

**August  
2016**

**Dr Mark Hamilton** from West of Scotland Genetic Service, Glasgow and **Dr Richard Petty**, Retired Consultant Neurologist, also Glasgow have kindly written the enclosed brochure on Myotonic Dystrophy and the Brain.

Letters...2

Annual  
General  
Meeting...3

Katherine...3

Conference  
Report...4, 5  
and 6

Fundraising...  
7

Research...8

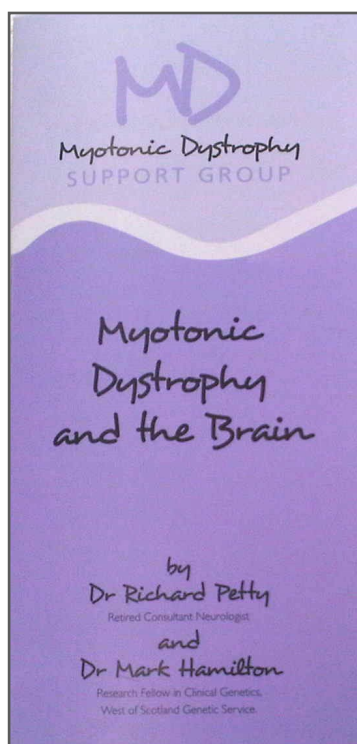
Bits and  
Pieces...9

New  
Advisor...10

Japan...10

Meetings...11

Contact  
List...12



Dr Mark Hamilton



Dr Richard Petty

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Dr D Hilton-Jones  
Prof D Monckton  
Dr M Phillips  
Dr M Rogers

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Julie and Mike

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## Letter from Margaret

Myotonic Dystrophy Support Group continues to grow. We have 2000+ family members and regularly send 70 copies of the newsletter abroad.

I have lots of lovely memories of MDSG families and how enthusiastic people are at wanting to help. People have travelled many miles to be with us. In Glasgow 2004, Jill and her daughter Emma came from New Zealand!

Thinking of Glasgow meeting, (which was also IDMC meeting), we had a Ceilidh, Phil Walker was helping people into the lift to bring them to the right floor of the hotel.

One man with a walking stick said 'I'm looking for my wife!' Phil had brought him up to our function and he was only going to one floor (finished up on the 4<sup>th</sup> floor!) The gentle man was taken back to meet his wife!!

Jill Browning letting Peter Bowler present a £1000 cheque to Lord Attenborough at the Muscular Dystrophy Group conference.

At one MDUK conference, Dr Ian Bowler (my son) and I looked for a man with DM, who was like my husband bald! We knew the man lived in Wales so we kept standing near bald headed men to listen to their accents. In desperation at the end of the day we asked someone where he was sitting. That's him over there came the reply, "the man with all that hair and a beard"!! (Mr Ware)

Another memory was conference year 2000 at Liverpool, Elycia Ormandy chaired the meeting and as soon as the Conference started there was a power cut. Dr David Hilton-Jones gave his talk without his presentation, Dr Alex McGee carried on with the programme and Elycia carried on chairing with no microphone or lights

Times have changed from those early days, from sitting on the floor eating our lunch to the high standard of professional catering and plated service we enjoy now!

Thank you to you all, Margaret

## Letter from Elycia

Sincere thanks to everyone who has come forward to contribute to this the latest issue of our Newsletter. The variety of content from local events to international news serves to remind us that, 'behind the scenes', there is a great deal going on that should encourage and inspire us all.

It is good to have included some of the reports and comments about the recent 2016 Conference so that we can consider what delegates valued and what to put forward when planning ahead for our next Conference in 2017. Thank you to everyone who shared their thoughts and ideas. If some of our readers wonder about trying to be at our Conference next time, read what others have said. If you do decide to share in this special event that is great. Looking for an informal Get –Together? Check with your nearest Contact Person about future meetings. When we have new information that we feel will be of benefit to members, we like to ensure that it is distributed as widely as possible. We are indebted to Dr Richard Petty and Dr Mark Hamilton, both invited speakers at our meeting in Aberdeen last October, who have together written the most recent addition to our information leaflets. This new leaflet really does address frequently asked questions regarding some of the very complex aspects of living with Myotonic Dystrophy. We are pleased to send you a copy with this Newsletter. Enjoy the rest of the summer and your reading.

