

Inside Number 10

May
2023



Tom Randall, MP for Gedling, nominated Margaret for recognition as a Community Champion.

The photo shows Tom, Margaret and Prime Minister Rishi Sunak, inside Number 10 Downing Street.

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National Co-ordinator

Margaret Bowler

Directors

M Bowler
E Cumming
P Ferrari
C McAlonan
E Ormandy
L Perry (co-opted)
M Walker

Advisors

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

Office Staff
Margaret, Wendy
and Mike

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Hello to all members and friends of Myotonic Dystrophy Support Group

For over 30 years I have sent greetings in this newsletter to all our readers. This letter will be my last to you as I retire from being the National Coordinator of the Myotonic Dystrophy Support Group. What a fantastic journey it has been. Lots of happy and sad memories since I started the Support Group in 1989.

During this time many people have given their time to being Trustees of the Charity, contact family organisers, fund raisers, and other volunteers who have helped keep the charity going. The charity must carry on going on!! It is for all the helpers to do what you do best, and that is doing what members have been doing for over 30 years.

The annual conference on the 17th June, will be a sad farewell, but I will have wonderful memories of all the people I have met, and spoken to on the phone, or received greetings from cards and letters during these years.

To everyone reading these words, my message is to spread the awareness of myotonic dystrophy, so that in the future, you will not hear the statement, "I have never heard of that condition".

Bye

Margaret

Letter from The Editor

Hello Everyone,

We have much pleasure in sending out this newsletter complete with conference details and pages to encourage us all as activities "take off".

Spring is springing!

I am reminded of the words "to everything there is a season, and a time for every purpose under heaven."

These words old and so refreshingly new, reflect our human endeavours. They start with small beginnings, are nurtured and encouraged until the time comes for others to take the mantle.

Margaret and I have worked together for MDSG for more than 30 years and it will be hard to think of a time when we will not be planning, tackling challenges and looking forward. "Do you remember when?" will be a much used phrase in our future conversations. We have to come to terms with becoming members of MDSG, without having the responsibilities of National Coordinator and Vice-Chair.

I am keen to recognise that 17th June 2023 will be a day of Celebration for Margaret.

Margaret is the face, the voice and the beating heart of MDSG. As the founder, MDSG will always be her 'baby'. Appropriate I think for a retired midwife.

What an achievement it is for Margaret to have founded the Support Group and guided it through infancy to maturity. Like all good parents, it is now time to let go and allow the group to move into a new era. With your help as members, it will continue to grow, develop and embrace a new future.

My love and heartfelt thanks to Margaret, and all MDSG members and friends,
Wishing you all every blessing

Elycia Ormandy

Annual General Meeting

As we have not had face to face meetings for four years, with the compliance of the Charity Commission during the pandemic, most Trustees continued in their role. The exception was Ruth Harrison who resigned, with our thanks for handling Facebook. There were two additions; Claire McAlonan, who was co-opted in 2020 and became a full Trustee in January 2021. She is now handling Facebook and Linda Perry, who has been the Minutes Secretary for the past 15 years at our Board meetings and the Annual General Meetings who was co-opted in 2022.

This year, as we return to face to face, all Trustees will require you, the members, to approve their nomination. In accordance with our M & A's (Constitution) and Charity Law, each nominee requires over 50% of those eligible to vote, for them to become a Trustee. In order to vote, you must be over 18 and a paid up member.

We will return to the three year term of rotation. Each Trustee will serve for a maximum of three years. To avoid all Trustees coming up for re-election at the same time, at our AGM some Trustees will be re-elected for one, two and three years.

The AGM is also **your** opportunity to ask the Trustees about any aspect of the workings and running of MDSG.

The profiles of those standing are on the following pages. Although our M & A's states we must have a minimum number of five for a quorum, it does not specify a maximum number. Therefore all those who have put their name forward, can be elected, with the proviso that they receive more than 50% of those present and eligible to vote.

Profiles

Hello, my name is Michael Walker. I have been a Trustee since 2010.

Prior to that, I started helping out in the office working with Margaret since 2007.



I became involved when my wife, Sharon and one of my twin boys, Nathan were diagnosed 30 years ago.

Being involved in the printing business, I print all the publications for MDSG, which has grown to 18 different brochures.

