MD NEWSLETTER

of Myotonic Dystrophy Support Group

December
2022

Christmas Greetings
to all our readers
from Margaret Bowler
and the Trustees of MDSG

THE ANNUAL CONFERENCE IS BACK!

Book the dates
NOW!

for our
31st Annual Conference

16 to 17 June 2023

Venue
Radisson Blu Hotel
East Midlands Airport

Herald Way, Pegasus Business Park
East Midlands Airport, Derby DE74 2TZ

Myotonic Dystrophy
SUPPORT GROUP

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Hello to all members and friends of Myotonic Dystrophy Support Group

At the Trustees meeting in June 2022, Prof David Brook announced that I would be retiring from my work with MDSG. My retirement will take effect from June16/17th 2023, the date of the next AGM and Annual Conference.

MDSG has been a BIG part of my life for the last 30 years. I cannot explain how much I will miss the contact with families, but the charity will continue, the Trustees will see to that.

We have missed three Conferences because of the Pandemic. We could not put anyone at additional risk of infection. We are at last able to plan for a Conference Day and enjoy meeting together.
At this early stage of planning, please note the day on your calendar. We will confirm more when details are available. As always the meeting is largely funded by MDSG, but there will be a small charge for all delegates.

In 2019 at our last face to face Trustees meeting, Elycia Ormandy told those present that she had decided to step down as a Trustee at the next AGM, which is in June 2023.

The first public meeting of MDSG was held in 1989 at West Bridgford, Nottingham. Elycia and family arrived, and were “landed with the job of looking after the bring and buy stall!”

During the 30 years, Elycia took on the responsibility of organising the Young People’s Workshop-many young people, now a bit older enjoyed that time together.

The speaker was Dr Peter Harper (later Professor) and 90 people heard his talk. The talk was printed and distributed worldwide until the faulty gene that causes DM was discovered in 1992. The genetics that were printed in the lecture notes were now incorrect and had to be amended.

Congratulations to Dr Ian Bowler, a consultant anaesthetist in Cardiff and one of our advisors, has just received an award for the Queens Platinum Jubilee Medal. Ian is also a doctor on the South Wales Air Ambulance, the post he has experienced for the last 5 years.

We welcome Wendy as our office secretary. I trust she will be happy with us and will not have too much trouble reading my writing! **Margaret Bowler**

Letter from The Editor

Hello Everyone,
Here we are with MDSG news from around the world.

Rather later than we had hoped, this Newsletter does have some reports of events that took place earlier in the year. We make no apologies for including them here, as each one is an important event in the life of MDSG. Thank you for the orders we have received from you for packs of Christmas cards. It is good to know that there has been a good response from notices on our website and Facebook.

Continued on next page

Sharon Walker 1958-2022

It is with great sadness that we tell you that Sharon, Michael Walker’s wife, died at the end of May.
Sharon met many of you at Conferences and at regional meetings when she was able to travel with Michael.
Sharon was Mum to twin boys, Connor and Nathan.
Nathan died five years ago.
We send love and prayers to Michael and Connor in their loss.

Continued from previous page

Regional meetings have been resumed during the summer. MDSG sent out invitations to members living in the South West, North and mid Wales, Belfast, Dublin and Cardiff. .Our sincere thanks to Mike Walker who travelled to and hosted these informal get-togethers, joined by Margaret Bowler in Cardiff. More invitations will be sent out for other regions in 2023.

We are currently putting together plans to hold our next Conference Day and AGM. Planning was never an easy task, (ask Margaret Bowler!), but we recognise that it is the meeting together that people really value.

Conference booking form is enclosed

We face challenging times for everyone in the coming months. There are no easy answers for any of us. Any helpful suggestions to share? Please do.

Some individuals have set themselves tasks that will help others, by raising funds and awareness for MDSG. We are happy to share their stories here.

Keep safe and well. Make the most of every moment. **Elycia Ormandy**

Acknowledgements

Thank you to all those members who have renewed their membership, or made donations. Thank you also to those who have lost loved ones and asked for donations to be given to MDSG. A number of people have remembered MDSG in their wills.

