

NEW DATA PROTECTION LAWS

HELP US TO KEEP YOU ON THE MYOTONIC DYSTROPHY SUPPORT GROUP MAILING LIST

STAY IN TOUCH

New Data Protection Laws that will come into force on 25th May 2018, require us to have **your consent** to keep your personal details on our database.

We use this information in order to send you Myotonic Dystrophy Support Group Information Leaflets, Newsletter, Alert Card and to update you with Research developments and Management updates relating to Myotonic Dystrophy.

Your personal details include your name, address, telephone number, mobile phone number, e-mail address, age, genetic diagnosis if known.

With this Newsletter you will find a Myotonic Dystrophy Support Group Data Protection Consent Form, and a freepost envelope (no stamp required).

If you wish us to keep your details on our Myotonic Dystrophy Support Group Database, it is important that you complete and return this form as soon as you can, and by Friday 18th May 2018 at the latest.

If we do not hear from you, we will, with regret, have to remove all your details from the Myotonic Dystrophy Support Group database in order to comply with the Law.

You will no longer receive the Newsletter, or benefit from any of our publications, updates and news of developments and Conferences, Local Meetings etc. that could help you or family members.

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HELLO EVERYONE

Now Easter time is over, Spring is here and the lighter nights are with us, we see many lovely flowers coming out.

I remember having an Australian midwifery student with me who kept commenting on the beautiful show of daffodils that we have here in UK. This lady told us that in Australia the daffodils fade very quickly in the heat, and do not give lasting pleasure.

We look forward to meeting many of you at our conference, to be held in Thame, near Oxford. I do hope that by relocating this year's Conference further South, MORE FAMILIES from the London area and the South of England as well as other areas of the UK will feel able to attend this great meeting of families who are affected by Myotonic Dystrophy. Time to share with each other and to talk informally to the many medical professionals who give up their time to meet with us, is really encouraging.

The Front cover of this newsletter asks an important question. We need permission from you to keep your contact details, if you would like to receive the news including the research updates.

We sincerely value your membership, and hope that we can have your permission to stay in touch.

Let's trust we will meet soon!

From your friendly, **National Co-ordinator, Margaret Bowler**

Hello Everyone, and welcome to our Spring edition of the Newsletter. We have sent you Essential Information requiring you to act now.

The worker Bees in the office are well aware that the weeks are rapidly moving along towards our 2018 Conference Day and AGM. There are all the ongoing discussions between

Conference venue staff, invited speakers, programme preparation to be finalised, workshops to be allocated to rooms around the centre, preparation of all the forms and with dates and deadlines agreed. This all makes for an office with a buzz. A real hive of industry.

However, just for a short time the hive is missing the Queen Bee, Margaret Bowler.

In early April Margaret had some planned surgery to her foot. She is unable to drive and REST is on prescription. Bandaged foot, and open-toe surgical sandal will soon be a thing of the past we hope, but don't worry, even when resting Margaret can still keep *us* on our toes! I'm sure you will join me in wishing Margaret a speedy recovery.

Now I must mention a 'key' word, **'RESPOND'**.

Please, Please, Please, ***Respond immediately to the Data Protection Form. Without your response we will NOT be able to keep in touch with you.**

****Respond ASAP** to our invitation to the MDSG Conference.

*****Respond** if you feel that you have skills that you can offer as a Trustee. Contact the office to discuss.

****** Respond** by ensuring that you become a subscribing member of MDSG, and encourage other extended family to become members too. Membership subscription is currently just £15 per household.

DO PLEASE RESPOND QUICKLY. We do need to hear from you!

We are all looking forward to meeting up with many of you at our Conference.

Join us for a day packed with information-gathering opportunities. See you soon,

Elycia Ormandy, Editor

**29th Conference and Annual General Meeting
15 to 16 June 2018
Oxford Belfry Thame, near Oxford OX9 2JW**

Have you booked yet?



At the time of writing, we have 86 members booked, with 53 members attending on the Friday evening for the Annual General Meeting.

Friday

Our Patron, Professor David Brook will once again be the Chairman for the AGM on the Friday evening.

The meeting will start at 7.30pm, followed by a two course meal.

Saturday

Dr Mark Hamilton, from Glasgow, will be the Chairman for the Conference day. Dr Hamilton is a Neurologist, having worked with Prof Darren Monckton looking at how Myotonic Dystrophy affects the Brain.

The format of the day will follow the successful pattern of the last three years. We will have an introductory talk by Professor David Brook and Dr Eric Wang from Florida, on the latest research news. There will be three sessions of workshops, covering a wide range of topics including Benefits, Anaesthetics, Orthotics. The conference will end with a talk on Respiratory Management in Myotonic Dystrophy by Dr Mark Roberts.

Many of the Professionals attending this year's Conference have joined us on several previous occasions and you will recognise their names; Prof David Brook, Dr Ian Bowler, Dr Margaret Phillips, Prof Darren Monckton, Dr Mark Roberts, Dr Mark Rogers, Jane Freebody, Dr Chris Turner.

We already have families from across the UK who will be joining us for the Myotonic Dystrophy Conference.

Do come along and join us for what will be an informative and enjoyable weekend.

You have a Conference Booking form with this newsletter. This can also be returned along with the data consent form in the reply paid envelope.

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Christmas Concert

I would like to thank Katie Robertson who runs a local ladies choir called 'Sing', in Fleckney, Leicester who organised a Christmas charity concert at St Nicholas Church in aid of MDSG. The choir were accompanied by the Fleckney Silver Band. The concert raised £200 My son Ashley also performed as a guest performer and my sister Sally provided some incredible cakes for sale which are still being talked about. **Steve Lloyd**

Carol Singing

MDSG were the chosen charity by the South Willingham Christmas Choir for their village Carol Singing. South Willingham is in the Wolds, not far from Louth and Lincoln. Their poster advertised 'sublime singing brought to your door'. Well it must have been as they managed to raise £290 for the work of MDSG. **Steve Brown**

Running Rainbows

On a fresh Sunday morning in late September the moment we had all been waiting for arrived. A number of Rainbow Guides and their families and Leaders were all ready to run the Robin Hood Mini Marathon along the banks of the river Trent at the Trent Embankment in Nottingham.