In recent years, I have been the Treasurer and doing the bookkeeping. I am involved in organising local contact get togethers, something which we are hoping to expand. Attending conferences with exhibition stands in the United Kingdom and in the Republic of Ireland, spreading awareness amongst the health professionals. I have been involved with the organisation of the Annual Conferences and attended many functions representing MDSG.

Not forgetting the most important aspect of MDSG, that is the support, to members and the families affected by myotonic dystrophy, the charity is also a business and I believe my business acumen and logistics skills along with financial awareness will help the charity in the future.

Peter Ferrari



My stepdaughter and her father (John) were both diagnosed with Myotonic Dystrophy during their adult lives. Since 2012, my wife Pauline and I have been providing detailed and practical support to them both. Sadly John passed away in the earliest days of the

Covid pandemic.

Prior to my becoming a Director, our wider family was very grateful for the wide-ranging support received from MDSG, and we set up the local group in Wakefield.

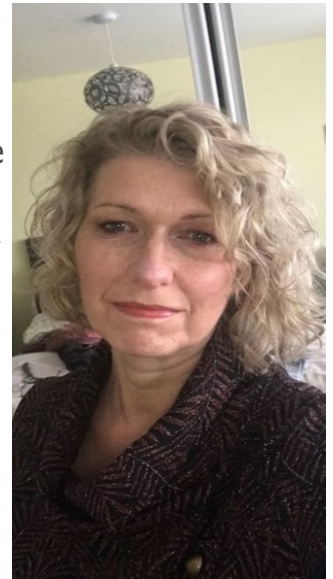
After 40 years with NatWest Bank/RBS, I retired in 2015. For most of my career I focused on managing client relationships, and I believe that many of the skills acquired over that period are of value to MDSG today. These include the ability to listen, to analyse complex issues and financial accounts, and to solve problems.

In the past I have held other voluntary roles; I was a Director of Counsel and Care for the Elderly for 10 years, and held the post of Honorary Auditor for a financial industry discussion forum for over 12 years.

My charitable interests are now focused on MDSG along with a trustee role for my local Civic Society in Pontefract. I believe that my background as an 'old fashioned bank manager' offers a different perspective, and allows me to contribute in some key areas such as;

- Raising awareness of Myotonic Dystrophy
- Advising on key aspects of the strategic direction for the Support Group
- Supporting my fellow trustees to plan for the future, following the retirement of Margaret and Elycia in 2023
- Bringing commercial/banking skills to assist with the day to day running of MDSG and the annual conference.

Mrs Claire McAlonan



My name is Claire McAlonan and I have been a Trustee of the Myotonic Dystrophy Support Group since January 2021, having been co-opted for a few months beforehand. I have Myotonic Dystrophy as do four other members of my close family.

I am now retired but prior to this I was an administrator in a multi academy trust and I have been able to use these administrative skills to help out in the office when needed. I also look after the Facebook pages for the group and have recently [with help from Ami Ketley] started up a new forum page where people can ask questions and share their stories of living with Myotonic Dystrophy.

I would like to continue to work alongside the other Trustees and support the group as we move forward into the future.

Dr Ami Ketley



Hello MDSG members, I am Ami and I would like to put myself forward as a trustee for the support group. You may have met me before at the MDSG conferences or fish and chip lunches, where I have given talks or updates on my work.

I am a research scientist and started my career working with Professor David Brook in 2006 at the University of Nottingham. During this time I have been doing research to try and understand more about myotonic dystrophy with the hope to develop a treatment.

I have 2 children, Harry (7) and Maisy (4) and I took a break from the lab to look after them over the last few years. Now that Maisy has started school I have recently returned to research and have won funding support to start a project looking at the heart symptoms in myotonic dystrophy and the genes that may be involved. I feel very lucky to be able to return to research and be working on a project that I feel so passionate about.

The MDSG has always been supportive of me and my research and so I would love to return that support by becoming a trustee and contributing to the continued success of the group.

Mrs Linda Perry



For almost fifteen years I have attended the Trustees Meetings and Annual Conferences of the Myotonic Dystrophy Support Group as minutes secretary, where hopefully, I have recorded accurately the events of those meetings.

During that time I have been privileged to learn a great deal about the condition and consequently how important it is to support the research and create awareness. I hope to be able to build on this interest in the future.

