    |
| Conferences                                                                |       | 3,010                      | -                        | 3,010                    | 2,585                    |
| Fundraising Income                                                         |       | 4,534                      | -                        | 4,534                    | 2,147                    |
| Bank Interest (Gross)                                                      |       | 7,404                      | -                        | 7,404                    | 9,461                    |
| Gift & Charity Aid                                                         |       | 5,292                      | 1,020                    | 6,312                    | 7,103                    |
|                                                                            |       | <u>63,604</u>              | <u>31,610</u>            | <u>95,214</u>            | <u>94,179</u>            |
| <b>Expenditure</b>                                                         |       |                            |                          |                          |                          |
| Wages                                                                      |       | 12,771                     | -                        | 12,771                   | 7,080                    |
| Payroll/Bookkeeping services                                               |       | 2,279                      | -                        | 2,279                    | 2,490                    |
| Travel, Subsistence & meetings                                             |       | 10,744                     | -                        | 10,744                   | 7,125                    |
| Conference                                                                 |       | 14,745                     | -                        | 14,745                   | 8,163                    |
| Rent, Rates & Utilities                                                    |       | 2,724                      | -                        | 2,724                    | 3,283                    |
| Premises Repairs & Maintenance                                             |       | 400                        | -                        | 400                      | 3,214                    |
| Insurance                                                                  |       | 1,802                      | -                        | 1,802                    | 1,175                    |
| Telephone, internet, Website & Database                                    |       | 8,007                      | -                        | 8,007                    | 1,443                    |
| Printing, postage & stationery                                             |       | 8,411                      | -                        | 8,411                    | 4,282                    |
| Office Equipment rental                                                    |       | 946                        | -                        | 946                      | 788                      |
| Subscriptions (affiliated organisations)                                   |       | 370                        | -                        | 370                      | 536                      |
| Equipment repairs & renewals                                               |       | 505                        | -                        | 505                      | 175                      |
| Fundraising & Advertisement                                                |       | 7,324                      | -                        | 7,324                    | 5,494                    |
| Training                                                                   |       | 3,764                      | -                        | 3,764                    | -                        |
| Awareness                                                                  |       | 6,038                      | -                        | 6,038                    | -                        |
| Donations to Research                                                      |       | -                          | 13,090                   | 13,090                   | 22,093                   |
| Newsletter                                                                 |       | 4,055                      | -                        | 4,055                    | 4,080                    |
| Professional Fees                                                          |       | 6,259                      | -                        | 6,259                    | 1,934                    |
| Independent Examination                                                    |       | 599                        | -                        | 599                      | 553                      |
| Bank Charges                                                               |       | 124                        | -                        | 124                      | 68                       |
| Depreciation                                                               |       | 813                        | -                        | 813                      | 592                      |
| <b>Total Expenditure</b>                                                   |       | <u>92,681</u>              | <u>13,090</u>            | <u>105,771</u>           | <u>74,568</u>            |
| <b>Net incoming/outgoing resources on ordinary activities for the year</b> |       | <u>- 29,077</u>            | <u>18,520</u>            | <u>- 10,557</u>          | <u>19,610</u>            |
| Funds reallocation                                                         | 8     | 29,000                     | - 29,000                 | -                        |                          |
| <b>Net Movement in funds in the Year</b>                                   |       | <u>- 77</u>                | <u>- 10,480</u>          | <u>- 10,557</u>          | <u>19,610</u>            |
| <b>Balance brought forward at 31st December 2008</b>                       |       | <u>152,103</u>             | <u>84,549</u>            | <u>236,653</u>           | <u>217,043</u>           |
| <b>Balance carried forward at 31st December 2009</b>                       |       | <u>152,026</u>             | <u>74,069</u>            | <u>226,096</u>           | <u>236,653</u>           |

