

Facts about Myotonic Dystrophy

February
2019



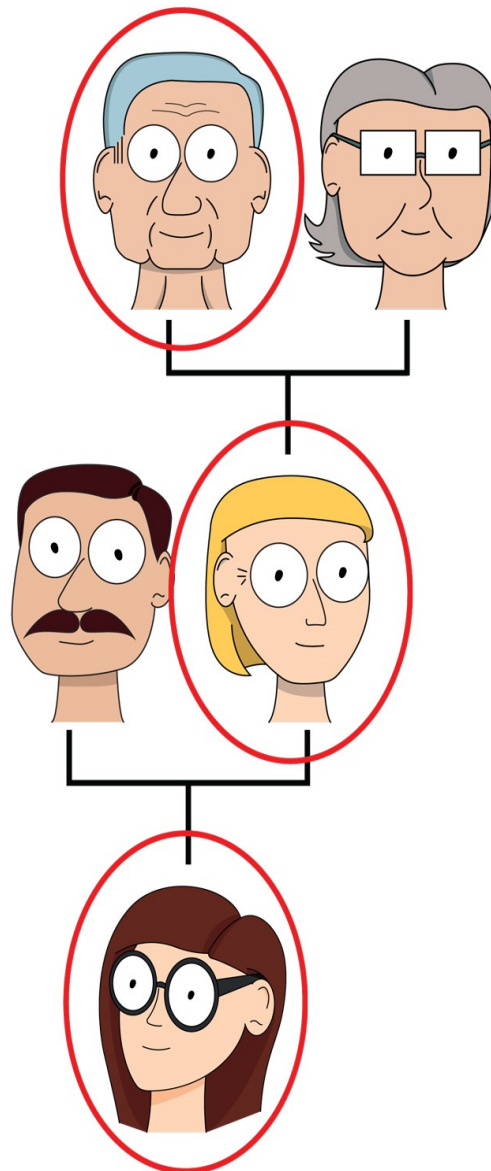
Why do I have Myotonic Dystrophy?



Myotonic Dystrophy is a genetic condition that you get from one of your parents.

There is a 50% chance that someone with Myotonic Dystrophy will pass it on to each child they have.

That means that one of your Grandparents passed it on to one of your parents, and they passed it on to you.



Letters...2

Conference...
3

Fundraising...
4

Office...5

Awareness...6

Meetings...7

Contact
List...8

MYOTONIC DYSTROPHY SUPPORT GROUP



National Co-ordinator

Margaret Bowler

Directors

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

Advisors

Prof D Brook
(Patron)
Dr I Bowler
Prof P Harper
Dr D Hilton-Jones
Prof D Monckton
Dr M Phillips
Dr M Rogers
Dr C Turner

Office Staff
Julie and Mike

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

Printed by
L & T Press Ltd.,
Bedford
07831 347143

HELLO EVERYONE

A Happy New Year to our members. I will encourage you by saying that the Genetic research is moving ahead, and in this little country of UK, lots of work is being done to find a treatment for myotonic dystrophy.

We, MDSG, had a busy year arranging meetings and visiting conferences—to raise awareness about Myotonic Dystrophy.

To help to set up Contact Families we will be arranging local meetings and asking if anyone in a specific county would be interested in being a Contact Person. Then a training day will be arranged.

Recently we visited Kent and had volunteers. Other counties in the South will be a focus for this year.

A training day will be given as all Contact people will have attended a Conference day, and of course be a subscribing member, (membership only applies to those who pay the annual subscription).

Wherever you live, if you are interested in becoming a Contact Person, please speak to someone at the office, 0115 987 5869. Thanks.

During the next six months we will be trying to contact more families with DM2, by contacting Neurologists in the UK. Depending on the response, we could then invite a Consultant Neurologist who has expertise with DM2 patients to come to the conference this year.

We welcome two new students to Professor David Brooks laboratory.