My background is as a medical secretary, a role I have pursued for many years and one from which I retired some ten years ago. My intention is to work alongside my Trustee colleagues to further the work of the Group and to assist with office duties where possible.

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Rose Walton



I have followed MDSG and admired the work with families affected by myotonic dystrophy for many years. I am motivated to be a Trustee as the challenges and effects of DM are close to my heart after my father and extended family were diagnosed with the condition. In 2014, I was diagnosed with DM1. I am learning, understanding and coming to terms with the challenges both mentally and physically, on a day to day basis.

I realised how much more awareness was needed and I am eager to put my time towards helping those where I can. I would therefore like to use my skills towards MDSG and help to steer it to greater success.

I served as secretary and head of business for a charity, namely Blackburn Youth Zone. I was responsible for the membership base, developing the income through fundraising and managing the governance department and dealing with Charity Commission.

I believe I am well suited to being a Trustee, as not only am I and members of my family affected by myotonic dystrophy, but I have significant experience of a charitable organisation.

Euan Cumming



I have been a Trustee for MDSG since June 2017.

I have three children, four granddaughters and one grandson. Twelve years ago, following genetic tests it was revealed that I carry the myotonic dystrophy gene repetition. Subsequently, other members of my family were tested and some were found to have it, including grand children.

Following my diagnosis, I wanted to do what I could to help others that are more severely affected than I am. Having family members who are affected, gives me a personal insight into the support that is required.

Although I am now retired, I believe that my professional qualifications and experiences, along with having the condition, will enable me to provide proper effective business skills and support for MDSG.

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Conference stands

Leaflets

Leaflets produced by MDSG. These are free and can be useful to show or give to any health professionals that you visit.

MDSG Goods

These range from pens, wristbands, car stickers, pill punchers to a brand new range of sweatshirts, poloshirts, with a new selection of colours and all sizes.

Bring and Buy

The ever popular Bring and Buy, but please, no food produce, no cakes or preserves.

If your item has not been sold, please take it back home at the end of the day.

SPECIAL CONFERENCE OFFER

All those attending the Conference will be given a book, covering the History of the Myotonic Dystrophy Support Group. This will consist of approximately 200 pages (100 leaves), size A4. This covers the period from 2010 to 2023.

There will be copies of the previous years for those who may be newer members and have not previously had a copy.

If you are unable to be at the Conference, both books will be for sale at a modest price to cover Postage and Packing.

31st Annual Conference June 16/17 2023

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

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

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

Proxy votes are permissible for Election of Directors/Trustees only. Please contact the office for a form, which **MUST** be returned 72 hours before the Annual General Meeting.

Please return all the forms back by the **6th JUNE**.

Payment Machine

We are currently exploring the purchase of a payment machine, so you may pay for items using your contactless card. Of course, we will still be accepting cash.

Provisional Conference Programme

(these details are correct at time of going to press, but may be subject to change)

Friday 16 June Evening

6.00pm Evening Meal

followed by
approx. 7.30pm Annual General Meeting chaired by
Professor David Brook—MDSG Patron
(Registration will be open for those attending the AGM)

Saturday 17 June Morning

8.30am...Registration and refreshments on arrival

9.30am...Welcome by Margaret Bowler, Founder and Chair of the Board of Trustees
Chair for the Morning...Professor Darren Monckton

9.40am...Welcome to Nottingham, Mr Tom Randall, MP for Gedling, Nottingham

9.50am...The Peter Harper Memorial Lecture: Professor David Brook

10.20am...Research: Professor Charles Thornton (USA)

10.50am...Refreshments (during which the auditorium will be partitioned for workshops)

11.20am...Workshops Session One

12.00noon...Workshops Session Two

12.45 for 1.00pm...Lunch

Saturday 17 June Afternoon

2.15pm...Workshops Session Three

3.00 to 3.10pm...Short Break (during which the partitions in auditorium will be removed)

Chair for the Afternoon...Professor David Brook-Patron

3.15pm...Modern Treatments for Myotonic Dystrophy...Dr Chris Turner

3.45pm...Thank you...Elycia Ormandy

Afternoon Tea

5.30pm...Finish

Workshops: There will be three workshop sessions, two before lunch and one after.