Wherever possible, we like to acknowledge your gift in whatever form it comes. Unfortunately, we do not always have the information.

Please accept our apologies if you have not had an acknowledgement for past donations. If you make a payment through the bank or via our website please state what the donation is for, whether it be in memory or a gift in lieu of a special birthday or maybe your membership subscription. If you have made a donation along with your subs, via these methods, unless you tell us we will not know you have re-joined and we do value your membership.

For online giving, we no longer use ‘Worldpay’ through the website, only, ‘Just Giving’.
We still accept cheques, but as more and more people are using online banking, please return your membership form either by post or scan and email it, so we can keep our records up-to-date.

If you think we have missed your information, please contact the MDSG office and let us know.

IDMC-13

I recently attended the IDMC-13 conference in Osaka (Japan). A meeting place for all the experts in myotonic dystrophy, whose papers I have been voraciously consuming for the past four years….for sure I was signed up and excited to attend in person!

The lead up to the trip itself was bumpy – lots of documents, preparation of slides for the talk…but I was determined to not let my foot off the gas. Japan and the myotonic dystrophy conference were waiting for me!

Fast forward a bit and the day of the trip was nigh! I was a bit stressed, but knew all was going to go smoothly. I’ve travelled long distances many times in the past, after all. Once I got past security and jumped on the flight, as it usually happens, all my worries melted away! The unlimited drinks on the plane didn’t hurt either…

Once I landed it was clear I was in a new land. The change in scenery was incredible! From the way people behaved, to all the signs mostly being in Japanese!

Continued on next page

IDMC 13 REPORT

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Takahashi San (the conference chair) was pleased to see that I made it in person as I was constantly emailing him about different documents before my travel. The conference itself was an absolute blast! Getting to meet with all the people I look up to was an otherworldly experience. The talks and posters about all the research being done in the field were incredible. It's so amazing to see the amazing strides being made and hearing more about the clinical trials and patents in the works.

In the back of my mind I was constantly doing my best to prepare for my talk and reading tons of papers in preparation for any questions people might ask me – it was a bit scary! It was a great learning experience to present my research in front of the experts. And to top it off, David got a couple congratulatory emails on my talk, which made me glad that people enjoyed the talk!

David and Margaret were very kind to contact Tetsuo Ashizawa (Tee) to look after me as I was on my own. Tee and Takahashi suggested I go sightseeing around Kyoto and introduced me to some of the students there as both of them thought that it will be overwhelming for me to navigate the places on my own.
So the next day came and myself, Haruna and Kosuke spent all day together shopping, visiting places and trying all kinds of food.

And just like that, a whole week flew past! A week I will surely remember the friends I made there, the country, the experience for the rest of my life as one of the happy places.

Anjani Kumari
PhD Student,
Nottingham
University.

* * *

It was an interesting and unusual experience attending the IDMC-13 in Japan. Because I decided to participate virtually and there was an 8 hours time difference between Japan and the UK, I had to burn the midnight oil to listen to all the talks and also give a talk at 4am. Nevertheless, I really enjoyed it, the talks were very informative and could shed the light on some unsolved questions to our projects.

Amongst all the presentations, what impressed me the most was the Peter Harper Memorial Lecture given by Dr. Mark Rogers, Prof. David Brook and Mrs Margaret Bowler. From the stories they told, I understand that it must have been beset with difficulties starting the Myotonic Dystrophy Support Group from scratch. But luckily, Margaret wasn't fighting alone. She not only had other patient families being there with her, but also had unconditional support from Peter Harper who was such a great, wise and selfless person.
It's my honour to be his student's student. It's also my honour to be a member of the support group, to fight the disease with all the patients and to devote my skills to the service of all who are in need.

Xiaomeng (Belle) Xing
Nottingham University

News from another charity, ‘Contact a Family’

The impact of rising prices on families with disabled children

At Contact we are hearing from more and more families affected by increased prices. Did you know there is help available to some families for some journeys to a hospital?

