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This is the proud and emotional moment when Margaret Bowler, Founder of MDSG received a Lifetime Achievement Award from Dr Tanya Stevenson CEO of the Myotonic Dystrophy Foundation at their Conference in Washington DC.

Professor Darren Monckton gave a presentation of her work and achievements worldwide for the communities of myotonic dystrophy.



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R Walton

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*The Lifetime Award*





*Margaret in her thank you speech, returned the favour by presenting both Tanya and Darren , world famous Robin Hood hats. Always room in her case for cherished gifts.*





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*Accompanied by her son Stephen and wife Tracy what better way to see the sights, than travelling in style, with Capitol Hill in the background*

## LETTER FROM A TRUSTEE

Hello everyone,  
Readers with a keen eye will notice that this column has a different title.

The board decided to include a letter in each newsletter from one of the trustees and it is my honour to be the first to put 'pen to paper'. Having succeeded Mike as your Treasurer, I am looking forward to taking on the responsibilities that come with the role, which will be keeping me busy in the months ahead.



If you have not been to a Conference before, please do think about it for next year and come along if you can. (Details on following pages) It is a great day for meeting with other families in an informal and friendly way, and to share your stories and experiences. Our professional advisors are also there to take your questions and to provide guidance where they can. My wife Pauline and I looked after the merchandise stall, where your generosity really blew us away. Thank you so much if you came along and bought something from our range of items, or from the sweatshirt and t-shirt stall, or if you donated via the Bring and Buy stall.

The impact of the Covid pandemic was very significant, as it meant that many plans had to be put on hold for such a long time. Happily, we can now look ahead with more confidence and in the coming months we will be letting you know what is in store. Keep an eye out via Facebook and the website, alongside our future newsletters. If you have any ideas that the board should consider, such as a new activity or a publication, please do get in touch at any time. The contact details are on the back page of this newsletter.

I want to close by saying thank you to you all for your amazing support over the years, and to say that the Support Group will remain just that in the years ahead. It is here to support you, members, families, and friends – both old and new. We will be here when anyone needs our help and advice. **Peter Ferrari**, Treasurer.

All the best for now and a **Happy Christmas from The Trustees**



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## TWO Conferences in 2024

Yes, we are going ahead with two conferences next year

We know wherever we have the conference, it only suits a very small number of you the members. Travelling long distances can be an issue for many and not just because you are affected by myotonic dystrophy.

We are planning one in the **NORTH** of England, and another in the **SOUTH**.