The following workshops are being planned;

DM2-to be confirmed

PGD-Mr **Abraham Francis** (Care Fertility, Nottingham)

Daily Care-Alana **Mossop** (St Georges Hospital, Tooting, London)

Disability Benefits-Mr **Tom Randall MP** (Morning only)

Anaesthetics-Dr **Ian Bowler**

To be confirmed-Dr **Chris Turner**

Swallowing-Jodi **Allen**

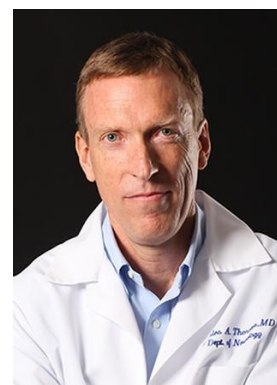
Research-Professor **Charles Thornton**, Professor **David Brook**
and Professor **Darren Monckton**

Questions and Answers-Dr **Mark Hamilton**, Dr **Richard Petty**

Resuscitation-Nick **Bowler**

Speakers:

Prof. Charles Thornton, USA is a Professor at Department of Neurology and Neuroscience, University of Rochester Medical Centre, Rochester, New York. He specialises in the diagnosis and treatment of Neurogenetic disorders, including myotonic dystrophy, therapeutics and antisense approaches.



Dr Ian Bowler; Anaesthetist, Cardiff and Vale Hospital

Dr Chris Turner; Neurologist, National Hospital, London

Prof Darren Monckton; Professor Human Genetics, Glasgow University

Prof David Brook; Professor Human Genetics, Nottingham University

Jodi Allen; Speech and Language Specialist, National Hospital, London

Alana Mossop; Neuromuscular Care Advisor, St George's Hospital, London

Abraham Francis; Obstetrician and Gynaecologist, Care Fertility, Nottingham

Tom Randall; Member of Parliament for Gedling, Nottingham

Dr Mark Hamilton; Neurologist, Scotland

Dr Richard Petty; Retired Neurologist, Scotland

Nick Bowler; Senior Paramedic

Friday evening 16 June at 6pm

Evening meal followed by the Annual General Meeting.

Saturday 17 June approximately 4pm

Margaret Bowler would like to invite delegates, family and friends for Afternoon Tea to conclude the Conference. PLEASE BOOK.

A Conference booking form is enclosed with this newsletter. Please fill in the form and return to the office. Remember to make a note of the date in your diary.

Accommodation: If you are staying overnight at the Radisson on the Friday Evening, MDSG will pay for 50% of the room costs. You will need to pay the Hotel in full and let Michael Walker have the receipt or send into the office by 31 July 2023 and you will be reimbursed.

Parking: All hotel car parking is free;
PROVIDED YOU REGISTER YOUR CAR AT RECEPTION

Dietary: Please remember to state any dietary requirements on the Booking Form.

Stalls: There will be a variety of stalls, including Bring and Buy.
PLEASE NOTE; **NO FOOD ITEMS**

Forms

You will notice you have **two menu forms**, one for Friday evening and one for Saturday.

On Saturday we are closing the Conference with Afternoon Tea. We would like you all to stay.

If you can stay, please let us know on the form by ticking the box.

Please make your choices from the menu and return the forms by Tuesday 6 June 2023.

There is also a **workshop form**, please let us know which workshops you would like to attend and return by Tuesday 6 June 2023.

Thank you. We look forward to seeing you soon.

Glasgow Get-together

We had a very positive meeting last Saturday and enjoyed re-connecting. We had about 15 people at the meeting. Dr Sarah Cummings, a researcher working in Professor Darren Monckton's lab, Glasgow University, gave an interesting talk and held a Q and A afterwards. Dr Richard Petty, Retired Neurologist also came along so it was really good to see him.



Kent

It is with great sadness, we show this picture of the Kent get together held in March, as since that day, we have to report the death of Kirsty Blount, (permission given by husband Neal) the contact person for Kent area. Kirsty is the Lady facing at the end of the table.



We, do offer our condolences to Neal and son Logan and thank them all for being a Contact Family.

No 10 Downing Street

Here I come!

I received a phone call from the office of our local MP Tom Randall. Sam, the PA of the MP, told me I had been nominated for a Community Champion Award and was invited to go to No 10 Downing Street on 22nd March 2023. I was a little surprised. I said, "Will I have to buy a new hat?" and Sam said "no just a new dress!".