*On a personal note,  
Lynne and I would like to thank  
Margaret Bowler, Trustees, members  
and friends for their very kind  
expressions of love, sympathy, care and  
comfort during our time of sadness.  
Katherine truly valued her time with  
MDSG friends. She was and always will  
be a precious daughter to me, and a  
loving big sister to Lynne. Now we must  
learn again to enjoy 'All things Bright  
and Beautiful', and to go forward with  
Faith, Love and Courage as Katherine  
did throughout her life. Our heartfelt  
thanks to you all, Elycia and Lynne.*

### Annual General Meeting

About 90 delegates turned up for the Annual General Meeting, which was chaired by our Patron, Professor David Brook.

This meeting is the formal side of the weekend. It gives delegates an insight into the business and running of the MDSG and provides an opportunity for delegates to ask questions.

Michael Walker gave the financial report for the year 2015. On behalf of the Support Group, he gave thanks to all who have raised funds through a variety of events. He highlighted a donation by way of a legacy of almost £150,000, towards research. The Trustees gave £50,000 to Professor Darren Monckton and to Professor David Brook, with £20,000 going to Dr Jeremy Rhodes (not present). Both Darren and David expressed their grateful thanks to the MDSG.

Alex Appleby, gave a report on the relaunch of the website, which is now up and running. Alex has kindly volunteered to be the web administrator, adding news items, events, updating and keeping it modern.

### New Trustee

For MDSG to continue supporting those with Myotonic Dystrophy, their families and their carers, it requires new people to join the Board of Trustees.

We are thankful that a new name was put forward to join the Board Members at the Annual General Meeting approved the nomination of Peter Ferrari.



Peter and his wife Pauline are MDSG contact people for the Wakefield area. Peter was formerly a bank manager to being in charge of bank managers for almost 40 years.

Whilst living in London, he was a Trustee of a charity, called Counsel and Care for the Elderly, before its merger with Independent Age UK.

Peter has now retired and has offered his services to help MDSG in any way possible. He enjoys travelling, a wide spectrum of sports and social activities. We welcome him to his new role.

The following Trustees had served a term of three years and were willing to stand for a further term of three years. Helen Brownlee, Luke Appleby, Margaret Bowler and Michael Walker, were all re-elected.

### Katherine Ormandy

On 5 July 2016 we said our good-byes to Katherine Ormandy who sadly passed away on the 20th June.

For many years Katherine, along with her mother, Elycia, and Lynne her sister, worked with the Young Adults Group at the MDSG Annual Conferences.

Katherine welcomed new members to the group and helped them in their activities during the day giving them confidence to have a go and join in.

At our Trustees meetings many refreshments were made by Katherine and Lynne. Katherine, was part of the team that collated the delegate packs and newsletters, getting them ready for the post.

We thank you Katherine and we will miss you.

Said with love, Margaret



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The Annual Conference was held in the East Midlands Conference Centre, Nottingham University. This was the third consecutive year we had celebrated our conference at the East Midlands Conference Centre. We welcomed 230 delegates and medical professionals. Professor David Brook welcomed everyone and Professor Darren Monckton was the chairman for the day.

Dr Tetsuo Ashizawa of the USA gave a talk on research, with Professor Brook introduced genetics. Delegates this year had the opportunity and choice of three workshops at the conference. In previous years it was restricted to two.

**Workshop One 11.30am**

Benefits...Mrs Rebecca Brown-MDUK, Wales

Overnight Breathing and Fatigue...Dr Paul Maddison

Congenital...Dr Gabrielle Chow

Research 1...Professor David Brook

Research 2...Professor Darren Monckton and Dr Tetsuo Ashizawa

**Workshop Two 2pm**

Maintaining Mobility-Orthotics, Aids and Keeping Active  
Mrs Jane Freebody-John Radcliffe Hospital

Benefits...Mrs Rebecca Brown-MDUK, Wales

Questions and Answers ...Dr Margaret Phillips

Genetics...Dr Mark Rogers

Heart and Pacemaker...Dr Chris Turner

Speech and Language Therapy...Jodi Allen

**Workshop Three 3pm**

Research 1...Professor David Brook

Research 2...Professor Darren Monckton and Dr Tetsuo Ashizawa

Maintaining Mobility-Orthotics, Aids and Keeping Active  
Mrs Jane Freebody-John Radcliffe Hospital

Questions and Answers...Dr Margaret Phillips

Heart and Pacemakers...Dr Chris Turner

Speech and Language...Jodi Allen

The end of the conference day saw Erich Maurer from Switzerland giving a short talk on the Myotonic Dystrophy Support Group he has formed in Switzerland.