**BOOK NOW!** (Booking form is enclosed with this newsletter)

for the one in the North which is taking place at the

**Grand Hotel, Gosforth Park, Newcastle  
on 17 and 18 May 2024**

with the AGM taking place as it has done in recent years on the Friday evening (*subject to change*). The B & B rates are extremely good if you wish to stay overnight.

~~~~~

The one in the South will be at

**The Hampshire Court Hotel near Basingstoke  
on 18 and 19 October 2024**

The booking form for this will be available next year. As the AGM will have taken place earlier in the year, something else will be arranged on the Friday evening in its place.

We hope that this will make it easier for more of you to come along and mix with others at our conference. You read in the last newsletter, the letters from those who attended for the first time, how much benefit they got from the talks/workshops and meeting many other people affected by myotonic dystrophy.

If you wish to come to both, then DO! The two conferences are open to all wherever you live, Scotland, Wales and Northern Ireland. If you would like to come, but various situations including cost, may be stopping you, ring the office and talk to me, we may be able to help. We are here to support you, in any way possible. **Michael**



**Fiona Sinsbury** after completing the Highclere 10K run. She raised funds for MDSG in memory of her Aunt Janet who passed away earlier this year. Janet had myotonic dystrophy. Fiona wearing the MDSG t-shirt raising awareness as she ran. She said, "Despite the wet and windy conditions, the run went well".

*Thank you Fiona and well done.*

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**First Carlton Rainbow Troop**, having fun and raising money for the support group. Our founder, Margaret Bowler, has been involved with them for many years and they have always supported us, usually by running the Robin Hood Mini Marathon. Unfortunately this year we had trouble registering them



so undaunted and adhering to the Scout motto "Be Prepared" their leader Sheryl organised an evening of fun activities for which the Rainbows asked family and friends to sponsor them. They raised the fantastic amount of £203! Well done Rainbows and thank you very much from the Myotonic Dystrophy Support Group.



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**Charis Mccready** ran the Tonbridge half marathon. Wearing the T-shirt, she raised funds and awareness, for MDSG as her two brothers Jordan and Oliver, both have myotonic dystrophy. Note the trainer tags with their names on, so were running with her. Charis crossed the line in a time of two hours and 18 minutes.

*Well done  
Charis*





## Anyone for Tennis?

Here is a photo which includes our treasurer Peter Ferrari and his wife Pauline, who were invited to the annual fund raising event held by Welwyn Tennis Club in Hertfordshire. Each August Bank Holiday, the club hosts 'Mac's Tournament' in memory of a former member who died 17 years ago.

The event aims to raise funds for a designated charity, and this year MDSG was nominated by the Poole family from Hertfordshire. Simon is a member of the Welwyn Tennis Club and nominated Myotonic Dystrophy as he has an affected son and grandchildren.

On a beautiful sunny day, the tennis was competitive but fun. Thankfully, Peter and Pauline did not have to enter the competition!! Following a magnificent buffet lunch, Peter and Pauline had the opportunity to give a brief outline of Myotonic Dystrophy and of the work of the Support Group. There then followed a raffle and an auction of some amazing prizes, which contributed towards an overall total of £3400 that was raised on the day!!

The rest of the afternoon was given over to the tennis and a great time was had by all.

We would like to take this opportunity to thank Simon, the Poole family, Sue McFayden, and the members of the Welwyn Tennis Club for their amazing generosity and hospitality on the day. If you would like to know more about the Club, you can find them on Facebook and at [welwyn-tennis.co.uk](http://welwyn-tennis.co.uk)

*Simon is on the left.*



One of our members Lynne Cocker, along with her husband Joe, have had many fundraising events in the past, including cake stalls and having stalls at outdoor events and fetes raising much awareness and funds. Joe passed away several months ago and Lynne has a hoist available, complete with instructions which she would like to donate. Joe used it to get in and out of the hot tub! Good idea for the cold winter months. As well as a hot tub, it can be used for pools or even Horse riding.



Lynne lives in the Southampton area.

Please contact the office if you are interested and we will pass your details on to Lynne.

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## International Myotonic Dystrophy Awareness Day

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In 2021 a group of myotonic dystrophy organisations joined together to initiate an international awareness day for DM. The date was decided for September 15<sup>th</sup> with the aim to spread awareness of the condition to a wider community, including the general public, healthcare providers, policy makers, regulators, biopharmaceutical companies and researchers. Supporters are encouraged to undertake any activities they can to spread the word, talking with friends, distributing leaflets or posting on social media.

One part of DM awareness day is the illumination of buildings in green to mark the occasion. MDSG wanted to participate in the day and after a few email exchanges and filling in the necessary forms the University of Nottingham kindly agreed to light up the Trent Building on their University Campus. So, on Friday 15<sup>th</sup> September I collected Margaret Bowler and we drove to the University and met with David Brook and Becky Trueman from the research group to wait for the grand light switch on!

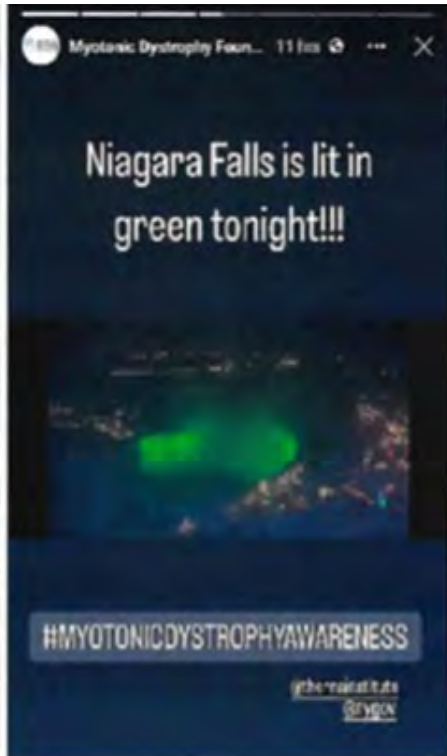
