

September
2023

31st
Conference

Report



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Dr C Turner

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Elycia Ormandy

Office Staff:

Michael and
Linda

Hello to all members and friends of Myotonic Dystrophy Support Group

Dear Friends,

I thought the last newsletter would be my last contribution as I said, "Goodbye", to members of the Myotonic Dystrophy Support Group.

The Conference in June, the MDSG 31st Annual Conference, was one to be remembered, following the covid infection that prevented the conferences of the last three years.

I would like to say "THANK YOU" to people who gave a donation to the plaque I received, plus some money. I have not decided just how to spend that money in connection with MDSG.

At the end of the Conference, there wasn't the opportunity to say thank you, as the afternoon tea was prepared and we needed to eat it, before it was spoilt.

In my prepared notes—which I never saw on the Conference afternoon, I had dedicated the Myotonic Dystrophy Support group to my husband Keith and youngest son, Peter, both who had myotonic dystrophy. Without their diagnosis (1985) there may not have been a National Charity.

They managed their lives—sharing it with other people. Without their consent, we would not have had you!

Over the years, several thousands of people have been contacted and made contact with MDSG.

So many changes in the care for families now, who have myotonic dystrophy.

My husband, Keith could not see across the road to read a number plate when taking his driving test—the week of our wedding. He was later diagnosed with cataracts; but not connected with myotonic dystrophy.

He was in his 40's before he had the cataracts removed and then had to wait five months for his glasses!!
So different now in 2023.

Peter did not have cataracts, he didn't mind the intrusion into his life of the BBC and ITV and local radio.

Several times he was in a community programme on the TV, as other families were in those early days.

The Independent newspaper via an article in the medical journal gave us a good start. The family story printed, resulted in 50 people making contact with us. So a Support Group was founded. Thank you Keith and Peter Bowler for being the foundation stones of the National charity called "Myotonic Dystrophy Support Group" Bye (again)

Margaret

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

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Conference 2023

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Finally after three years of covid, we were able to meet face to face again and all looked forward to listening to research updates, going to the varied workshops, browsing the many stands and displays and of course, having a good old chat and socialising.

There were 130 delegates for the 31st Annual Conference, this year as in 2019, being held at the Radisson Hotel, East Midlands Airport.

Add the Speakers, helpers and Trustees and we had 158 for the sit down lunch.

In the September 2019 Newsletter, we mentioned the idea of having two Conferences, one in the North and one in the South.

We are again looking into that possibility. We hope that more of you will be able to attend as the venue may be closer. More news to follow.

It was encouraging to see many familiar faces from four years ago, and catch up on family news. Equally encouraging to see so many new faces, with some first time reports in this newsletter.

The Conference stands manned by Trustees and volunteers were extremely busy. Thanks to Janet Milne for the very colourful hand made Muffs. There are some left, which will be available at the next Conference.

Linda Perry organised a raffle and donated the three prizes. There were photos and memorabilia on display from 'yesteryear'. Many memories of those who have sadly departed that helped to make MDSG what it is today.

Payment Machine

Following on from the note in our last newsletter, we did go ahead and purchase a payment machine.

It is a 'Zettle' which is part of Paypal Group. As we are registered with paypal, all payments go through them and straight into our account. It was used by many delegates at the conference for items such as clothing, pens, conference fees, and donations.

We have bought the machine, so there are no rental or interest fees. The only fees we incur are transactions fees, which is no different to all payment methods, including via the high street banks. We do incur bank charges because of the volume of transactions, made into our account.

Gift Aid

Talking of finance, may I give a gentle reminder to you all, that we are able to claim Gift Aid on your membership fees and your donations.

This is only if you give your permission.

You must be a tax payer and pay more in tax than we are able to claim. We are able to reclaim 25% back from the tax man, namely HMRC.

Please remember to sign the membership form, when returning it.

We receive many donations from you in lieu of special events, such as Birthdays and others in memory of a loved one. When communicating with us, by letter with your cheque or email if you have done it electronically, please give us permission to claim Gift Aid, if you meet the requirements as above.

Thank you, for the generous financial support you make to MDSG whatever the reason, we are extremely grateful.