**MYOTONIC DYSTROPHY SUPPORT GROUP**  
**BALANCE SHEET**  
**FOR THE YEAR ENDED 31ST DECEMBER 2009**

|                                                          | Note | £       | 2009<br>£ | £       | £       | 2008<br>£ | £       |
|----------------------------------------------------------|------|---------|-----------|---------|---------|-----------|---------|
| <b>FIXED ASSETS</b>                                      |      |         |           |         |         |           |         |
| Office Equipment                                         | 3    |         | 1,703     |         |         | 2,516     |         |
|                                                          |      |         |           | 1,703   |         |           | 2,516   |
| <b>CURRENT ASSETS</b>                                    |      |         |           |         |         |           |         |
| Stock                                                    |      | 1,296   |           |         | 1,371   |           |         |
| Debtors and Prepayments                                  | 4    | 8,333   |           |         | 2,652   |           |         |
| Cash at bank                                             | 5    | 218,342 |           |         | 231,488 |           |         |
|                                                          |      |         | 227,972   |         |         | 235,511   |         |
| <b>LIABILITIES : Amounts falling due within one year</b> |      |         |           |         |         |           |         |
|                                                          | 6    | 3,580   |           |         | 1,373   |           |         |
|                                                          |      |         | 3,580     |         |         | 1,373     |         |
| <b>NET CURRENT ASSETS</b>                                |      |         |           |         |         |           |         |
|                                                          |      |         |           | 224,391 |         |           | 234,138 |
| <b>TOTAL NET ASSETS</b>                                  |      |         |           |         |         |           |         |
|                                                          |      |         |           | 226,095 |         |           | 236,654 |
| <b>FUNDS OF THE CHARITY</b>                              |      |         |           |         |         |           |         |
| Restricted Funds                                         | 8    |         | 74,069    |         |         | 84,549    |         |
| Unregistered Funds - General funds                       |      |         | 152,026   |         |         | 152,105   |         |
|                                                          |      |         | 152,026   |         |         | 152,105   |         |
| <b>Total Funds</b>                                       |      |         |           |         |         |           |         |
|                                                          |      |         |           | 226,095 |         |           | 236,654 |

## Margaret speaks to Gordon Brown

On Saturday 24 April 2010, I was given the opportunity to speak with Gordon Brown, then Prime Minister, when he visited Nottingham. Gordon Brown had been informed about the work of the Myotonic Dystrophy Support Group. He told me he knew that the Support Group was known World Wide. The subject I highlighted was the need for more Physiotherapists to help people with neuromuscular conditions. We discussed research, and I told him about Nottingham and Glasgow being Centres for research in Myotonic Dystrophy. Thank you to Vernon Coaker MP and Dr Ian Campbell for arranging this opportunity to spread the awareness of Myotonic Dystrophy.



## Heart gene

UK researchers have discovered a gene variant that regulates the rhythm of the heart, raising the prospect of new treatments for avoiding heart attacks and heart disease. The finding, by a team led by Imperial College London and part funded by British Heart Foundation, may also help doctors to better understand why some patients are more susceptible to heart problems than others. A team member said the results 'may enable us to predict and diagnose serious heart rhythm disturbances better, and in the future develop improved treatments for preventing ventricular fibrillation'.

## NHS Support for the South West

A new network has been set up by the South West NHS Specialised Commissioning Group to support people living with a neuromuscular condition, their families and the professionals working with them. The Neuromuscular Network Manager is Jennie Shine who is a qualified children's nurse and midwife and specialises in Non-invasive Ventilation and Palliative Care. As part of this network there are also three new care co-ordinators (Neuromuscular Advisors) who join the two existing ones. They are familiar with the range of neuromuscular conditions and are able to visit families at home to discuss a range of practical issues, liaising with local professionals where appropriate. One of these new co-ordinators is someone we are familiar with and has spoken at many of our conferences, namely **Jane Stein**.

Jane would like to hear from anyone in the South West Area. Jane used to be in Oxford working alongside Dr David Hilton-Jones. The area covered is Isles of Scilly, Cornwall, Devon, Dorset, Somerset, Wiltshire, Gloucestershire, Bristol, Bath and North East Somerset. She is keen to make contact with people in her area who have Myotonic Dystrophy, her contact number is 01392 314649.

## Opportunities for Carers

The National Extension College with support from Equitable Charitable Trust and Henry Smith Foundation, is offering free study places for carers aged between 16 and 25 living in your area.

NEC is a major provider of home study courses in a wide range of subject areas including Basic Skills, GCSEs and IGCSEs, A Levels, Childcare, Book-keeping, Counselling and Creative Writing.

Young adult carers accepted on one of the courses need not worry about attending school or college on a regular basis as they could work from home at convenient times with flexible deadlines.

All course materials and tutor support are free, the only additional costs would be stationery and exam fees.

If you or know of someone who might be interested contact Priscilla Barlow on 01223 400386 or email [Priscilla.barlow@nec.ac.uk](mailto:Priscilla.barlow@nec.ac.uk)

## Happy Birthday

We would like to wish The Jennifer Trust for Spinal Muscular Atrophy a Happy 25th Birthday. You may come across some of the many fundraising initiatives they are organising for their year of celebration.