Margaret Bowler
National Co-ordinator

Letter from The Editor

Hello Everyone,
I wish you all a very Happy New Year as you pick up this first Newsletter for 2019. This year we are preparing for a very special Event....Our 30th Conference and AGM. The latest information that we have is here, along with Booking Forms. Do seriously consider attending this year, as we celebrate our MDSG Past and look forward to an exciting MDSG Future.

The dates are June 21st AGM and June 22nd CONFERENCE DAY. The Hotel promises to be the most suitable for our Celebration Weekend! Don't worry that we will be close to the East Midlands Airport. You may see the aircraft but will not hear them whilst in the hotel!

In recent weeks, I have had the pleasure of meeting some families affected by Myotonic Dystrophy at the NeuroMuscular Centre, Winsford. Most of them have been pleased to find other families there who have DM. All of them have been happy to be included on our MDSG Database, and I sincerely hope that they will feel able to join us at our Conference. Regulars and first – timers will all find a warm welcome and lots of opportunities to share information and learn from Experts and MDSG Members alike.

Are we Human Beings or Human Doings? Some of us are often so busy 'Doing' that we almost forget to 'Be'. Things will still need to be DONE, but we all need time to BE. Something to ponder on for this New Year. Whatever you decide to do or be in 2019, take care and be Happy. See you in June, **Elycia Ormandy**

**30th Conference and Annual General Meeting
21 and 22 June 2019
at Radisson Blu Hotel**

Herald Way, Pegasus Business Park,
East Midlands Airport, DE74 2TZ, Derby
Telephone: 01509 670575



30TH

C

O

N

F

E

R

E

N

C

E

2019

We are currently putting the programme together for the 30th Conference. So far we have confirmed;

Chairperson Dr Helen Gregory from Aberdeen, who will also be giving a drama presentation.

Dr Chris. Turner

Dr Gabby Chow on Paediatrics

Dr Ian Bowler on Anaesthetics

Professor Darren Monckton

Professor David Brook

Dr Gillespie on Challenges of Myotonic Dystrophy

Dr Margaret Phillips

Dr Anton Emmanuel on Gastroenterology

He is a Senior Lecturer in Neuro-Gastroenterology at

University College London and Consultant

Gastroenterologist at University College Hospital and the

National Hospital for Neurology and Neurosurgery

(Queen Square).

To be confirmed an Eye Consultant

STOP PRESS

If you require
overnight
accommodation at
the hotel, please
book through MDSG

NOT

the hotel, see
booking form for
more information.

Nottingham Robin Hood Marathon

The 2018 Robin Hood Mini Marathon last year was again supported by the Carlton Rainbow Guides. Their parents and friends joined in running-some of us walked! They also collected sponsor money. The mini-marathon is expensive to enter, this year being £12 each person. A big thank you for the Rainbows, parents and MDSG members for the effort made to even get to the starting line!

Dr Jeremy Rhodes (a researcher) was in the Half Marathon again this year. Unfortunately, after two miles, Jeremy had to 'drop out' due to a hip problem. He had to walk all the way back to the starting line and he was very cold when he found us.

Thank you again Jeremy,

Margaret Bowler

Sky Dive



"Hello, my name is Jordan Beale, I am aged 17 and currently studying A-levels Maths, Computing and Biology, I am a self-motivated person and always feel the need

to help people in any way possible hence the upcoming charity event! This charity event is a tandem skydive consisting of me flopping out of a plane at 13,000ft, plummeting down to the ground at the terminal velocity of 120mph(I'm just a little nervous!). After the unfortunate passing away of my grandmother and my raised awareness of this hereditary disorder, I have made it my goal to help raise awareness of this widely unrecognised disorder and to help raise as much money as I can for the Myotonic Dystrophy Support Group so the victims undergoing the hindering symptoms of the disorder can live the best lives possible!"

30

???