I have to admit that I was slightly apprehensive if it was actually going to happen when we all arrived at 7pm to see the building looking very normal and definitely not green! But thankfully at 7.30pm, as it was starting to get slightly darker, the lights sprang into action and the building was green for DM! I think you'll agree that the building looked brilliant, and not forgetting the added bonus of turning our very own Margaret Bowler and David Brook green too!!

In addition to the University building, the Nottingham council building was also illuminated green and when I looked online it was amazing to see the various landmarks around the UK and the world that were also green and spreading the word for DM awareness. I have attached a few photos!

Please keep the date in mind for next year and if you have any ideas of how to spread awareness on September 15<sup>th</sup> 2024 then let us know! **Ami Ketley**







**Exhibitions**

Increasing awareness amongst health professionals is something we feel is extremely important. The more health professionals in all areas know about the condition, the more they can help you with the day to day management.

We have attended the Anaesthetics Conference, held in Edinburgh in September. We were there when it was International Awareness Day, handing out flyers and with a pull up on the stand increasing awareness amongst the anaesthetists.

A month later we attended the GP Conference in October also held in Scotland, this time in Glasgow. We also recruited a new member. A GP surprised to see us and surprised we existed, became a member as she had family with the condition. A further GP, still training, also amazed to see us as she had Myasthenia Gravis, another neuromuscular condition. She was trying to have a support network in her area, so was interested in the history of MDSG.



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## Get together

There have been several get togethers the past three months.

### Ipswich/Nottingham/Pontefract/Northampton/Glasgow

#### Pontefract

Over in West Yorkshire, our local contact officer Pauline Ferrari organised a Fish and Chip luncheon in Pontefract. The date coincided with the arrival of Storm Babet and four families battled through the wind and rain to enjoy a good catch up over a good meal.

This was the first time that we had tried this type of event in West Yorkshire and gives 'food for thought' for similar events early in the new year. Pauline will be looking to hold an event in a different location in West Yorkshire, so if you have any ideas for a good venue please do get in touch with Pauline directly. Her contact details are shown on the back page of this newsletter.

#### Nottingham

Claire McAlonan, contact person for Nottingham arranged with the help of Linda Perry, a get together in the Newark area of Nottinghamshire. Trustee, Dr Ami Ketley gave a talk on her research she is carrying out on the heart. New faces and new members have joined MDSG as a result.



#### Ipswich

After receiving several calls from the Ipswich/Stowmarket area, it was decided to arrange a get together. This was the first time in this area and 16 people turned up and with the exception of Brenda Ashby, who has been a member



for many years and been to a number of conferences, no one had met another family with the condition. Brenda worked tirelessly in the kitchen, with the help of Natalie.

The afternoon went well, with plenty of food to keep everyone going. A text message less than an hour after we finished, said "I got a lot out of it and exchanged some numbers, hope there will be another one". *This is exactly what we hope you will get out of the local get togethers. Look out for more next year.*



## Ireland

### Dublin

We were invited back to Dublin by the Muscular Dystrophy Ireland for another hybrid get together for people in the Republic of Ireland with myotonic dystrophy. Fellow trustee Euan Cumming who has family in Ireland joined with Michael Walker to represent MDSG at the gathering. I was invited to give an outline of what is happening within MDSG and how we are supporting you the members. This year was different, in that Dr Chris Turner gave a talk via zoom to those in the room at the MDI office and those online. He spoke on "*Modern Treatments for myotonic dystrophy*". This was an updated talk that Chris gave at our Conference back in June. Despite the clock ticking way past the allotted time, Chris gave up extra time to answer the many questions.

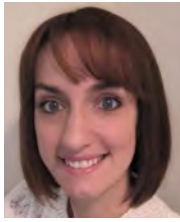
*Picture below shows some of those who attended in the MDI office, there were others, but some had left for long journeys home.*



### Belfast

The following day, I continued North to Belfast, whilst Euan went to spend time with his family. I prepared for a get together taking place the day after with our friends and members in Northern Ireland. As well as an amazing 22 people turning up and some who had hoped to come, but were not able, we welcomed Sarah Mason, a Neuromuscular Nurse from the Neurosciences Department at The Royal Hospitals. Sarah gave a presentation on her work and that of the department, which was well received as a number of people present attend the hospital for their appointments. It was good to have a few young people and the food prepared by the Maldron Hotel was excellent. Two families even filled in membership forms. It was a great time, with me just hoping the 8 hour ferry crossing across the Irish Sea would be calm. *It was not too bad, albeit, extremely windy.* Michael

## My research project by Dr Ami Ketley



As some of you may know, I spent over 10 years working with Professor Brook in his research lab. For some of this time I worked on a project looking at heart development but for most of the time I worked on a project looking for possible drug opportunities to treat DM.