Hello, my name is **Susannah Moore** and I am 21 years old. I have two brothers and one sister. I was diagnosed as having Congenital Myotonic Dystrophy when I was 8 years old. When I was 7, I went to a special needs school for speech therapy. I always had problems talking as my lips and soft palate are very stiff and I also had very delayed language. I have learning difficulties. When I was 11, I transferred upstairs to the secondary department. Just before that I had to start wearing AFO's (Ankle Foot Orthotics) to enable me to walk better as I have foot drop in both feet. I got 4 GCSE's in maths, French, single science and art and design. I also had six entry level GCSE exam passes. I really liked Brent Knoll School and made lots of friends.

When I was 16 I joined the sixth form at Marjorie McClure School for 3 years. I really, really loved this school. It is very small and very specialist school. All the teachers and helpers are very kind and helpful. I made lots of new friends. I also did more speech therapy and my language really developed. I also had O.T. and Physio and I also did horse riding for 3 years. I studied life skills and got a 'Silver Challenge' award for ASDAN (Award Scheme Development and Accreditation Network).

When I was 19 I went to Bromley College for Further Education in the special needs department. In the first year I continued to study life skills. I'm now in the second year and I am studying Social Independence. Next year I am going into 'GreenGoose' which is a performing arts course—I am really looking forward to this. I have always belonged to lots of social clubs;

Fun Physical  
Fun Movement  
Sharks Swimming Club  
Beavers  
Brownies  
Monday Club (Activities Club)  
Thursday Club (LYWRP)  
-Lewisham Young Women Resource Project)  
Friday Club (LYWRP 16+)  
Rockbourne Youth Club  
New Lodge Horse Riding  
Conquest Swimming Club and many more!!



### Collecting Boxes

If you want to know what to do with your small change or know of somewhere you could put a collecting box, then we have some available. They have Myotonic Dystrophy Support Group on the label and a chain for locking it to a secure place. If you are interested contact Sue Kelly on 01725 519233.

### For Sale

2011 Diaries now available £4  
Sweatshirts £12.50 various sizes and colours  
Polo shirts £11, white, blue and black  
**Pink now available in all sizes and designs**  
Gilets £18  
Enamel badges £1  
Good quality pens 50 pence  
High quality pens with thicker barrel and black ink £3  
Pens with torchlight £4  
Key ring/bottle opener £3  
Calculators £3  
Servealls £14  
Childrens book, 'Swankypants' price £13

### Facts Book

Also available, Professor Harper's second edition of *Myotonic Dystrophy, the Facts*

This book, priced £5, has new material, regarding 'Type 2' myotonic dystrophy. Includes Key points and Frequently Asked Questions.

All these items are available on request from the MDSG office. Please be prepared to specify size and colours if ordering garments and please note, postage and packing is extra.

### Tea Towels

A commemorative Tea Towel is available at a cost of £4 plus postage and packing. It has the signatures of many of those who attended the 2009 Annual Conference in Marlow. If you were at Marlow but not at this years conference in Nottingham you may have missed the chance of purchasing one with your signature. Contact the office for a 100% cotton tea towel.

## Muscular Dystrophy Campaign's Parliamentary Reception Briefing

'Get moving-the case for Wheelchair Services'

Margaret Bowler, Elycia Ormandy, Sharon and Michael Walker represented MDSG at this Parliamentary Briefing held at Portcullis House, Westminster, London, amongst Members of Commons and Lords. This was to raise awareness to parliament of the fact that children and adults with muscle disease in England are forced to wait weeks, months to receive wheelchairs that are essential for their health and quality of life, and that the needs of people living with neuromuscular conditions are at the top of the health and social care agenda. It was a very well attended gathering with a wide variety of neuromuscular conditions represented. Whenever we looked around for Sharon, she was



busy talking and making conversation and sharing experiences of having to use a wheelchair. Only that morning, coming by train from Wellingborough, you either carried your chair across the bridge or a member of staff wheeled you across the lines. Despite improvements in the last few years awareness amongst corporations, businesses, shops is still an ongoing problem.

### Get togethers

#### Leicester

Despite it being the first sunny and warm Saturday for some time, 20 people representing eight families met at Leicester General Hospital including two families attending for the first time. A local Speech Therapist gave a talk on speech and swallowing followed by a lot of questions and comments on the subject. Dr Max Damian talked about sleep problems and the different causes and methods of treatment. He

demonstrated a new piece of equipment used to measure restless leg movement which will help to identify one of the causes of sleep problems. After refreshments people socialised for some time exchanging news and views in a relaxed atmosphere. The Speech Specialist also continued to talk to individuals about their particular problems.