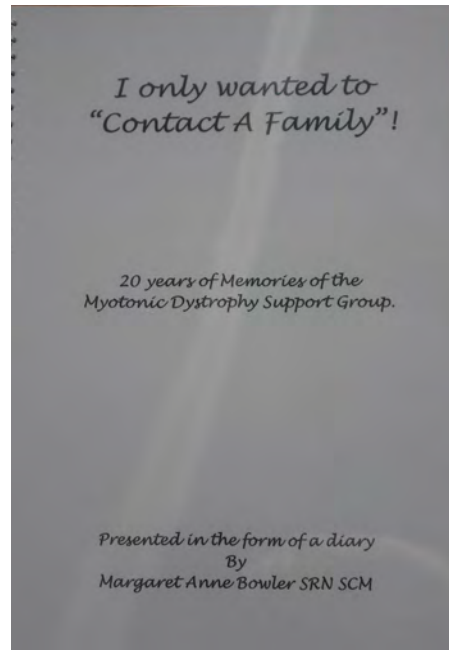
Sale items

Items on these pages were available at the Conference.

Some like the 10 year book, were produced in time to celebrate the stepping down of Margaret from a life of day to day working for MDSG.

It highlights a lot that has happened since 2010, full of colour, containing a massive 236 pages.

We have limited stock, if you wish to buy a copy.



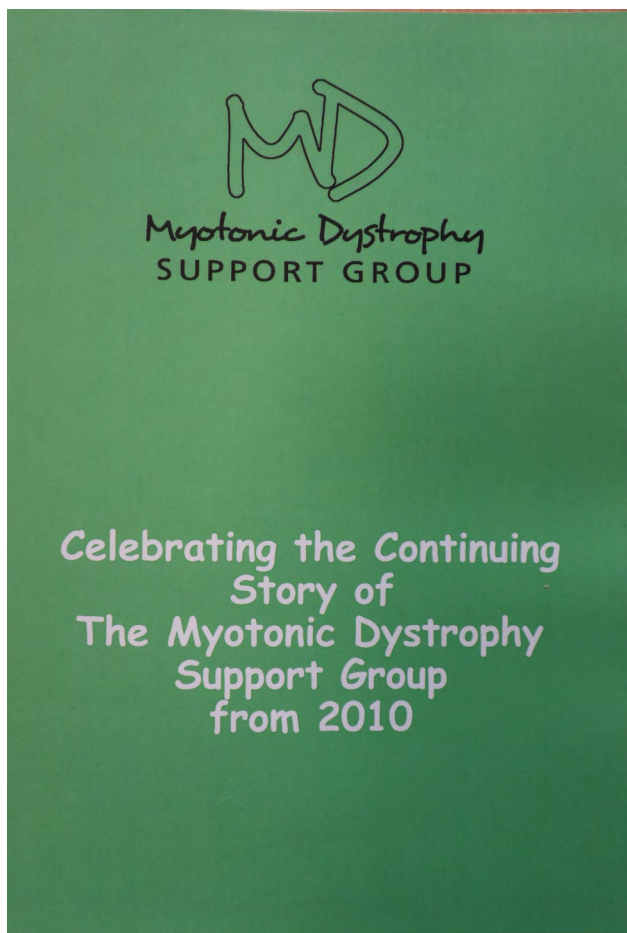
For Sale:

Top right; History of first 20 years of MDSG **£5**

Top middle; Pill Punchers **Free**

Above; water bottles **£3**

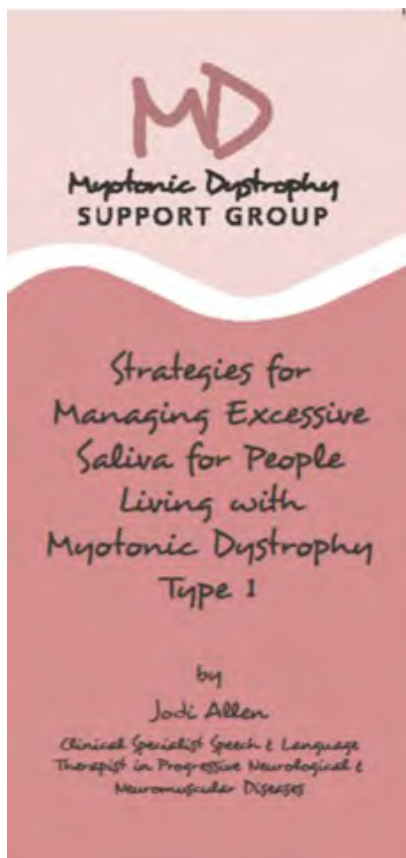
Above right; Thank you cards **£3 pack of 10**



For Sale-continued

*Left; History of MDSG from 2010, colour throughout, 236 pages
£20*

Below; Sweatshirts/T-shirts, all sizes, many colours £15



New Brochure

Thank you to Jodi Allen in following up the brochure on Swallowing with the new brochure on Managing Saliva (drooling) in Myotonic Dystrophy.

Please contact the office if you would like a copy of this new brochure or any others that we have produced.