Find out more about Contact’s Out of Energy campaign and how we continue to make the case for additional financial support for families affected by energy price rises.

Families better off with Contact helpline’s financial advice

Eligible families who make a call to the Family Finances team on Contact’s helpline **(020 7608 8700)** are better off by an average £97 a week. In total in 2021/22, we increased eligible household incomes by £439,000 by helping families claim the benefits to which they’re entitled.

* * *

Registry

If you are registered with the Myotonic Dystrophy Registry and we do hope you are, then you will shortly receive a request to fill in a very simple survey.

Do you have Myotonic Dystrophy, or care for someone who does? If so, you are invited to complete a very short survey about your experiences with the UK DM Patient Registry.
You do not need to be participating in the registry to complete the survey, and it should only take 2 minutes to complete. The link below will also take you to it, if you are not on the Registry

Survey Link - bit.ly/DMREGSURV

31st Annual Conference June 16/17 2023

We always try to have a varied selection of topics for the workshops.

Would members let the office know of any subjects they particularly wish to hear and learn more about.
Maybe there is something that we have not covered or not had for a number of years.

One subject we will be covering is DM2. The speaker is Dr Benedict Schoser from Germany.

We will be having research updates from our Patron, Professor David Brook, and from Professor Darren Monckton.

The Annual General Meeting will take place on the Friday evening, (provisionally 7pm) after early evening refreshments at 6pm.

CONFERENCE

Fundraising

Thank you so much to you all for participating in and donating to my chosen charity in the June challenge.

I am delighted to say that we raised £140 for the **Myotonic Dystrophy Support Group** and in the process I hope we all gained a little more knowledge about the condition, as well as a little more empathy for Our Stuart, Marni and Logan. In total, we covered 1805 kilometres on a target of 1350, so 134% which is amazing. Thank you, well done!!
Ruth Ashton (Nationwide, Manchester)

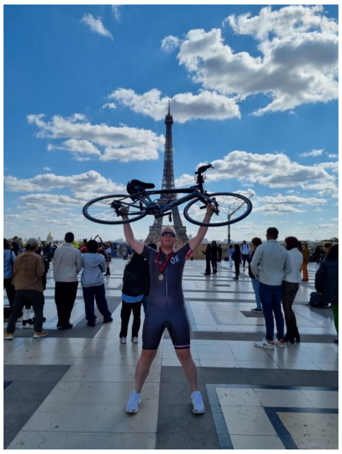
Logan

Logan and his father Stuart

Ruth (blonde) who organised the fund-raising with friends and colleagues

Fundraising

Bradley Collett did the London to Paris bike ride, raising over £1000 in memory of his friend Alex Thurston who had myotonic dystrophy
Well done Bradley, thank you



Christmas Cards

To date, we have had an amazing response from you all, for the sale of Christmas cards. Each pack has ten cards plus envelopes. Card size 6" x 4" with the greeting ‘Happy Christmas’.
You can either have a pack of Pack A or B.

The cost including postage is £3.50 (35pence per card). Please contact the office either by phone or email on contact@mdsguk.org to order your packs.
(Pack A, on the left, Pack B, below)

To date, 230 packs have been sold, that means two thousand three hundred cards will be spreading awareness about MDSG.

P I P R E N E W A L

Letter from a member

Hello everyone,

Back in October 2021 I received what I feared most - my dreaded PIP renewal form. I completed the form telling them how my needs have increased and the help I require from my husband will all aspects of daily living.

On the 15th March 2022 (it had taken the DWP this long to reply) I had a telephone assessment and was asked only 3 questions. These being how long was I in hospital for my cataract surgery x 2 and the same for my shoulder surgery? Of course, I answered these questions and nothing else was discussed.

