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2019**

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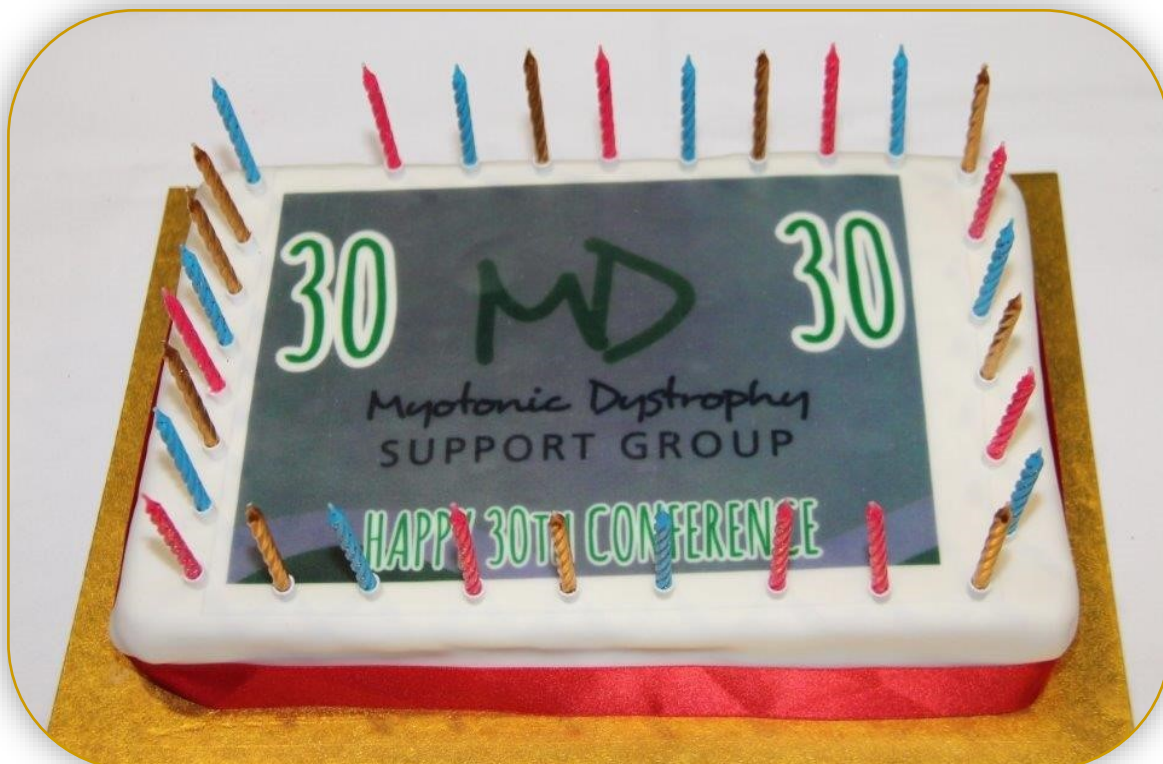
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**Celebrating 30 years  
of Annual Conferences**

## National Co-ordinator

Margaret Bowler

## Directors

M Bowler  
E Cumming  
P Ferrari  
R Harrison  
E Ormandy  
M Walker

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Prof D Brook  
(Patron)  
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Prof P Harper  
Prof D Monckton  
Dr M Phillips  
Dr M Rogers  
Dr C Turner

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Julie and Mike

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## Letter from MDSG Founder Margaret Bowler

Several area meetings have taken place during the last 12 months. This is encouraging as people have said it is good to have the opportunity to meet other families in Kent. Hampshire, Dorset and Sussex are new contact groups.

Local sales – Coffee mornings. Thank you to all the people who work hard to make these money raising events worthwhile.

Gifts of money are also sent to us from birthday celebrations. Today, as I write this, money has arrived from a family who have had a wedding. Congratulations and thank you. Generous donations are also received from families and friends in memory of loved ones.