The final talk of the day was by Dr Ian Bowler, giving a talk on Anaesthesia and Myotonic Dystrophy.

Our young people joined the end of the day meeting and presented all our speakers and workshop leaders with Thank you cards they had made and the young people were presented with a medal on a ribbon.

Thank you to Jaine Meredith-Kite for raising £110 from the raffle. Professor David Brook and Dr Chris Turner were amongst the winners.

Thank you to all those who contributed to the Home Produce stall, name the teddy, and the lovely cards on sale.

*(would the lady who made the cards, please let us know who you are, as we have lost your details, thank you).*

*Anyone who wishes to have a copy of the Powerpoint presentation by Rebecca Brown on Benefits, please contact by email to the office, and this will be emailed to you.*



## Young Peoples Group

Well, Elycia, I just want to say, you are a hard act to follow and in your absence, Eileen, Jan, Judith, Rob, Jake and myself Janet, undertook the awesome task of facilitating the young peoples activities on Conference day.

Judith had the great idea of organising some indoor games, tennis, football and other strenuous delights which kept especially, Greg and Charlie amused, while the rest of us were busy with various craft activities, Laura, Ellie-Beth, Hannah and Sarah made great contributions.

Some of the young people were attending for the first time, it was great to see new friendships being forged by William and Kelly who are great story writers and spent much time sharing their extensive knowledge of the diaries of Anne Frank, phone numbers were exchanged and we hope the communications will continue to blossom during the coming year.

Special thanks too for Nathan Walker's help throughout the conference performing many tasks alongside his dad Mike.

At the end of the conference the speakers were presented with the gifts made in the group. I think we can safely say a good time was had by all and we look forward to seeing you all next year for more fun and games.

**Janet Walker**



Dear Margaret and The Team

A big THANK YOU for all your hard work in arranging such an interesting and very well organised conference. I attended with my daughter, Susanna (who has DM), her partner and my daughter Linzi. We thought that the speakers, the workshops and the catering were excellent, and throughout the conference there was a warm and friendly atmosphere. The hotel was faultless too. We all came away inspired, encouraged and with hope for the future. Well done!...Rita Clarke

Learned lots of new information, interesting talking to other people from different parts of the UK to share experiences...Anne Smith

Be good to have more time for each session, but excellent, thank you  
Karen and David Taylor

We have not attended for years, but have gained knowledge and expertise that have been overwhelming and interested

Excellent informed conference...L. Stock

Really friendly and informative, the research presentations were terrific, great venue

Thank you to all who organised and all who spoke...Siobhan Duane

Very good, helpful, research looks hopeful for a future remedy

We very much appreciate how much work was involved. The day was very informative and great fun. We appreciate having more workshops  
Marion and Alison

More workshops and fewer talks was an excellent innovation...M. Cliff

Perhaps a topic for next year dealing with Counselling and Depression in coping as a sufferer and a carer. Talks on the website, thank you all  
Elizabeth and Ruby

So well organised—thank you...Tim Atherton

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### Views of Two 'First Time' delegates

"It was really interesting to attend our first Conference of the Myotonic Dystrophy Support Group in June. The venue at Nottingham University was excellent and everyone was very kind and welcoming. Conferences in our experience, are as useful for networking and friendships, as much as their formal content.

The context for us was a recent diagnosis of Congenital DM on our granddaughter, who was born at Christmas. Meeting so many people of all ages, was like taking a ride on the Tardis to look into the future.

We are both very glad to have made contact with the MDSG. It has provided help and support to us all. Having heard only of Muscular Dystrophy before, we have done a lot of reading on the Internet. This does not provide a good enough picture. The Conference, and the leaflets provided by the MDSG have been very useful to us and the wider family. It is so important to provide clear and concise information in an accessible form. We also appreciated hearing from the Scientists and Researchers, of work being done in other parts of the world. "Gene Scissoring" was fascinating. The workshops were excellent, giving practical advice.

