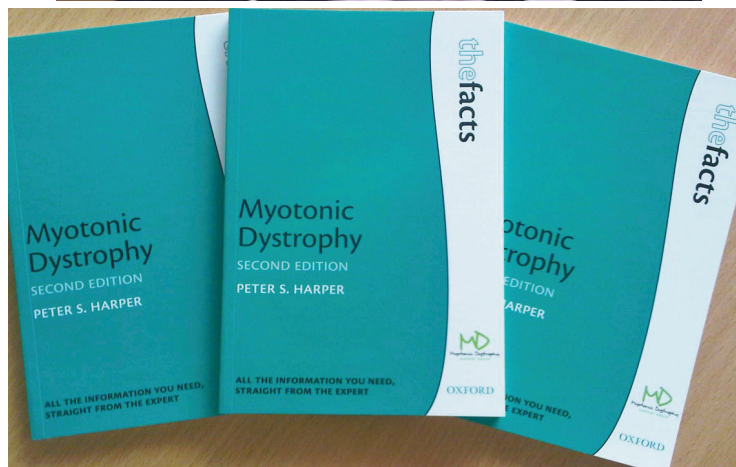


# NEWSLETTER

**PROFESSOR SIR PETER HARPER  
1939 — 2021**



Professor Sir Peter Harper gave families the benefit of his care and compassion in every page of his book, 'myotonic dystrophy, The Facts'. This is his legacy to all families who are affected by Myotonic Dystrophy.

**February  
2021**

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## National Co-ordinator

Margaret Bowler

## Directors

M Bowler  
E Cumming  
P Ferrari  
E Ormandy  
M Walker

## Advisors

Prof D Brook  
(Patron)  
Dr I Bowler  
Prof D Monckton  
Dr M Phillips  
Dr M Rogers  
Dr C Turner

Office Staff  
Julie and Mike

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## Hello to all members of MDSG

*Sadly, we have to inform you of the death of Professor Sir Peter Harper. Throughout his whole life, he did so much for families affected by myotonic dystrophy. We remember his family in our thoughts and prayers.*

It is difficult to plan for the coming months. Maybe a conference could be arranged for later in 2021, as we talked about last year. We were also considering the possibility of two meetings, one in the south and one in the north.

Dr Benedikt Schoser, a consultant from Germany was going to come and speak to us about DM2. If we are able to hold a conference later this year, hopefully he will still be able to come and run a workshop on DM2. Another important topic we can still plan for is PGD (pregnancy).

Our researchers have still been working, their Professors wouldn't let the ongoing research stop.

A sincere thank you to Ruth Harrison for covering the MDSG facebook page on the website for the last two years. This role is now being overseen by Claire McAlonan. As I write this, many people (36 to date) who I delivered as a midwife have come on the normal facebook page and left comments on the book 'Scribbings of a Community Midwife' that I have written.

Earlier this month as I walked down stairs, just getting up at 8am, my thoughts went to the number of times I was getting up at 5am to go to the railway station to catch a train. The reason to meet MDSG members in another part of the country for a local get-together. Yes, you have guessed, it wasn't last year as MDSG have not been having area meetings. Let us look forward to the return of meeting together. I have had more hours in bed, but you cannot call it beauty sleep! Keep safe and warm. Hugs sent free of charge. **Margaret Bowler**

## Letter from The Editor

Hello Everyone,

It is not easy to send out a Newsletter that tells of the passing of someone who has been such a constant source of encouragement, inspiration and hope to the entire Myotonic Dystrophy community.

*Professor Sir Peter Harper gave families the benefit of his care and compassion in every page of his book, 'myotonic dystrophy, The Facts'. This is his legacy to all families who are affected by Myotonic Dystrophy.*

When asked what changes the MDSG should consider when looking to the future of the charity, his response was immediate and very simple. "Keep on doing what you are doing."

We send our love and sympathy to his family and friends in their loss.

In December we learned of the passing of a former Trustee of MDSG, Bryan Smith, who in the early days, shared the role of Treasurer with his wife, Rosemary. Bryan worked for many months writing the MDSG Constitution together with another former Trustee, Colin Mason, who also died last year. This governing document formed the legal basis for all future developments of MDSG.

In our sadness at the loss of these friends, we must resolve to continue to build and maintain a Support Group worthy of the name. We all need to have a sense of 'belonging' and to make connections, especially as we all face a different future and many uncertainties in the coming months.