Sponsored walks are popular, I have just joined in with a church who did a 12 mile sponsored walk in Nottingham. Half the amount raised was for MDSG. The students from Professor David Brook's laboratory also joined in and got wet through!! I only did 4 miles, then was offered a lift!! It was the day after arriving home from an activity holiday at Calvert Trust in Exmoor. Belle, Qazi and Anjani really enjoyed walking and getting wet! They did very well! If anyone else would like to sponsor them donations will be welcome.

**Margaret Bowler**

## Letter from Editor Elycia Ormandy

Hello Everyone,  
"Significantly cooler" says the weather forecast – it must be September! Welcome to a Newsletter that covers a variety of topics to cheer you. Meetings, conferences, both local and international, benefits and personal interest stories and more. It's all here!

When I was supporting family and a friend through the PIP process two years ago, the distress that it caused prompted me to attempt to reassure and encourage families to continue through the process. It is so tempting to give up at the first refusal of benefit. It is sad that in this day and age people suffer real upset when the PIP letters arrive. Many have experienced humiliation and feel that the whole process is undignified, demoralising, sole-destroying and degrading.

While I am no expert, I have knowledge of the process now, and felt I could use this to help others move forward more confidently. Only you, the applicant, can do the form filling, but hints and tips may help you on the way, for it is usually the detail that paints the true picture.

Some people have told us that their application has been successful. Others not! We make no promises but welcome feedback. Contact the office for a copy of our PIP presentation if you think it may help you. It will be sent out to you from the office ASAP. Remember the office hours are TUES, WED, THURS 9am-1pm

September onwards is the time to plan for your flu jab again. Remember that carers as well as people with Myotonic Dystrophy do all qualify - be quietly firm with G.P. receptionists who do not always know this!

We had a great 30<sup>th</sup> Conference day in June. Lots of speakers, lots of people and LOTS OF FUN, thanks to our chairperson for the day, Dr Helen Gregory. She, who entertained and educated us throughout the Conference day, especially with apron and duster during her talk about good management and essential care. We loved it! We were all born with a sense of humour. Lets keep it well exercised on a regular basis. As a GP, Dr Helen recommends a regular smile and daily dose of laughter. See you next year.  
Best wishes

**Elycia.**



## Sharing an Experience from the Charity Walk on 29<sup>th</sup> July 2019

The increasing popularity of walking and running with time has led to making these activities as an important part of non-profit fundraising. Myotonic Dystrophy Support Group (MDSG) is run by volunteers to offer support to people affected by this disease. Moreover, it's a torch bearer striving to develop treatment for the disease through its support for research. The walk, arranged under the auspices of St.Cyprian's Church, was organised with the aim to create awareness about the disease and generate funds to support research with expected breakthrough to treat patients with this debilitating disorder, regardless of colour, creed or race. This walk was also intended to bring people together to help others and engender greater understanding and promote goodwill amongst people from all walks of life.



The walk started and finished at Vicar Water Park, Clipstone, Mansfield, passing through the lush green fields of the country side of Sherwood, Nottingham. The showery weather of the day really tested

our zeal and vigour for the noble cause. The scratches of the thorny bushes while passing through the fields seemed trivial before the joy of sparing time from our day to day routine. Aching legs after the day long walk were in fact a source of comfort giving an invaluable feeling of gratification for our endeavour for the betterment of ailing fellow beings. The participants of the walk were a great mix of people from different walks of life ranging from educationists, healthcare providers, researchers, philanthropists, social workers to members of the church. The organisers of the walk did a marvellous job looking after all the



participants with regards food arrangement, provision of first aid and security. The enthusiasm of all irrespective of age was really invincible. The great determination and dedication of Margaret Bowler, who is the soul of MDSG, to the cause was evident this time. Thanks to those walkers who remained in the forefront and walked four miles despite the wet weather. This was a great source of inspiration for all participants, especially the youngsters. Hence we would like to conclude with a short poem!