The most valuable part of the experience however, was talking to other families and hearing their stories. The small local support groups around the country obviously supply comfort to many people. We would hope to be able to help with one in the North East of Scotland. Our daughter and her husband at present know of no one in the same situation. Moral support, as provided by the local groups would be good for them, and allow them to contribute too.

In the meantime our little granddaughter is making good progress. She is very loved and is very loving. Hearing the stories of so many others was both heartbreaking and inspirational. The Conference has helped us realise that we are still in a bit of shock. We, and our family, have a lot to come to terms with. The future is even less predictable. We will be back at conference again next year, and both hope to be able to contribute something useful to the MDSG."

**Alasdair and Marion (Aberdeen)**

~~~~~  
Having recently started to work at the NeuroMuscular Centre in Cheshire, I was delighted to be invited to the Annual Conference of the Myotonic Dystrophy Support Group.

The conference was described as offering an opportunity to 'learn, to socialise, and to listen to the latest research and medical information in Britain and across the world.'

Attending for the first time I can confirm that the conference offered all those opportunities and it achieved a great deal more.

Myotonic Dystrophy is not a familiar condition for most people or professionals. This conference provided a wealth of knowledge from people who are very familiar with the condition. The programme presented a valuable balance of current medical and clinical information and the expert knowledge of people who understand the reality of living with this condition. This knowledge of the condition was clearly shared in the presentations about current research, the Support Group in Switzerland described by Erich Maurer and Anaesthetics by Ian Bowler.

In an atmosphere of professionalism all the sessions informed and explained how aspects of Myotonic Dystrophy affect daily lifestyle choices. Added to this was a feeling of caring, support and welcome which made the event so enjoyable.

My first workshop was 'Overnight breathing and fatigue' with Dr Paul Maddison which gave real insight into the need for informed specialist management of this condition and the impact of excessive daytime sleepiness.

Next I moved to 'Maintaining Mobility-Orthotics, Aids and Keeping Active' with Mrs Jane Freebody from John Radcliffe Hospital. Jane challenged our balance, our posture and our problem solving in a thought provoking and informative session.

My final workshop was Speech and Language Therapy with Jodi Allen. Jodi gave an excellent presentation of the process of swallowing relating this clearly to the impact of Myotonic Dystrophy on the daily task of eating and drinking. My thanks to the Myotonic Dystrophy Support Group for an enjoyable and memorable day.

**Denise Boyall**



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### RAF Cranwell

In a previous issue we gave you a report of Margaret's visit to RAF Cranwell. This was followed by a second cheque and the total received was £5,926.47

### Marathon des Sables

Johanna Sutton, Mother of Three Children, Personal Trainer & Former GP, is running one of the world's toughest races for MD Research

Jo says: "In April 2017, I will be among over 1000 people from around the world competing in the Marathon des Sables or Marathon of the Sands.

The Marathon, considered the toughest foot race on the planet is a gruelling, multi-stage running event that crosses a 250km stretch of the Sahara desert in southern Morocco. In 1984, its founder, a French man called Patrick Bauer, walked 350 km in 12 days across the Sahara and had the idea to create an ultra-marathon experience for others to enjoy (endure!)

The event is divided into 6 stages, the longest of which is always about 90km. Competitors run across endless scorching sand, steep dunes and rocky jebels in searing temperatures of 50\*c. They must be self-sufficient, carrying backpacks with their own food and equipment for the entire event and a daily ration of water. Each night communal tents are pitched for the weary runners to rest and recover enough to repeat the effort the following day!

The race attracts some big names, James Cracknell ran the race in 2010 and finished in 12th position, at that time the highest placed Briton ever and Sir Ranulph Fiennes became the oldest Briton when he completed the event in 2015.

So why have I a 44 year old mother of three decided to attempt this seemingly insane race? I admit it does sound like madness, but what a challenge too! I love running and have fairly recently slipped into the world of ultra-distance running. I find it liberating to be able to cover great distances on foot and enjoy the peace and head space it affords. At times I enter an almost meditative state, at others I revise French verbs, make plans or compose letters. When possible, my husband will run with me, which is a great opportunity to properly talk!