In 2018 I had my second child Maisy and decided to take a break from the lab to be able to look after her and my son, Harry. During my career break I was still involved in various meetings and tried to keep up to date with things as much as possible.

Then in 2021 I saw a job advert for a fellowship (funding) scheme that was specifically aimed at people who had had a career break from research and would like to return to work. The application process was long and I had to pass numerous selection stages, including a telephone interview, writing my research proposal and a day out in London for a further interview in person. After a year of the application process, I received the good news that I had won the funding!

I started in January of this year and I am researching the heart symptoms seen in myotonic dystrophy. This is a nice fit for me as my previous work in David's lab covered both heart development and myotonic dystrophy, so this project is a good mix of the two! Instead of working in a laboratory I am doing mainly computer research. I am looking at lots of different genes to try and understand what is happening in the DM cells and to try and understand how the different genes might work together. So far it has been a steep learning curve but an enjoyable challenge. I am really enjoying being back at work and I am very happy to be working on a DM project again!

**Ami**

## What is a Patient Registry? by Curator Helen Walker

Without a system in place to track patient data over time, it can be difficult to make informed decisions when it comes to treatment, care management and research. This issue is multiplied when it comes to rare neuromuscular conditions, as there can be very little data available. This is where patient registries can help!

A patient registry is a database used to collect and store information from people with a particular condition, genetic mutation, or disease. Usually this will be information you provide by answering online questionnaires relating to your diagnosis, general health and wellbeing, and how the condition affects your daily life. This collection of data can then be analysed to track patient outcomes, monitor effectiveness of therapies and interventions, or identify patterns or trends in care. In short, patient registries are an essential tool for improving healthcare outcomes for people with rare conditions.

MDSG help to fund and promote this registry and encourage all UK residents living with Myotonic Dystrophy to sign up, regardless of your age or whether you are symptomatic.

### Why is joining a Patient Registry Important?

There are several reasons why joining a patient registry is so important:

**Empowering patients:** Patient registries can give patients a voice in their own care. By sharing their experiences and outcomes alongside others with the same condition, they can help shape clinical practice and advocate for better care.



Providing valuable data: By collecting and analysing data from patients with a particular condition, registries can provide valuable insights into the effectiveness of different treatments and care management approaches. This data can be used to inform clinical practice guidelines and improve patient outcomes.

Supporting research: Patient registries can be used to identify potential study participants and track patient outcomes over time. Researchers can also apply to use registry data as a source of data for clinical research studies.

Promoting collaboration: Patient registries can facilitate collaboration between rare disease communities, healthcare providers, researchers, and patient advocacy groups. By sharing data and insights, stakeholders can work together to improve patient care.

Protecting your data: The use of any registry data is governed by our Steering Committee. This is made up of expert doctors, scientists, and patient representatives (including MDSG). We are completely independent – we don't get any data or funding from the NHS or the government, and no-one can access your data other than the registry team.

### How do I know if I'm already registered?

If you are already signed up to the UK Myotonic Dystrophy Patient Registry, you should receive email reminders at least once per year from [myotonicdystrophyregistry@jwmdrc.org](mailto:myotonicdystrophyregistry@jwmdrc.org) and other correspondence such as surveys and the registry newsletter. The registry is supported by DM specialist doctors and patient organisations such as MDSG, but we do not get any identifiable patient information from them - you will not have been registered automatically, even if you have joined other DM mailing lists or groups.

If you aren't sure whether you have registered yet and would like the Registry Manager to check, please complete the short form here: <https://bit.ly/UKDMREGINFO>. Alternatively, you can get in touch using any of the contact information below. The Registry Manager will be able to help you through the registration process if you need any support.

### Contact the Registry Manager:

If you have any questions about the registry, or would like to speak to the curator, please give Helen a call on 0191 241 8640 (please leave a message if no answer) or send an email to [myotonicdystrophyregistry@ncl.ac.uk](mailto:myotonicdystrophyregistry@ncl.ac.uk). To

sign up online now, please visit [www.dm-registry.org.uk](http://www.dm-registry.org.uk). A registration User Guide is also available from the website homepage with step-by-step instructions on how to register.

*The JWMDRC Team (Helen, centre) supporting International Myotonic Dystrophy Awareness Day on September 15th*



## 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

### **Glasgow**

Michael Kneafsey  
01360 311440

### **Kent**

Amanda Scott  
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**

Claire McAlonan  
07887 986576

### **Somerset**

Lucy Howard  
07748 636122

### **Sussex**

Rita Clarke  
(contact the MDSG office)

### **West Yorkshire**

Pauline Ferrari  
01977 799565  
Jack Lawrence  
01977 790886