An email arrived giving me the details to be at No 10 for 5pm to meet the Prime Minister and leave by 6pm to come home.

I arrived at St Pancras Station early, so I sat on a seat and watched people rushing along. After a while I boarded a taxi and soon arrived at the entrance to Downing Street at 4.40pm. Four security men were standing keeping the public out of the street. I talked to a few people and offered to take their photograph and in return they took mine.

At 4.50pm a small crowd of us went through security checks, and we were soon facing the door to Number 10.

As the group 40 to 50 people we were instructed to leave our phones in a "pigeonhole" - all numbered. I chose the number of my age so I would remember! We were checked in under the name of our MP. I was offered the lift instead of the staircase. Out of the lift came the Prime Minister.

In one room I found people being offered drinks and snacks. From a window seat, I could see the large expanse of grounds below, The MP Tom Randall found me and told me I was looking at Horse Guards Parade. We both did a short tour. One of the rooms had a huge table, with about 12 chairs on each side. I guess it was the Cabinet Room.

There was an official welcome, then Tom said, "we had better join the queue to meet the Prime Minister and have a photo taken with him". I asked for Tom to be on the photo.

After a short wait, I was introduced to the Prime Minister. Tom explained I was the Founder member of the Support Group which I explained was the Myotonic Dystrophy Support Group.

With big smiles, we shook hands. After collecting my coat and phone, I found myself leaving the building.

Tom and a friend escorted me to the roadside, where Tom hailed a taxi for me to get back to St Pancras Station. I was met at Nottingham station by Philip and Janet Walker. We went home and enjoyed a lovely cup of tea, while I explained my extraordinary day to them!



Scribbler of the Year!

Margaret has written about her exploits as a Community Midwife in Carlton/Gedling area of Nottingham.



60 pages of lots of stories, many funny situations throughout her career. The front cover shows Margaret standing by her first car.

If you wish to buy a copy of her book at a cost of £10, please contact Margaret via the office.

Funds from the sales are going to DEBRA towards research for Epidermolysis Bullosa.

Christmas Cards

Thank you, to all those who purchased the MDSG Christmas Cards. They were a great success, with over 270 packs being sold. The 'camels' ran away with 183 packs.

If all the cards were sent to people, then that is 2700 cards spreading awareness to family and friends.

SwallowDM1

Jodi Allen, Highly Specialist Speech and Language Therapist, based in Queen Square, London, part of Dr Chris Turner's team has begun a PhD.

Her project is to improve the assessment and treatment of swallowing difficulties for people living with Myotonic Dystrophy Type 1. She is recruiting people with the condition to take part in this three year project. MDSG is donating £10,000 towards the cost of £300,000.

Awareness

MDSG are once again, having an information stand at the Primary Care exhibition. This is held at the NEC, Birmingham on 17/18 May. Delegates, which number about 6000, are, midwives, speech therapists, podiatrists, orthotists, physiotherapists, nutritionists, general practitioners and other associated Primary Care professionals. It is an extremely busy affair, with ample opportunity to inform delegates about



Fundraising

Many people have been or are presently raising funds and awareness for MDSG.

Helen Blake is still celebrating her 50th Birthday by drinking plenty of tea

Claire Butler is walking the Camino Way in Portugal, **ONLY** 400 miles!!

Claire Drury and Mike ran the Manchester Marathon 16 April

Martin Radford did a 'Wolf Run' on Saturday 22 April, followed by Blackpool half marathon, the following day.

The man in the telephone box, *Syd Keyte* is running the London Marathon. Please note the MDSG stickers on the side.

Rob Leach and Michael Walker's nephew *Philip Birchley*, also ran the London Marathon.

We are pleased to say all the runners and walkers finished the course.

A very big thank you to you all for your amazing efforts

Each of them have their own 'Just Giving' fundraising page, if anyone wishes to make a donation. Pages stay open for some time after the event.

Katherine Lancaster-Usher on Saturday 3 June along with her best friend Ella and Ella's son Oliver (both have myotonic dystrophy) are attempting to walk a half marathon through Jeskyns Community Woodland (near Gravesend, Kent). Katherine has a Just Giving page.

The End of an Era as Margaret and Elycia step down as Trustees, after 30 plus years.



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

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
01977 790886