I do not underestimate the enormity of the Marathon Des Sables and the amount of training I must do in order to succeed, however I feel very lucky to be fit enough to undertake such a challenge. I hope that the sheer scale of the event will encourage a lot of people to donate and I will be able to raise a considerable amount of money for Myotonic Dystrophy Research.

Please donate or share Johanna's fundraising page: <http://uk.virginmoneygiving.com/JohannaSutton1>

## Myotonic dystrophy, developing a European consortium for care and therapy

Over the weekend of 1<sup>st</sup> to 3<sup>rd</sup> July 2016, 20 researchers from across Europe gathered in Naarden in the Netherlands for the 22<sup>nd</sup> European Neuro-Muscular Centre international workshop. The focus of the workshop was to discuss developing an European consortium for care and therapy for myotonic dystrophy. Fortunately, despite the recent Brexit result, researchers from the UK (Newcastle) were represented, in addition to representatives from France, The Netherlands, Germany, Sweden, Canada, Italy, Denmark and Serbia. Providing additional perspective, the meeting was also attended by two researchers from North America, two family representatives (one each from the UK and France), a pharmaceutical industry representative (from Ionis, the company currently conducting the first trial of a custom designed myotonic dystrophy drug in the USA) and a representative from the European Medicines Agency (based in London for the time being at least!).



The aim of the meeting was to build upon the strong research base in Europe and the success of the OPTIMISTIC project and ensure that Europe is ready for additional trials of new therapies in myotonic dystrophy. Although the results of the trial of exercise and cognitive behavioural therapy are not yet in, (end of 2016) it has already been highly successful in demonstrating that it is possible to conduct a large multi-country myotonic dystrophy trial in Europe. At the meeting the lessons learned from OPTIMISTIC and other myotonic dystrophy trials were discussed, along with the latest developments in defining what aspects of the symptoms should be measured, what molecular changes in blood and muscle might provide clues as to whether a drug is working, and how genetic studies might be used to explain some of the variability and increase the efficiency to detect drug effects. In addition there was a review of the current state of play of the various national myotonic dystrophy patient registries and databases.

Most importantly however, much of the weekend was taken up with discussions on how to build on these successes and ensure that the full range of myotonic dystrophy research expertise across Europe is exploited to the best benefit of patients and families. To this end it was unanimously agreed that we should indeed establish a formal European myotonic dystrophy trial readiness consortium. The next steps will be to ensure that the full range of myotonic dystrophy research expertise across Europe is

incorporated into the consortium and that we develop the best ways to share data and samples, establish agreed protocols and ensure that best practice in current management is distributed across Europe.

**Professor Darren Monckton**

*The OPTIMISTIC study is testing the effect of cognitive behavioural therapy (CBT) on people with myotonic dystrophy type 1. The aim of the study is to compare how effective sessions of personally tailored CBT are on levels of fatigue and physical activity compared to standard patient care (no behavioural therapy).*

*As part of the study lots of things are being measured and people involved have answered a number of questionnaires, completed a walking test and worn an activity monitor during four separate visits to Newcastle over 16 months. These tests will help the researchers understand if there is any difference to those people receiving (CBT) and those in the control group.*

For more information check the OPTIMISTIC website [www.optimistic-dm.eu](http://www.optimistic-dm.eu)

PhenoDM1 is a study being carried out by Professor Hanns Lochmuller at John Walton Muscular Dystrophy Research Centre, Newcastle and Dr Chris Turner, National Hospital of Neurology and Neurosurgery, Queen Square London. Together the two sites hope to recruit up to 400 adults affected by myotonic dystrophy type 1 (DM1) into this study. This research has been funded by the National Institute of Health Research (NIHR), who are supporting lots of projects looking at rare conditions like DM1. This is a natural history study. A natural history study is one that follows a group of people over time that have a specific medical condition or disease. It collects information in order to understand how the disease develops and potentially how to treat it. PhenoDM1 is looking at lots of different aspects of myotonic dystrophy type 1 (DM1), including muscle strength and function, quality of life, pain and fatigue. Blood samples are also being taken to see if changes are detected at the molecular level. The same tests are being carried out one year apart to see what changes and what stays the same. If you would like to take part you must have a diagnosis of DM1, be over 18 years old and able to carry out assessments involved such as walking for at least 10 metres and completing questionnaires. For additional information or if you would like to take part please contact: Dr. Nikoletta Nikolenko  