### All for a good cause!

*An early start to the day  
Keeping the sleep at bay,  
Off to Carlton we go  
Enjoying an early sun's glow!*

*We reach Vicar Country Water Park  
To leave time, an indelible mark  
We start to walk and it starts to rain  
Yet, determined to not let any energy drain.*

*We end up mapping 11.27 miles  
Faces sparkling with great smiles  
We think for a second and pause.....  
Everything seemed worthwhile for a good cause.*



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## Annual General Meeting

The Annual General Meeting was chaired by Prof Darren Monckton



and attended by over 100 delegates. One of whom, Dr Margaret Phillips, arrived on her bike.



Margaret Bowler, Peter Ferrari and Michael Walker were all re-elected for a further term of three years to the Board of Trustees/Directors.

Some members who attended the conference have shown an interest in becoming Trustees. They will be joining the committee at its next meeting as observers.

We need to point out that you must be a paid up member for two years and have attended at least one annual conference.

Copies of the accounts for the year

ending 31 December 2018 were distributed and approved. If any member wishes to see a copy, please ring the office.



Dr Cecilia Jimenez-Moreno gave a short talk on the work of the Registry.

## MDSG Conference 2019

Was again well attended with 170 delegates on the day. Most came with another person, which means that we had approximately 80 people with Myotonic Dystrophy attending. That's great but we would like to increase that figure.

We have 1800 names on our mailing list! How can we encourage more people to join in the MDSG Conference Day?

Time, travel, cost of accommodation and distance can all influence the decision to attend. So, would our members like to offer suggestions that will bring more of our members together? Should we have a conference in the North and another in the South with the AGM at one of the venues?

***Please let me know what you think! M***





# C O N F E R E N C E 2019



*Top Left: Prof David Brook, Patron with Dr Helen Gregory and Margaret Bowler*

*Middle Left: Dr Ian Campbell welcoming delegates to the Conference*

*Middle Right: Margaret Bowler talking on the History of MDSG*



*Celebration with Cake and blowing out of the candles.*



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*Left: Professor  
David Brook  
Right: Professor  
Anton  
Emmanuel*



*Middle Row: Dr  
Helen Gregory  
as Mrs Mop*



*Bottom Left:  
Dr Chris  
Turner  
Right:  
Professor  
Darren  
Monckton*





# C O N F E R E N C E 2019



*Information, sales goods including sweatshirts and t-shirts, Bring and Buy and Teddies. Thank you to everyone who manned and supported these popular stalls between sessions.*



## Young Adults Report

The young adults started the day in the auditorium as usual. After the welcome and the cutting of the cake to celebrate Our 30<sup>th</sup> Conference, they went to do an alternative programme.



Bantock, which we all enjoyed, Andy travelled from Cheshire and brought the drums etc in his car. We all took turns to play our own rhythms and used percussion instruments to join in with his drumming. This is an activity that encouraged social interaction and team work. All of the group said they would like to repeat this again.

Although some of the group were first timers, by the end of the session they were enjoying laughing and talking together about what they had done during the day. We all had a great time together.

We started off by saying our names and where we came from. This led on to us finding where we lived on a map and sticking it to a wooden plaque. Then we decorated them with stickers. During the day we each planted a marigold to keep or give as a gift. We made and crafted cards from a wide selection of materials, sharing ideas of how to decorate them.

Dr Margaret Phillips came in and gave us an inspirational talk and then discussion about healthy exercise. We all learnt from this.

After lunch we joined up again and had a lively session of African Drumming run by Andy



We went back to the auditorium to join our families and to see Dr Helen Gregory do her entertaining performance as Mrs Mop.