Do keep in touch. Warmest wishes to you all, Elycia. **Elycia Ormandy**

## Memories of Professor Sir Peter Harper by Margaret Bowler



Gill Browning, one of the original Committee members of MDSG when it was first formed met Dr Peter Harper before MDSG was thought of, in 1973. Gill's family was diagnosed with Myotonic Dystrophy when they had their boy Jonathan. Dr Harper travelled from Cardiff to Northampton to talk with the family.

Dr Harper returned to visit and took blood samples.



Dr Harper wrote 15 books covering all aspects of myotonic dystrophy



The Bowler family attended the Genetic Clinic at the University of Wales, Cardiff on the advice of Nottingham Genetic Department. I was told if you want your family to see the best geneticist in the world, go to see Dr Harper in Cardiff, so we did. Diagnosis confirmed that my husband and son Peter, had myotonic dystrophy in 1985.

Dr Harper came to Nottingham and was met at the station by Ian Bowler. He attended a meeting of medical professionals at the Post Graduate centre of Nottingham City Hospital. He then joined in with a meeting of families who had myotonic dystrophy at the West Bridgford Day Centre, Nottingham. The talk was taped by Peter Bowler who sat behind a curtain and turned the tape when it ended one side! The lecture notes, (that's what they were called) were typed by a Muscular Dystrophy secretary and they travelled to many parts of the world.

In 1992, when the faulty gene was isolated, the notes had to be discontinued as genetics changed. On 6th February 1992, Dr Harper telephoned me and asked if I would find two people who had myotonic dystrophy and were willing to be interviewed on TV by the BBC. Mr Ware of Cardiff and Susan Kingham of Enfield were willing and Peter Harper was thrilled. From 1973 to 1992 Peter researched myotonic dystrophy and worked with other researchers in Cardiff.



Dr Peter Harper became the Patron of Myotonic Dystrophy Support Group, a post he held for 10 years.

After writing his 3rd medical book called Myotonic Dystrophy, he asked if a book for families would be a good idea. It was written in a language that lay-people could understand.

He spent the time on Bardsey Island, North Wales, writing it. He told me there was no electricity or gas or even phone connections on the island. Just peace. A second book was written several years later and every member of MDSG was given one.



Professor Sir Peter Harper, we are so grateful for all you have done for families with Myotonic Dystrophy.

**Margaret Bowler**

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**Sir Peter Stanley Harper CBE; FLS; FRCP** was a British physician and academic who was University Research Professor in Human Genetics at Cardiff University. His work has focussed on researching neurogenetics and has resulted in discoveries concerning Muscular Dystrophies and Huntington's Disease. There is a whole archive of his work at Cardiff University.

### **Personal Memories of Peter Harper by Gill Browning**

I first met Peter Harper in 1973. This came about as his brother (who was the paediatrician at our local hospital) looked after our baby son Jonathan who had Congenital Myotonic Dystrophy. He came to our home in Northampton quite a journey from Cardiff where our extended family were gathered, he was just starting out in his career in research into Myotonic Dystrophy. He talked to us and then took some blood samples and I remember him asking if we had any ice to keep the samples cold.

The years went by and one of Peter Harpers colleagues visited this time taking blood and saliva samples. Over the years more blood samples were taken by my GP and sent off to Cardiff. My children were growing up and I wrote to Cardiff to see how the research was progressing. Not only did Peter Harper reply he invited me and my daughter to Cardiff and my husband came too. This was the first of several visits where we were always put at ease.

I think it must be over 30 years ago when we heard about the Support Group Margaret was forming. Terry and I went to Nottingham where we were given a warm welcome. My husband Terry and I were keen to be involved and were both on the committee for several years and I was also a contact person to Northamptonshire area for many years. Peter Harper was then a Professor and he became our Patron for many years.

In his book for Doctors and scientists our son was mentioned and pictures of his ECG and cardiac involvement were printed. Professor Harper wrote a book for patients and families in laymens terms, he did this on Bardsey Island with a background of sea seals and birds to accompany the peace and quiet.

I was sad to learn that Professor Harper had died, such a special man we will always remember you with all you did for so many.

**Gill Browning**

## Speech and Language

Peter Just, Head of External Affairs of the Royal College of Speech and Language Therapists, writes “Last chance to respond to the Covid 19 SLT survey”. If you wish to take part go to; <https://www.rcslt.org/has-coronavirus-affected-your-access-to-speech-and-language-therapy/>

## Facebook

Are you aware MDSG is on Facebook? You can ask questions on it. If they are very personal questions, our new Trustee, Claire McAlonan (who is looking after social media) will answer you privately.

I often check facebook on my phone and try to answer by encouraging people. It is amazing how people all over the world are asking or sharing their experiences of living with myotonic dystrophy.