E-mail: [Nikoletta.Nikolenko@newcastle.ac.uk](mailto:Nikoletta.Nikolenko@newcastle.ac.uk)  
Telephone: 07870517410



**A case of unusual hand pain in general practice**

At last years GP Conference, a very excited general practitioner trainee came to our stand in total amazement that we were exhibiting at the Conference. Dr Faraz Mughal had only that week had a case review published in the British Medical Journal, highlighting the case of a 34 year old man who had been diagnosed with Myotonic Dystrophy. Never having seen a patient with this condition and fascinated by the procedure of discovery, which stemmed mainly from the unusual hand pain, he wrote an article and had it published. We had a long and happy conversation with Faraz and were extremely grateful to him for highlighting Myotonic Dystrophy in a highly respected professional magazine. *We hope to see him at this years GP conference being held in Harrogate in October.*

**Archives**

Has any one kept newsletters from time gone by? One of our members is seeking a copy of the Autumn/Winter issue of 1994. if anyone does have one, could they please ring the office on 0115 987 5869.

**Standing order**

We all forget things and if they only happen once a year, there is more chance of forgetting. Have you considered paying your annual subscription by standing order? This way you will continue to be part of the family of MDSG and receive the newsletter on a regular basis. Reminders are sent out, on the anniversary of you joining, but we are all guilty of putting it to one side. You need to arrange this yourselves with your own bank, giving them MDSG bank details which are account number.....sort code.....

**Fundraising**

The 'silly committee' from Dover Fire Station have kindly donated £500 towards research from their collections made at Christmastime. Jordan and Ann went along for the presentation of the cheque. *A big thank you.*

Stephen Fisher on behalf of his partner Claire Wigham is raising money for MDSG by taking part in the 'Nuts Challenge' next month.

Alison Hulse is holding an event to raise funds for MDSG in remembrance of family members Ben and Lindsey. We have sent them T-shirts to help spread awareness on the night.

**Contact Training day**

This will be held at the Holiday Inn, Coventry on 1 October. We are in need of more contact families. If you are a member and have a landline phone and would be interested in helping MDSG, please enquire about the training day. We hold them every two years. Please note, you must be a paid up member.

**Newsletter**

If any member would like to have the newsletter sent to them by email, please email your address to the office at [mdsg@tesco.net](mailto:mdsg@tesco.net)

**Glasgow**

MDSG received a letter from the Development and Alumni Office of the University of Glasgow.

"I am writing to thank the Myotonic Dystrophy Support Group for your very generous donation towards Myotonic Dystrophy Research, carried out by Professor Darren Monckton and his team.

We would like to commemorate your Major gift with an inscription as a way of acknowledging your support. Your chosen dedication will appear in our publications, such as Giving to Glasgow, and also on our Online Benefactor Wall, which is a web based version of a traditional donor wall recognising the generosity of our donors."



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### New Advisor-Dr Chris Turner

Over the years, members have sought answers to questions and concerns, and required advice. Response to those enquiries requires a professional answer. To this end, we are grateful to our Advisors, who give their time and expertise.



We are delighted that Dr Chris Turner is willing to become one of our advisors. Dr Turner is a Consultant Neurologist, with expertise of Myotonic Dystrophy. He is based at the Institute of Neurology, Queen Square, London. Chris, has for a number of years, been a regular speaker at our Annual Conferences.



### Japanese DM Patients Association

Dear Margaret,

I have an interest in Myotonic Dystrophy, because my sister, Akane Hatano has been affected DM1. She established Japanese DM patients' association from March in 2016. I have supported her, because she can't go out without the wheel chair.

Akane always read "the facts- Myotonic Dystrophy". She had many organs' diseases. She understood why these organs' problems happen on her body when she first read this book.