**Lynne Ormandy**



## My First MDSG Conference 21-22<sup>nd</sup> June 2019

I imagine everyone has a rather unique experience of learning that they have Myotonic Dystrophy. Mine was a phone call following a DNA test to rule out the scary but unlikely reason I was having problems with my hands. Several months later and six more of my family members diagnosed with Myotonic Dystrophy Type 1, here I am.

Maybe because of my medical background or maybe because of my family's way of tackling problems head on, my immediate response was to learn as much as I could. So I turned to the internet and found my way to the Myotonic Dystrophy Support Group website. The idea of attending a conference was intimidating but I relished the opportunity to meet others going through something that my family were grappling with.

I am lucky that my mum agreed to come with me and we turned up at the Radisson Hotel with some trepidation. But mixed in with the devastation that living with a chronic condition can bring was a real sense of warmth and optimism. Many of the people we met at dinner on Friday night had been coming to the conference for years. They spoke of the friendships that they had made as well as the sadness at seeing people's health declining.

Saturday kicked off with Margaret talking about the beginnings of the support group. Her proactive way to deal with the isolation she felt when dealing with DM in a family member has led to so many of us feeling less alone. As the talks

continued I gained more knowledge – from the “fried egg doctor” explaining the mechanisms behind DM and promising areas of research to Professor Emmanuel



breaking taboos by speaking emphatically about faecal incontinence. As both a GP & a patient I sat slightly sheepishly through ‘Ask Your GP’, identified with the psychological challenges in ‘Living with Myotonic Dystrophy’ and even plucked up the courage to ask a question in ‘Research’ in which I mentioned my recent diagnosis.

As the conference drew to a close, a few people told me how sorry they were to hear about my recent diagnosis. They understood that despite the fact that my symptoms are minimal, having DM is tough. In a world where rare health conditions can be ignored or poorly understood, the Myotonic Dystrophy Support Group has created a community where it's ok to be angry or upset or optimistic. That permission to recognise and experience all these feelings is priceless and with that in mind I am looking forward to seeing as many of you as possible in 2020!

**Dr Genevieve Allum**

*Thank you for contributing to our Conference Report/Newsletter. Lets hope that your shared thoughts will give others the incentive to join us at our 31st Conference in 2020!*

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## IDMC 12 – Three Musketeers

Journeying to Sweden via Stockholm to Gothenburg was interesting! Lynne has a mobility scooter. Some airport staff wanted the battery to be kept with the scooter in the hold, others insisted that it was removed and kept in the cabin. All the same airline.



*The Three Musketeers, Margaret Bowler, Elycia and Lynne representing MDSG in Sweden*

As we were late booking, our accommodation was away from the Conference Centre and uphill. It was clean and comfortable, and we knew several Consultants who were also staying there. On arrival we were greeted by the organisers and shown to the exhibition area where we set out a table-top display of MDSG literature. Delegates from UK soon found us, but overall there was little interest from the international research delegates.



*Display of MDSG literature. Home base for UK delegates*

The Posters from UK were impressive and covered different areas of research. Anjani and Belle contributed to these. (MDSG paid towards some of the cost of attending this scientific gathering).



*Prof David Brook and Margaret Bowler tell delegates about the work of MDSG in the UK*

I was as given the opportunity to speak to the 250 researchers and was the last of the presentations. I had asked Prof David Brook to share the platform with me. I intended it to be an informal presentation. It certainly was! After 5 minutes I hadn't even started my prepared talk. Prof Brook spoke about MDSG, and we shared a few laughs. The 5-7 minutes session was much longer than the time we had been given. David told the delegates that when I leave his laboratory after my visits I always say "WORK HARD". That was our message to all the researchers at IDMC12.