On the 30th March (my birthday) I received a letter saying they had reduced my enhanced rate mobility to the standard rate of PIP. Despite the fact that I have been on higher rate DLA and enhanced rate PIP since 2004! They decided themselves that I have no mobility issues that qualify for the enhanced rate. They had 'made up' things which were totally untrue.
I asked for a reconsideration and sent in supporting letters from myself, my G.P and Margaret with all 3 stating emphatically that I should indeed be receiving the enhanced rate for mobility. My local MP also wrote to the DWP supporting my plight. They wrote to me on 20th May, again refusing my request to be granted the enhanced rate.

At this point I had to decide either to buy my Motability car or give it back. I decided to buy the car (to be able to use for hospital appointments etc.).

I bought my car in June. It was such a stressful time for me. I had to 'beg, steal and borrow' £17,250 to buy my car from Motability because I cannot get on public transport (bus and train) and needed my car - which incidentally my husband drives, me to all my appointments.

I then decided to appeal against their decision and lodged my appeal with the tribunal service. I actually told the tribunal that the DWP had made up things and told untruths about my mobility in their report. I also said that I was never seen face to face or examined but just had a telephone call assessment.

My appeal was lodged on the 21st May. On the 21st July I received my last letter saying they had reversed their decision and I was awarded the enhanced rate again. I never actually went to tribunal, the reversed decision was made before I needed to attend court.

So…..at the end of my story I urge every one of us suffering with Myotonic Dystrophy to have enough fight left in you to take the DWP to tribunal to receive what we so rightly deserve

Ann Law

Peter Harper Memorial Symposium: Celebrating a Life in Medical Genetics

Monday 12th September 2022

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Margaret Bowler was invited to talk about Prof Peter's contributions to families with Myotonic Dystrophy. She writes,

I was very privileged to be invited as a speaker at this very special occasion. It was an opportunity to offer words of thanks for all the invaluable support and encouragement that Prof Peter Harper had given to MDSG through his time as our Patron, and throughout his years of work with families affected by Myotonic Dystrophy.

About 100 people had gathered at the lecture theatre, at the National Museum Wales, Cardiff. Each speaker was invited to speak about a particular aspect of Prof Harper's work covering,

1) Peter's Legacy,

2) Huntington's and Myotonic Dystrophy

3) Genetics, Medicine and Society.

My talk was very different from any that I have done before. I read a tribute to Prof Harper from a MDSG newsletter, written by Jill Browning from Northampton. In 1973 Prof Harper had travelled from Cardiff to meet Jill and Terry in their home, and to see their young son who had been diagnosed with Congenital Myotonic Dystrophy. This was long before the Support Group was founded.

After my talk, a lady came to me and said that she had tears in her eyes because she could see the photograph of Prof Harper on the front cover of the Newsletter as I read Jill's story.

A tremendous amount of work had been done to find a treatment and cure for Myotonic Dystrophy.
Prof Peter Harper's youngest son, Dr Matthew Harper, from Melbourne, Australia, ended the day with closing remarks.
It was good to meet up with a number of people I knew who had worked in the field of Myotonic Dystrophy.

Thank you Prof Sir Peter Harper for being YOU.

Peter Harper

Tuesday 13th September 2022

Mrs Elaine Harper invited me to a Reception for Family and Friends the following day.
I was asked to give a five minute talk about the work of MDSG.
I was made to feel very welcome at this event, and Mrs Harper took me to look at a table-top display. It included a framed map of Bardsey Island and a photograph of me!
MDSG presented the map to Prof Harper when he retired as our Patron.
The significance of the map is that Prof Harper was staying on Bardsey Island when he wrote the book,

'Myotonic Dystrophy, the facts'

This book was requested by me so that patients and their families could have a reference book written for them in non-medical language. This popular book has been translated into other languages, and all members of MDSG have a copy to help their understanding of all that is known about Myotonic Dystrophy.

My thanks go to Elaine Harper and her family for including me in this very special weekend. It was a lovely fellowship of family and friends, and a very real tribute to Prof Sir Peter Harper.