First Timers

Attending my first Myotonic Dystrophy Conference in June was an unforgettable experience that exceeded all my expectations. As I approached the venue, I couldn't help but feel a mix of fear and trepidation, unsure of what to anticipate. However, those apprehensions quickly vanished as soon as I stepped through the door and was warmly welcomed with open arms. The sense of camaraderie and support among the attendees and organizers instantly put me at ease.

Throughout the day, we were immersed in a wealth of knowledge and had the opportunity to make invaluable connections with others facing similar challenges. It was astonishing how much we learned and how many meaningful connections we made surpassing what we had achieved in the previous year! The workshops conducted during the conference were fantastic, covering a diverse range of topics related to Myotonic Dystrophy and providing valuable insights into the condition, its management, and potential treatments.

Leaving the conference, I found myself equipped with a bag full of useful literature to delve deeper into the subject matter. The resources provided were comprehensive, empowering us with new tools to better understand the condition. The organisers had done an outstanding job curating these materials, and we couldn't have been more grateful for the abundance of information they offered.

I must also take a moment to commend the hotel staff for their exceptional service. Their attentiveness, kindness, and willingness to go above and beyond made our day even more enjoyable. The food was top-notch and it was evident that the staff cared about the conference attendees, their hospitality added a special touch to the overall experience.

In conclusion, attending the Myotonic Dystrophy Conference was a truly transformative event for me. It provided a safe and supportive space to connect with others in the community, learn from

experts in the field, and gather valuable resources to continue my journey with confidence. Our heartfelt thanks go out to everyone involved in making this conference an outstanding success.

Debra Share



My diagnosis of Myotonic Dystrophy type 2 came in 2020 during the pandemic. The conference in 2023 was the first opportunity to engage in an event like the Myotonic Dystrophy Support Group national conference.

I attended with my mother who was diagnosed last year. Going to the event I wondered how much would relate to me and if I would be viewed as the 'poor relation' due to the fact that type 2 is typically associated with milder symptoms.

From the first moments interacting with staff through to the end, my mother and I felt welcome, a part of wider community and validated by all and it was amazing to be amongst people who had similar experiences.

For my mother, the social side of the event was everything, she loves to talk and connect with people and the event was perfect for her. I appreciated that too but I also really valued the opportunity to hear and speak to clinic research teams and understand the science of what is happening to me and why.

We had an amazing time and we plan to attend every year now, perhaps trying to bring others from our wider family as more of us get tested.

Thank you to the Myotonic Dystrophy Support Group, this event was such a positive experience for my mother and I. We are so grateful for all the work you do for people like us and for the warmth we experienced.

Simon Walker



Before the Conference. Are the three Ladies praying that all goes well??





All set up and ready to go

Euan and Phil have worked so hard????



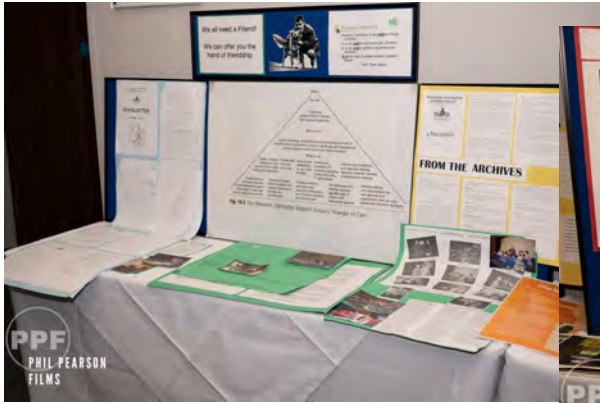
Preparing for
the Annual
General
Meeting





This year we had the evening meal before the AGM





Who am I?
Margaret receiving
her name badge

and what is going
on here, what are
the two D's, David
and Darren finding
so amusing?



Annual General Meeting

The Annual General Meeting was chaired by Professor David Brook and attended by over 80 delegates.

This conference was tinged with sadness and emotion as both Margaret Bowler, the founder of MDSG and Elycia Ormandy, the vice-chair, had decided to step down from their roles as Trustees and from the day to day running of the Myotonic Dystrophy Support Group.

Votes of thanks were led by David, with a special mention for Margaret in having the foresight and initiative to “find another family”, which then led to the formation of a Support Group, which in turn led it to become a charity and then a Company and 34 years later, going from strength to strength. For your information, MDSG was the first Support Group, in the World!

The good news was that there were seven nominations for Trustees, some of these were re-elections and some were new faces.