If you find yourself thinking that I could comment on that subject, try to be encouraging.

Remember there are researchers all over the world, all working to find a treatment for people with myotonic dystrophy.

Researchers from all over the world meet every two years at IDMC. However because of the world pandemic, the Conference has been deferred until 2022. Thank you to all researchers.

## Insurance

In response to a question posed to the Association of British Insurers regarding Life Insurance, this was their reply.

“I would highlight that underwriting philosophies can change over time, and the decisions of insurers twenty years ago would be very different to what is done today. Therefore, we would hope that this should not discourage individuals from applying for insurance. Insurers will assess each application on an individual basis, with a review of

medical history. While it may be that there are some applications which are declined or have some restrictions in policy term length, with the majority of providers there is no blanket decline for all Myotonic Dystrophy types. In fact, there may be some applications which insurers can accept at normal rates depending on the age of the applicant, the type of Myotonic Dystrophy and their symptoms or complications. These factors will all inform an insurer’s assessment of risk.

However, it is important to note that insurance markets are competitive, and insurers have different risk appetites, so may decide to offer terms where another does not. Whether, and at what price, to offer cover is a commercial decision for each individual insurer. We would encourage people to compare policies from different providers and speak to a specialist financial adviser who may provide additional support.

On the question around mortgages, many mortgage providers will offer a loan without life cover. We would again encourage people to explore and compare different providers when looking for a mortgage.

**Association of British Insurers, London**

## Christmas in the Car Park



**Margaret in the centre having a Christmas get-together with Professor David Brook on the left and three members of his Nottingham Research Team, socially distancing in the local University car park.**

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### The Jab!

Hello, my name is Emily Lockwood, I am 34 years old and have Type 1 Myotonic Dystrophy. I work in a care home and I was offered the Covid 19 vaccine. I have only had the first jab and I am due to have the second one soon.

On the 30th December 2020 I had my first jab. I can honestly say it was not painful; it was like having a flu jab. After the jab my arm was painful for a few days. In the hours after, I felt like I had flu; I was really sluggish, unable to eat and very tired. I went to bed early and woke up feeling ok apart from my arm hurting. After a few days my arm felt fine; it is now mid-January, I have had no other side effects and feel fine.

I hope this helps anyone who feels apprehensive about having the Covid 19 jab. I am hoping that it will soon give me some sort of normality back in my life.

**Emily Lockwood**

### Vaccination

*Do I come in the vulnerable people with underlying medical conditions?  
The following information was given by Dr Chris Turner*

As usual one size does not fit all for DM1. Some DM1 will fit into category 4, most in category 6, but some may not be in any category as they are so mildly affected. I would advise that if people with DM1 are symptomatic in any way from their DM1 they should be in category 6. Remember many will qualify based on age alone independently of DM1.

#### Category 4

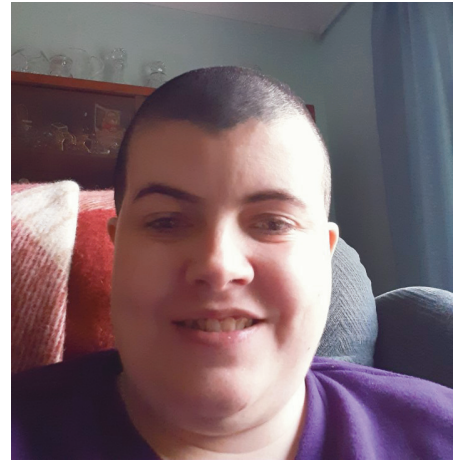
All those 70 years of age and over and clinically extremely vulnerable individuals.

#### Category 6

All individuals aged 16 years to 64 years with underlying health conditions which put them at higher risk of serious disease and mortality.

Should you have the vaccine? **YES**  
Whether it is the Pfizer vaccine or the Oxford Astra Zeneca or one of the new ones about to be available, they are all safe within the guidelines. Happy Jabbing!

### Haircut Anyone!!



*Picture of Ailsa Milne 10 minutes after having her head shaved*

I decided to shave my hair in March 2020 then Covid and lockdown hit!! So after many delays, my friend Janet shaved my head on 5 December. (top tip if you want to shave your head do it in the summer). My head was extremely cold so mum got to work and knitted me some hats. Two months on my hair is growing very fast. I will need another haircut soon!! I have raised almost £1000 so far for Myotonic Dystrophy Support Group. **Ailsa Milne**

### Leaving a message

*A little reminder please.  
If you ring the office or the Helpline,  
please speak slowly and repeat  
your telephone number twice with a  
pause between each number. This  
will help us to ring you back more  
promptly. Thank you.*

## Annual General Meeting and Conference

As we are still unable to meet even in small groups, we cannot say yet whether there will be an Annual Conference this year 2021.