*Dr Mark Hamilton with Glasgow colleagues after receiving a special award for his contribution to IDMC 12.*



## Report on IDMC 12 from Martin Payne who submitted a Poster and attended this meeting.



About 300 research scientists and clinicians, meet every two years to share and discuss the latest research findings in myotonic dystrophy. The latest meeting was held in Gothenburg, Sweden, a city with connections to significant contributions to the field and neuromuscular disease research, including the work of the local hosts and organisers Prof. Christopher Lindberg and Anne-Berit Engstrom. Researchers were joined by representatives of support groups, including MDSG, Myotonic Dystrophy Foundation (Molly White), and the Japanese Myotonic Dystrophy Association and a few DM1-affected people and/or their family members.

*Martin's very interesting scientific report is available on request from the office. Do contact us if you would like a copy. Thank you Martin for taking time to prepare this report for members of MDSG.*

### Hampshire/Dorset

At the beginning of August, we held another get-together for families living with myotonic dystrophy in Dorset and Hampshire. We met at the same venue as our first meeting which took place in April. Two of the MDSG trustees, Mike Walker and Ruth Harrison welcomed 14 attendees on this occasion.

We plan to keep these events going throughout the year and were very pleased to see people chatting together and exchanging phone numbers.

I was keen to find out during the meeting whether any particular topics might be of interest to those attending so that speakers could be invited to join us at future events but it was also apparent that participants were happy just to have an opportunity to meet others who live with the various challenges of myotonic dystrophy.

Since the meeting, we have received feedback from an attendee which has been very useful and practical. It was suggested that we should provide name labels for everyone and that we should think of some sort of ice-breaker as an introduction, just to get people talking to each other. We are working on it for next time! Feedback is always valuable and welcome.

By the way, if you live outside Dorset and Hampshire, please rest assured that we are aiming to set up get-togethers like this in as many areas of the country as possible so that we can all share experiences and, most of all, make valuable new friends. See you all again soon, **Ruth**

### Ireland

Do you know someone in Ireland, North or South, maybe a relative who is affected by Myotonic Dystrophy? We are arranging get togethers in Dublin and Belfast. Dublin is 4 October at the Muscular Dystrophy of Ireland headquarters at 6pm and Belfast on Saturday 5 October at Maldron International Hotel, Belfast Airport. Please contact the office if you wish to come along.

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**Rust 2 Rome** is a banger rally. It's a 4,500 mile endurance rally on some of the continent's most scenic roads. Bangers have to cost less than £500.

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### **Rust 2 Rome**

Stuart Hay from Scotland took part in this Banger Rally. "We made it to Rome!!! Cracking trip and a good few pounds raised" writes Stuart. He is raising money for the research centre at Glasgow headed by Professor Darren Monckton on behalf of his niece Mia who has congenital myotonic dystrophy. Stuart has raised £2331.25



### **Office Hours**

We would like to remind members that the office is open on

**Tuesday, Wednesday and Thursday mornings between the hours of 9am to 1pm.**

If you leave a recorded telephone message on a Thursday afternoon, it may not be heard until the following Tuesday.

If you wish to contact MDSG urgently, please ring on the Helpline number **0808 169 1960**. (this is a freephone number and will not cost you anything). Remember to leave your number and say it twice. The helpline is not in the office, it could be answered by Elycia in Manchester.

### **NO Postage surcharges please!**

A reminder that if you are sending a large letter (size A4 envelope), that it requires extra postage. We have a few instances recently where we have to collect the envelope from the sorting office and pay a £2 surcharge.

### **Robin Hood Marathon**

Each year, several of the local Carlton Rainbows, along with Margaret, Elycia, Lynne and others have taken part in this event, walking the Mini marathon of 1.5 miles. This year, **Dr Jeremy Rhodes** and **Dr Saam Sedehizedah** are taking part in the half marathon helping increase awareness of myotonic dystrophy. If anyone wishes to sponsor them, please contact the office. *Sincere thanks to Dr Helen Brownlee who has, once again, undertaken the time-consuming process of registering each participant.*

### **Tip**

A tip for toilet training for little boys !! Place a ping pong ball in the toilet for little boys to aim at when doing a wee in the toilet. This will encourage them to aim straight. This was suggested to me and it was very effective with my son! Margaret