Peter & Elaine - Bardsey Island 2001

SwallowDM1

A project to improve the assessment and treatment of swallowing difficulties for people living with Myotonic Dystrophy Type 1

Swallowing difficulties (known as dysphagia) are common in Myotonic Dystrophy Type 1 (DM1). For many, dysphagia causes coughing and choking on food, drink, and saliva, leading to fear and anxiety when eating and drinking. In severe cases, food and drink can go down the wrong way towards the lungs and cause pneumonia. I am part of a project called 'SwallowDM1' which aims to improve the assessment and treatment of dysphagia in people living with DM1.

Background information

In 2020, Jodi Allen, a speech and language therapist at the National Hospital for Neurology and Neurosurgery in London, invited people living with a neuromuscular condition to form a patient and caregiver advisory panel. I live with DM1 and felt able to provide valuable experience and insight to support the project. I therefore put myself forward, alongside five other people living, or caring for somebody, with a neuromuscular condition.

Our first advisory panel task was to develop a nationwide survey to better understand how dysphagia affects people living with neuromuscular disease. Over 40% of survey respondents lived with DM1, demonstrating to us how much of a problem dysphagia is for those diagnosed with this condition. The survey also showed that the ways we assess and treat dysphagia needed improvement, and thus our study was born.

The SwallowDM1 project

Led by Jodi, and other experts at the hospital and University College London, we have developed a research project which aims to better understand the causes and presentations of dysphagia in DM1. The study (called 'SwallowDM1') will require participants to undergo various swallowing assessments. The advisory panel were the perfect people to trial these out, ask relevant questions and provide feedback as to whether the assessments were appropriate in meeting the aims of the project. In addition to furthering the research, I have found the meetings invaluable in sharing experiences and receiving support from others with similar neuromuscular conditions.

What next?

Once the project has had essential and rigorous external quality checks, we will be looking for people living with DM1, family members and caregivers who might be interested in participating in this research. It is an opportunity to help shape the future treatment of dysphagia and benefit people living with DM1 in future.

If you are interested in hearing more about the project, or about my experiences as an advisor please do contact me on: neuromuscularswallowing@gmail.com

Donna Banks (15.xi.23)

Area Contact Person, Why not become one

Have you ever thought how you could help MDSG?

Why not become a Contact person for your area.

Help arrange get togethers, so you can meet with others in your area. Share experiences, useful tips with others who understand. You will not be on your own, the MDSG office will give you all the support you need and deal with the administration of sending invitations.
Think about it, ring the office for more information.

The details 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. **Is your area represented?**

Aberdeen
Jenny Watt
01224 580559

Cardiff
Margaret Ware
02920 869277

Croydon
Lesley Smith

Cumbria
Neil Braiden
01228 512385

Dorset and Hampshire
Ruth Harrison
01425 626133

Glasgow
Michael Kneafsey
01360 311440

Kent
Kirsty Blount and Amanda Scott
01622 764824/01622 764347

Kingston-upon-Thames
Penni Cotton
(contact the MDSG office)

Leicester
Michael Beale
07867 502745

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

Northampton / Milton Keynes
Michael Walker
07831 347143

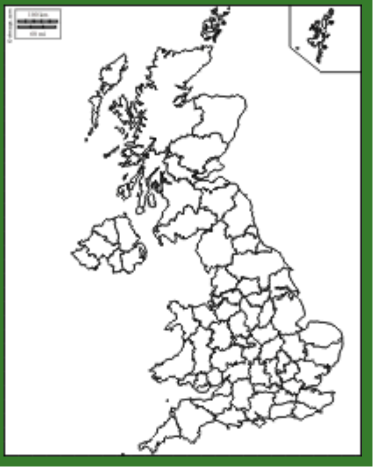
Northumberland, Tyne and Wear, Teesside
Peter Bodo
01740 620707

Nottinghamshire
Margaret Bowler
0115 987 5869

Somerset
Lucy Howard
07748 636122

Sussex
Rita Clarke
(contact the MDSG office)

West Yorkshire
Pauline Ferrari
01977 799565
Jack Lawrence



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Myotonic Dystrophy
SUPPORT GROUP

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