**John and Jenny Langley**

### Future meetings

#### America

Margaret has been invited to attend the Myotonic Dystrophy Foundation Conference in Minneapolis next month August, and will be giving a short presentation to the delegates.

#### Harrogate

We are attending and having a stand at the Annual Conference for General Practitioners in October. This will be a first for the MDSG, but continues our awareness programme to the professionals, this time GP's. It is also proposed to include a leaflet in the delegates pack.

#### Northampton

The next area get together is on 11 September where the speaker will be Dr Max Damian from Leicester. Ring Michael Walker on 07831 347143 for further details.

#### Kent

Denise and Rod Gough are arranging a get together on Sunday 10 October in Larkfield near Tonbridge. The speaker will be Dr Deborah Ruddy, Genetic Counsellor from Guys Hospital. Please contact the office for more details.

#### Sheffield

Shona Davison is arranging a get together in Sheffield on 26 September. The speaker will be Dr Jim Walker a GP. The subject 'How to get the most out of your GP'. Further details from the office or you can email shona on shonadavison@yahoo.co.uk

#### Hampshire

For the second year, Sue and John Kelly invite all local members and their families to join them at Damerham Village Hall on 10 August. Another chance to get to know each other sitting by the stream in the shade of the willow, chatting over tea, coffee and light refreshments from 3 to 5pm. They cannot guarantee the weather, but the welcome is assured. Contact office for details.

## National Co-ordinator

Margaret A Bowler

## Directors

M Bowler  
C Bruce-Jones  
S Cook  
K Ford  
J Kelly  
E Ormandy  
M Phillips  
E Tedman  
M Walker  
D Williams

## Advisors

Prof D Brook  
(Patron)  
Dr I Bowler  
Prof P Harper  
Dr D Hilton-Jones  
Prof D Monckton  
Dr M Phillips  
Dr M Rogers  
Dr D Wilcox

Office Staff, Julie  
and June,  
Bookkeeper - Judith  
Laurie

Disclaimer: The views and opinions of individuals printed in this newsletter are not necessarily those endorsed by the Myotonic Dystrophy Support Group.

## Regional Contact Families

These numbers are printed here so that you can make contact with someone else in your region. Phone to ask about local meetings, provision of services for families with neuromuscular conditions or to discuss concerns.

### NORTH and SCOTLAND

|                                            |                  |               |
|--------------------------------------------|------------------|---------------|
| Cumbria                                    | Neil Braiden     | 01228 512 385 |
|                                            | Barbara Batty    | 01768 352 667 |
| Glasgow                                    | Isabelle Mungall | 0141 883 6934 |
| Manchester, the North West and North Wales | Elycia Ormandy   | 0161 445 5844 |
| Northumberland, Tyne & Wear, Teesside      | Peter Bodo       | 01740 620707  |
| Pontefract                                 | Jack Lawrence    | 01977 705 496 |
| Sheffield                                  | Shona Davison    | 0114 255 2651 |

### WALES and the MIDLANDS

|                          |                                   |               |
|--------------------------|-----------------------------------|---------------|
| Cardiff                  | Margaret Ware                     | 02920 869277  |
| Leicester                | John Langley                      | 0116 287 9064 |
| Mid and South West Wales | Samantha Cook and Dafydd Williams | 01267 233668  |
| Northampton, North Bucks | Michael Walker                    | 01234 240518  |
| Nottinghamshire          | Margaret Bowler                   | 0115 987 0080 |
| Peterborough             | Paula Thacker                     | 01733 577 651 |

### SOUTH

|                              |                      |               |
|------------------------------|----------------------|---------------|
| Bedford                      | Kath Dixon           | 01234 708520  |
| Berkshire                    | Cynthia and Ken Ford | 0118 979 2288 |
| Bristol                      | Richard Martin       | 0117 964 3554 |
| Buckinghamshire              | Peter and Jill       | 01628 487741  |
| Devon                        | Josephine Hole       | 01363 773791  |
| Hertfordshire                | Christine Redshaw    | 01992 632730  |
| Kent                         | Denise and Rod Gough | 020 8300 5080 |
| East and West Sussex         | Rita Wood            | 01273 464638  |
| Wiltshire, Hampshire, Dorset | Sue and John Kelly   | 01725 519233  |

Please note we are now officially a Company Limited by Guarantee and have been issued with our new Company number 7144171 and because of change of status, the Charity Commissioners have also issued us with a new Charity number 1134499

### **National Co-ordinator**

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### **Editor**

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**Patron:** Professor J. David Brook Professor of Molecular Genetics, University of Nottingham.

Charity Number 1134499