How can we celebrate this special occasion, this amazing milestone in the life of Myotonic Dystrophy Support Group. The 30th Annual Conference and Annual General Meeting.

From the humble beginnings started by Margaret Bowler, MDSG has become a world-wide recognised organisation, a Charity and a Company, reaching out to many thousands over the years.

Do you have any suggestions, as to how we can make the next Conference worthy of its 30th Birthday. Please contact the office with any ideas, we would love to hear from you.

Consensus Based Care

The Myotonic Dystrophy Foundation of USA recruited 66 international clinicians experienced in DM1 patient care to develop consensus-based care recommendations.

Dr Mark Rogers, Professor Darren Monckton, Dr Richard Petty and Dr Chris Turner were part of that group, with Dr Mark Rogers also a member of the 10 strong steering committee.

The report was published in 'Neurology: Clinical Practice' on behalf of the American Academy of Neurology. The resulting recommendations are intended to help standardise and elevate care for those with myotonic dystrophy and reduce variability in clinical trial and study environments.

We look forward to more information about the project and how it will be implemented.

Insurance

Several companies specialise in covering people with medical conditions for life and travel insurance, including myotonic dystrophy.

One such company Orbis Insurance quote, 'although we cannot promise to cover everyone, we will not automatically decline and will try our best to provide cover.

We provide instant quotations for travel insurance enquiries over the telephone. Life insurance enquiries will require a GP report and can take a bit more time, however we always aim to give an indicative premium promptly'.

(Please note: We do not endorse any organisation that may be mentioned. As the name suggests as a Support Group, we pass information on in the hope that it may be helpful to your individual situation.)

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 contact the office outside these hours, please leave a message on the answerphone **0115 987 5869**. State clearly and slowly your telephone number and repeat it twice.

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). If the phone is not answered please leave a message and someone will ring you back, again remember to leave your number and say it twice.

Cartoon Brochure

In this newsletter you will find a cartoon brochure. This is aimed at teenagers and young adults to help them explain to their friends, peers at college, clubs or work, how Myotonic Dystrophy can affect them.

With its use of simple language and caricatures, the brochure has already had positive comments from young people, parents and health professionals.

Please contact the office if you require further copies.

I
N
F
O
R
M
A
T
I
O
N

Data Protection

Thank you to all of you for returning the data protection form sent last year. We are pleased so many of you wish to remain in contact with us. Thank you to those who have joined or re-joined your annual membership.

Sadly, despite three mailings, a large number (over 800) of those who have contacted us in the past and received the newsletter at least once a year have not returned the form.

This does mean, in accordance with GDPR (the new Data Protection Act) there names will be removed from our database.

Please check with family and friends if they have returned the form. We do not wish to lose contact with anyone. If you are not sure if you have returned the form or have any questions regarding filling in the form, please contact the office

Financial Support

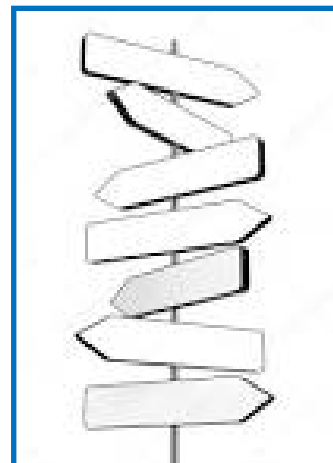


A large proportion of our income comes from the kindness of families who remember MDSG at the loss of a family member, asking family and friends to donate to the work of MDSG. Lynne Thomson did just that when her husband Stewart seen here on the left with their son Steven, (both having myotonic dystrophy) died suddenly whilst on holiday in France. £743 was donated from those attending the funeral.

Area Contact People Awareness Programme

We are coming to a place near you!

Over the past few years, a number of the Area Contact People have retired from the position, leaving more areas without a contact person, resulting in even fewer local get togethers.