### **Estate Planning**

One of the speakers at our last Conference, Bina Menz, spoke on Wills, Trusts and Powers of Attorney. Whilst MDSG does not endorse any commercial organisation, some members who are considering 'Estate Planning' may wish to contact her. Telephone: 0800 0029 235 or email [info@binamenzestateplanning.co.uk](mailto:info@binamenzestateplanning.co.uk)



### **Awareness**

This poster appeared on 21 buses covering five different routes in the Birmingham area. This awareness campaign lasted for four weeks and coincided with the first test in the Ashes series. Advertising is always difficult to quantify, but awareness is so important.



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E	D	P	D	E	V	M	E	M	O	R	I	E	S	S	F	W	R
L	L	G	T	S	I	T	K	H	R	U	M	D	P	E	R	O	A
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R	M	U	O	I	M	P	D	C	P	C	P	W	S	Z	O	T	B
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J	F	B	I	C	A	K	E	O	S	Y	R	E	T	D	V	E	J
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Here is a word search to finish our recap of the 30<sup>th</sup> Conference.

Thirty of the thirty-one words have been hidden in the diagram. They have been printed across (backwards or forwards), or up or down, or diagonally, but always in a straight line without letters being skipped.

ONE word in the list has NOT been included. When you have discovered which word it is, send an email with the missing word, your name and postal address to the office. The first correct answer received will win a £25 High Street voucher.

Good luck!!

ADVICE	CONFERENCE	LEAFLET	NETWORKING	SPEAKER	YOUNG ADULTS
AGENDA	DELEGATE	LUNCH	PATRON	SUPPORT	
AGM	FAMILIES	MARGARET	PRESENTATION	THIRTIETH	
ANNIVERSARY	FRIENDSHIPS	MEMBER	QUESTIONS	TRUSTEE	
BRING AND BUY	HOTEL	MEMORIES	REFRESHMENTS	VOLUNTEER	
CAKE	JUNE	MIDLANDS	RESEARCH	WORKSHOP	

## Dr David Hilton-Jones

*MDSG presented David with an engraved paperweight wishing him a Happy Retirement with our sincere thanks and good wishes.*



After 42 years continuous

years service to the National Health Service, David retired on 14 July 2019. He no longer has any involvement with medical matters. The Oxford Muscle service is now under the care of Dr Stefan Brady.

David has been my personal family neurologist for 26 years, diagnosing one of my twin boys and wife when the children were born. We travelled the 60 miles each way to his clinics several times over that period. Nathan loved having chats with David, took everything in and did whatever he asked. When Nathan was in hospital, David came the next day to visit him. I and the Myotonic Dystrophy Support Group are indebted to David for all the help he has given the hundreds of patients with myotonic dystrophy over the past 42 years. **Michael**

## BBC Midland Radio

When I go to bed I always put the radio on in the bedroom. Radio Nottingham after 10pm. It is the Midland Radio station that 8 midland stations join together for this 3 hour programme.

The announcer Graham Torrington was asking people to contact him if they had ever started anything. So I thought I could let him know about

Myotonic Dystrophy Support Group, which I formed in 1987. I couldn't remember the late night number. Each time they repeated the number I jotted down a couple of digits, One hour later I finally got the right number.

Nicole, the lady answering the phone-in calls told me that the feature ended at 11pm. I explained my problems with getting the phone number, and Nicole said that she would e-mail me in the next two weeks.

She kept her word, and sent an e-mail saying that they would arrange a twenty minute interview with me.

This she did one evening at about 9pm to be broadcast two hours later. Nicole provided the questions beforehand and it was evident she had done her homework about the charity.

I must have been meant to have problems with the number as I eventually had a 20 minute part of the programme, talking all about Myotonic Dystrophy Support Group.