All seven were elected:
Michael Walker;
Euan Cumming;
Peter Ferrari;
Claire McAlonan;
Rose Walton;
Dr Ami Ketley; and
Linda Perry.



Michael was elected as Chair of Trustees, Claire as Vice-Chair and Peter as Treasurer.

The financial report was presented and agreed as was the appointment of the Auditors, CA Plus.

If any member wishes to have a copy of the accounts, please contact Michael at the office. Please remember that the office is only open three mornings a week, from 9am until 2pm, Tuesday/Wednesday/Thursday, although you can leave a message on 0115 987 5869 or send an email to contact@mdsguk.org.



Following the Annual General Meeting, Professor Darren Monckton gave a short talk on the Myotonic Dystrophy Registry. One question that was posed, did members need to be on both the MDSG database and the Registry database? In short the answer is **Yes**. The MDSG database, is so that we can keep in touch with you regarding, events, local get togethers, conferences, newsletters and membership. The Registry which contains details you have given as to how myotonic dystrophy affects you, is the database, which will be used by researchers and drug companies for trials of a possible treatment, be it Genetic or day to day management. The good news is that trials are getting ever closer.



Conference Day, Saturday



This being the first face to face Conference for four years, it was opened by Margaret in front of 150 delegates. This represented a mixture of familiar faces and newcomers to the MDSG.

Margaret welcomed everyone and introduced the Chair for the Morning, Professor Darren Monckton.

The day began with the local MP for Gedling, Nottingham, (the Borough where the office is situated), Mr Tom Randall, welcoming delegates to the MDSG Conference. He was born and grew up in Arnold, Nottingham. As a teenager he was diagnosed with Ankylosing spondylitis. He later led a workshop on Disability Issues.





Professor David Brook, going away from his usual research talk, with the “fried egg”, gave the Inaugural Peter Harper Memorial Lecture. It was a moving talk about the life of a pioneer paving the way into this little known condition, that enabled researchers and neurologists around the world to research and diagnose myotonic dystrophy. His work highlighted the fact that more people had symptoms relating to DM than had been realised. He closed with thanks to the late Professor Sir Peter Harper for a lifetime of contribution to science and especially to the work of myotonic dystrophy.



Darren, introduced our Guest Speaker from the United States of America, Professor Charles Thornton. The title of his talk was, "Imagining the future of myotonic dystrophy".

Charles outlined the important work being done by his laboratory team, but also how research is developing across the world. He mentioned that many drug pharmaceutical companies in the USA are becoming actively involved and that trials in various areas were happening. Some of the trials were in the genetic field and others were in management of the condition. Still some way to go, the message of imagining the future of myotonic dystrophy, was that a treatment was getting closer, **it was a message of HOPE.**



The main talks were interspersed with a wide choice of workshops from the MDSG's loyal band of expert researchers and healthcare professionals.

These included;

Anaesthetics, Resuscitation, Daily Care, Fertility, Chest Infections, Swallowing, Myotonic Dystrophy Type 2 (DM2), Research and Questions and Answers.

With the usual excellent coffee breaks and meals, which the hotel catering staff must be thanked for the presentation and efficiency, the Conference, came all together at the end for the closing talk by Dr Chris Turner, speaking on, "Modern Treatments for myotonic dystrophy".

This talk highlighted the fact that there is help for the day to day management and that many of the symptoms can be helped.

The day closed with Afternoon Tea, but not before many gifts were bestowed upon both Margaret and Elycia, including a plaque for each, thanking them for the inspiration, the encouragement, the dedication and the hard work to bring MDSG to its National and International recognition.



Did you ever think the song, "Ten green bottles" could happen at a conference, well it did!!

Margaret in her usual 'expertise' proceeded to sing the song encouraging all delegates to join in as she gave clear bottles with name of the speaker engraved on the glass which also lit up. So ended the 31st Conference. THANK YOU



The Celebratory Conference Cake and below Tomas, who arrived straight from the Airport having travelled from Hungary, having only found out about the Conference TWO days beforehand.



The following pages are a selection of all things happening at this years conference. Delegates chatting and socialising, getting to know one another.









Tanya Stevenson CEO from the Myotonic Dystrophy Foundation USA came to the Conference from her home in California and gave International Thanks to Margaret. Thanking her for the achievement worldwide to the support for all families with myotonic dystrophy.



TEN
GREEN
BOTTLES





Where it all began,
Keith, Peter and
Margaret



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
0115 987 5869

Somerset

Lucy Howard
07748 636122

Sussex

Rita Clarke
(contact the MDSG office)

West Yorkshire

Pauline Ferrari
01977 799565
Jack Lawrence
01977 790886