To try and address this, the office over the forthcoming year will be arranging meetings in your area or nearby. We hope that after we have met you all face to face, some of you will be willing to act for the MDSG in this voluntary role.

We have already started and last month held a meeting near Maidstone in Kent for all those in the Kent area. This was well attended, despite the miserable weather. For some, it was their first time meeting others with the condition. Two ladies, Kirsty and Amanda have offered to be local contact people and will be arranging another get together sometime in the Spring. This is exactly what we hoped would happen.

For a number of reasons, mostly geographical, many of you are unable to attend the Annual Conference. It is of course true, that wherever it is held, it would not be suitable for the majority as travelling long distances can be difficult.

Look out for an invitation to a LOCAL meeting over the next 12 months. Please bear in mind, we cannot guarantee we will cover all the regions in one year, but we are making a start.

Dublin

At the end of September, MDSG had an exhibition stand at the Association of Anaesthetists Annual Conference in Dublin. Although there were not as many delegates as usual, owing to the high cost of accommodation, we still had many useful conversations increasing awareness.

Whilst in Dublin, with the help of the Muscular Dystrophy of Ireland, we held a meeting for people with Myotonic Dystrophy. Although arranged at short notice, 15 people turned up, along with two committee members of the Muscular Dystrophy of Ireland. Dr Ian Bowler flew over from Cardiff in the afternoon to give a talk on anaesthesia. Once finished, he then flew back that evening and we all retired to the restaurant for a meal. Special thanks to Dr Ian Bowler for fitting MDSG into his busy schedule.

GP Conference

The week after Dublin, MDSG went to Glasgow for the GP Conference. Ann Cobburn (Glasgow Contact Person) and Mike Walker manned a stand for two days. This was very well attended with over 1600 delegates. The trainee GP's wore a different coloured lanyard, so they were easy to identify and target. I met a trainee GP from my home town, who attended the same church as me when she lived at home. We met two young ladies on the catering staff who had studied Genetics at Glasgow University and attended lectures given by Professor Darren Monckton.

Dorset Get-Together

A small group of us based in the South of England get together from time to time at a local garden centre coffee shop just to meet up with other families affected by Myotonic Dystrophy and

exchange ideas. This time, there were ten of us and we were fortunate enough to be joined by Kathryn Docherty who is a Neuromuscular Care Advisor for Dorset Neuromuscular Service, based at Poole Hospital. Kathryn spent time talking to each of the attendees during the course of our meeting which everyone found very helpful. For next time, we plan to change location and Kathryn tells me one of our large supermarkets in Bournemouth offers a community room facility, with refreshments and accessible loos for no charge! Sounds perfect, doesn't it?

If anyone would like to join us at one of our meetings, you can find my number on the back of the Newsletter as the contact person for Dorset and Somerset. Hope to see you soon.

Ruth Harrison

Trustees Meeting

Support to the Research work

At our last Trustees meeting, it was agreed to continue our support to the work of Dr Jeremy Rhodes, donating the sum of £19000.

It was agreed to a request from our Patron, Professor David Brook for £21000. This was towards financial assistance for two students working in his laboratory.

The Postgraduate students; Anjani Kumari from India doing a three year PhD degree and Xiaomeng Xing (known as Belle) from China for a one year MRes degree. Both are working on the Myotonic Dystrophy project.

Rare Diseases Day

There will be a lunchtime get together (with fish and chips) in Nottingham on 6 March to recognise Rare Diseases Day. Professor David Brook and his team from Nottingham University will also be attending. Please contact the office 0115 987 5869 for more details.

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)

West Yorkshire
Pauline Ferrari
01977 799565
Jack Lawrence
01977 790886

Cardiff
Margaret Ware
02920 869277

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

DM2
Jaine Meridith-Kite
01732 841652

Croydon
Lesley Smith
020 8777 6587

Northampton
Michael Walker
07831 347143

Cumbria
Neil Braiden
01228 512385

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

Dorset and Somerset
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