In 2013, Akane and I know that "the facts 2<sup>nd</sup> edition" had been published in 2009. So we asked for Dr. Mitsuru Kawai and Dr. Yasushi Ooya for translating 2<sup>nd</sup> edition in Japanese. At last, they completed translating 2<sup>nd</sup> edition in 2015. Yuji sent you 2<sup>nd</sup> edition Japanese version. Akane wrote the foreword (as you) for this book on page iii.

Akena and I also met Professor Peter Harper in April. We were so glad to see him. Professor Masanori P. Takahashi (Osaka University) arranged this meeting. Akane is next to Professor Harper, and I am next to Akane.

In the back row, Professor Takahashi, Dr. Ooya, Dr. Kawai, and our group member, Yuya Tsuchida.

Yuji could not attend this meeting, so I handed his letter to Professor Harper.



Akane, Yuji and many patients begin to support each other in Japan. We hope associate your MDSG. MDSG is a great support group and we would be a good patients' group like MDSG someday.  
Best regards, Midori Senoo

## Wales Neurological Alliance in Cardiff

Margaret Bowler and Michael Walker were invited to attend the WNA Conference in Cardiff. Although fewer than expected attended the conference, we were able to pass on the message about Myotonic Dystrophy. One surprise was bumping into Jane Stein. Jane used to be a Family Care Officer and worked in the team headed by Dr David Hilton-Jones in Oxford.

## Primary Care at NEC

Again, Margaret and Michael attended this two day event, having an information stand. There are approximately, 7000 delegates, and it is busy, although this year the organisers had changed the schedule so that there were more breaks in between the talks. The delegates include, midwives, podiatrists, speech therapists, district and community nurses, and in fact anyone that you may find these days, working at or from your local surgery.

## GP Conference

Three of the Trustees, Margaret, Peter and Michael will be attending and manning an Information stand at the GP Conference in Harrogate at the beginning of October. There are about 1200 GP's who attend, giving us ample opportunity over the two days to chat and explain the tips to discover whether their patient might have Myotonic Dystrophy.

*We are inviting you the readers to suggest other conferences where MDSG could attend and exhibit and increase awareness amongst health professionals. (not all professions have an annual conference with exhibition).*

## Knaresborough

Our Spring meeting went well with 28 people attending. There are always many questions and experiences and our guest Catherine Falconer was able to speak to individuals wanting specific information. Catherine spoke to the group about her role as Principal Genetic Counsellor at the Department of Genetics in Leeds. Due to the complexity of DM her professional knowledge was invaluable. IVF came up as well on the affects of MD on families, testing and research studies presently taking place.

We must not forget carers who find the situation difficult at times and those who have loved ones in special care where changes are taking place concerning vulnerable adults. Hopefully our meetings helps to support and listen to each other. Thank you to everyone for coming.

Roberta Elliott

Other local meetings for the Autumn are being planned by Gillian and Chris Stock, Penni Cotton, Gwen Mumby and Michael Walker.

**Is there any member who would like to be a contact person for Norfolk, Suffolk, Kent, Sussex, Devon and Cornwall, Mid Wales?**

*MDSG would like to thank Isabelle Munghall—Glasgow and John Langley—Leicester for the many faithful years they have served MDSG as Contact People for their area.*

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## Regional Group Contacts

The numbers below enable you to make contact with someone else in your region. Phone to ask about local meetings, provision of services in your area for families with neuromuscular conditions, or to discuss concerns.

**Aberdeen**  
**Jenny Watt**  
(contact office)

**Kingston-upon-Thames**  
Penni Cotton  
(contact office)

**Pontefract**  
Jack Lawrence  
01977 705496

**Bedford**  
Kath Dixon  
01234 708520

**Leicester**  
(vacancy)

**Sheffield**  
Rachel Reeson  
0114 230 6177

**Cardiff**  
Margaret Ware  
02920 869277

**Manchester, North West and  
North Wales**  
Elycia Ormandy  
0161 445 5844

**South Birmingham and  
Worcestershire**  
Gillian and Chris Stock  
01527 64988

**Cumbria**  
Neil Braiden  
01228 512385

**Northampton**  
Michael Walker  
07831 347143

**Wakefield**  
Pauline Ferrari  
01924 377986

**Dorset and Somerset**  
Ruth Harrison  
01425 626133

**Northumberland, Tyne and Wear,  
Teesside**  
Peter Bodo  
01740 620707

**Wiltshire, Hampshire**  
Sue and John Kelly  
01725 519233

**Essex**  
Gwen Mumby  
01245 601343

**North Yorkshire, Knaresborough**  
Roberta Elliott  
01423 868455

Jaine Meridith-Kite who has DM2 is willing to be a contact person for people who have a DM2 diagnosis. Her contact details are 01732 841652

**Glasgow**  
(vacancy)

**Nottinghamshire**  
Margaret Bowler  
0115 987 5869