It is looking unlikely but we will keep you all informed.

## DM2

We have a new leaflet, kindly written by Professor Benedikt Schoser, Professor of Neurology at Ludwig-Maximilians University, Munich, Germany.

Although there is not, to our knowledge, a high prevalence of people with DM2 in the United Kingdom, nevertheless we do have members with this different type of myotonic dystrophy. In Germany there are more people with DM2. Professor Schoser is an expert in the field of DM2 sometimes called Promm.

Contact the office if you would like a copy of this new leaflet.

**Please tell us if you have had a diagnosis of DM2, we can then build up a register and be able to plan for better awareness and understanding.**

## Just Giving

At the beginning of the year, we were made aware of a problem with people making donations via the fundraising site, 'Just Giving'.

Just Giving, contacted us last May and we responded to their request in June. They wanted us to re-register and required the names and addresses of two Trustees along with the respective photos. This we did, but they complained it was not on the correct form despite the fact they had sent the

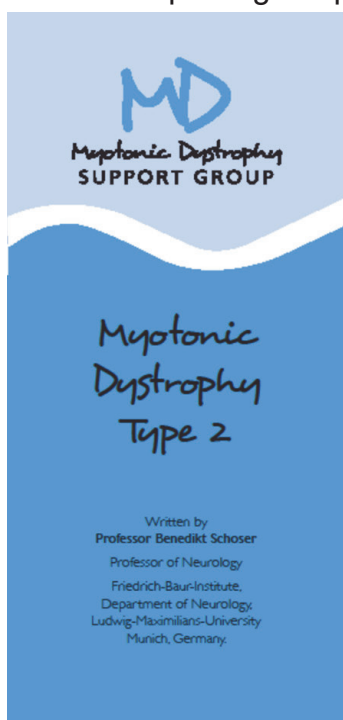
form. Owing to the pandemic, Just Giving put things on hold. We did contact them again in November, only to be told, it had not been sent from the correct email address. We discovered at a later date, that they had been using the mdsg@tesco and the webmaster@myotonicdystrophy email addresses, both of which we dispensed with about five years ago. We convinced them we were using the correct email address, but of course had to change the password. We have to pay Just Giving £18 per month for the privilege of people being able to

use the site to make donations to MDSG. We were still not off the hook as they needed confirmation of our bank details, so yet another form. How can they take a direct debit each month if they did not already have our bank details? Good question. Alas, no answer!

We can confirm that everything has now been sorted and must apologise to all members and donors who have had their

monies returned without an explanation. People felt let down and upset when some donations were in memory of a loved one.

If any member wishes to give through a fundraising site, we would encourage you to use Virgin Money Giving. They do not charge a monthly fee, they do not take a fee for working out Gift Aid and there administration charge is less. Of course, paying direct into the bank through online banking means no admin fees are deducted. We can still claim Gift Aid unless you email us to say otherwise. Apologies and thank you for all your donations.





## 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. Is your area represented?

**Aberdeen**  
Jenny Watt  
01224 580559

**Cardiff**  
Margaret Ware  
02920 869277

**Croydon**  
Lesley Smith

**Cumbria**  
Neil Braiden  
01228 512385

**Devon**  
Josephine Holmes  
(contact office)

**Dorset and Hampshire**  
Ruth Harrison  
01425 626133

**Glasgow**  
Ann Cobburn  
01389 381246  
Michael Kneafsey  
01360 311440

**Kent**  
Kirsty Blount and Amanda Scott  
01622 764824/01622 764347

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

**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

**Sheffield**  
Rachel Reeson  
07544 353076

**Somerset**  
Lucy Howard  
07748 636122

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

**Sussex**  
Michele Wilmshurst  
01424 421013  
Rita Clarke  
(contact office)

**West Yorkshire**  
Pauline Ferrari  
01977 799565  
Jack Lawrence  
01977 790886



### **National Co-ordinator**

**Mrs MA Bowler SRN, SCM** - 19/21 Main Road, Gedling, Nottingham. NG4 3HQ  
Helpline: Freephone 0808 169 1960 - Office Telephone/Fax Number: 0115 987 5869

Email: [contact@mdsguk.org](mailto:contact@mdsguk.org) - Website: [www.myotonicdystrophysupportgroup.org](http://www.myotonicdystrophysupportgroup.org)

### **Editor**

**Mrs Elycia Ormandy** - 21 Shireoak Rd, Withington, Manchester. M20 4NY  
Telephone: 0161 445 5844

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