**Margaret**

See below some of the comments that were received by the radio station after the interview was broadcast.

*'my goodness, I am a grown man and I am so moved by that'*

*'a quiet, kind lady, dedicating her life to help others'*

*'I am sure your son would be so proud of you'*

*'what an amazing story'*

*'what dedication throughout her life'*

*'I have never heard of this condition before. Thank you Margaret for telling us about it'*



## Genetic factors that determine disease severity in myotonic dystrophy type 1 – results from the OPTIMISTIC cohort

*Dr Sarah Cumming and Prof Darren Monckton, together with the rest of researchers of the OPTIMISTIC trial, just recently published a scientific paper that identifies genetic factors that impact on the severity of the disease and that play a role on how early patients might start experiencing symptoms.*

It was already known that myotonic dystrophy type 1 (DM1) is an inherited genetic disorder caused by a mutation in which a triplet of letters in the DNA, CTG, appear with more copies than they should. In the general population there are up to about 40 copies of the CTG repeat. However, in DM1 patients this triplet has increased in size to more than 50, and can be as many as 1,000 in some people. The more times these CTG repeats appear consecutively, the more severe the disease will present and the earlier that symptoms will appear. Notably, the number of repeats nearly always increases when passed on from one generation to the next, mediating the decrease in age at onset often observed in DM1 families. The number of CTG repeats also increases during the lifetime of the individual, which in addition to hastening disease onset, can complicate our ability to interpret the results of genetic testing.

For this study, researchers at the University of Glasgow carefully analysed blood DNA samples provided by 255 participants of the international trial of OPTIMISTIC (including patients from the Netherlands, France, Germany and UK). From these samples, the researchers were able to determine

the average number of CTG repeats that the patients' presented with when starting the trial, but also to estimate how many CTG repeats the patients inherited from their parents when conceived. These results confirmed that the number of repeat inherited is the primary determinant of the age at which symptoms first appear in a patient. This number also predicted clinical manifestations of the disease such as muscle function and walking performance, and the capability of patients to perform daily life tasks.

Although the majority of participants presented with a CTG expansion, there was a minor subset of patients (about 8%) that were revealed to have variant repeat interruptions within the CTG array. These interruptions seem to delay the appearance of the first symptoms, typically by around a decade and are associated with an overall lower disease severity. This effect appears to be associated with the observation that the presence of the variant repeat interruptions slows down the rate at which the CTG repeat grows during the lifetime of an individual.

"These results confirm the importance of carefully counting the number of CTG repeats as part of clinical trials in DM1 and increase prospects for detecting the effects of new treatments.

In addition, our finding that the increasing number of CTG repeats contributes toward both the age at onset, and severity of the many of the progressive symptoms, reinforces the idea that stopping the repeat getting bigger during the lifetime of the patient would be therapeutically beneficial."- Prof. Darren Monckton.

[link to manuscript: <https://n.neurology.org/content/early/2019/08/07/WNL.0000000000008056> ]

Research comes in all shapes and sizes. With this newsletter you will find an insert regarding research work into the affects of swallowing and myotonic dystrophy.

Jodi, is a Highly Specialist Speech and Language therapist working from the Institute of Neurology, London. Please respond to the letter if you feel it would be helpful to you.

## 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

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

**Sussex**  
Michele Wilmshurst  
01424 421013

**Cardiff**  
Margaret Ware  
02920 869277

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

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

**Croydon**  
Lesley Smith  
020 8777 6587

**Northampton / Milton Keynes**  
Michael Walker  
07831 347143

**Cumbria**  
Neil Braiden  
01228 512385

**Northumberland, Tyne and  
Wear, Teesside**  
Peter Bodo  
01740 620707

**Dorset and Hampshire**  
Ruth Harrison  
01425 626133

**Nottinghamshire**  
Margaret Bowler  
0115 987 5869

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

**Sheffield**  
Rachel Reeson  
07544 353076

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

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