Some had put in more training than others to run the one and a half mile course (some are well practised park runners) – or in the case of the Rainbow Leaders no training at all since running the same course last year! Maybe if we had then we would have possibly been able to say we had improved on our previous times, but sadly not.

Nevertheless the occasion was met with enthusiasm and good spirits showing what a brilliant group of girls and families we have. Everyone proudly wore their Myotonic Dystrophy Support Group T-shirts for the run, raised an amazing amount of sponsor money and had lots of fun.

Everyone was welcomed over the finish line with a medal, water and a treat to eat. Thank you to all our runners and supporters at 1st Carlton (St Paul's)



Rare Diseases Day- Nottingham

I was really looking forward to my fish and chip lunch with MDSG, so I was disappointed when it was cancelled because of the snow. Thankfully it was rescheduled for Monday 26 March.

I have been to this lunch for several years and its always enjoyable.

continued on next page

Its good to mix with other members, Professor David Brook and his team. He never fails on informing us all with his updates into research. This year we had another David; David Fletcher. He told us of his planned motorcycle ride around the world with his friend Gary Rice to raise money for DM.



Trustees
Euan
Cumming
attended
Rare
Diseases
Day in
Edinburgh
and Margaret
Bowler
attended in
London.

The lunch finished with us all having our photograph taken alongside the motorcycle. We were lucky to receive a free umbrella (*courtesy of Givingworldonline.com*) and another photo.

Already looking forward to next year's fish and chips and talking to Margaret Bowler, Prof David Brook and his team of researchers. **Anne Gamble**

Awareness

Anaesthetists Conference London

Margaret Bowler and Michael Walker manned an exhibition stand (*kindly provided free of charge by the AAGBI*) at this Conference in January. MDSG members appreciate how important it is that we help raise Awareness of the condition and of the Support Group, and in particular the special precautions needed when planning Sedation or General Anaesthetic.

Royal College of Paediatrics and Child Health Annual Conference Glasgow

This was the first time that MDSG have had an exhibition stand at this organisation's Conference.

It was also the first time that we had attended a three day conference. Ann Cobburn, contact person for Glasgow and Michael Walker manned the stand. They each had opportunities to chat to some of the 1500 delegates. A number of delegates had heard of the condition, but not come into contact with a child or young person with Myotonic Dystrophy. Many delegates had not heard of it and were grateful for the information brochures we were giving out.

We spoke to Dr Tracey Willis, a Paediatric Neuromuscular Consultant and one of the conference speakers. Dr Willis works at the Robert Jones and Agnes Hunt Hospital in Oswestry, where she sees families with Myotonic Dystrophy. Her predecessor was Dr Ros Quinlivan who wrote the Congenital Myotonic Dystrophy brochure for MDSG.

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Annual Report 2017 for UK Myotonic Dystrophy Patient Registry

Prepared by: Phillip Cammish, Hanns Lochmüller

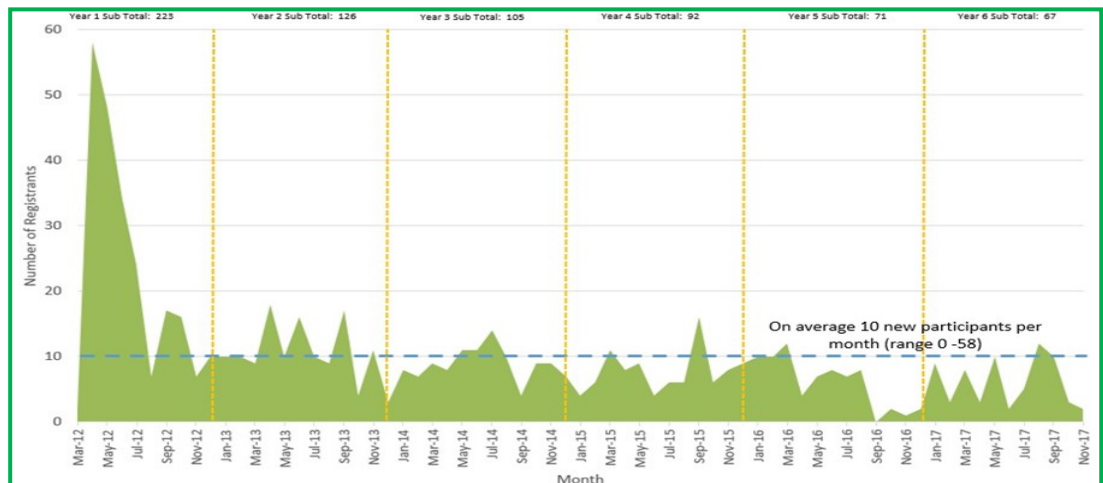
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Libby Wood left her role as UK DM Project Manager and Registry Curator to move to another role within Newcastle University. She was replaced in July 2017 by Phillip Cammish. Professor Hanns Lochmüller left at the end of the year. Dr Chris Turner has replaced him as Chair of the Steering Committee.

Summary of registrations:

Total number of people registered as of 16 November 2017: 684

Number of new registrations between 1 January 2017 and 16 November 2017: 67



Publications:

A research paper on the UK Myotonic Dystrophy Patient Registry was recently published in the Journal of Neurology (April, 2017). The paper is called, "The UK Myotonic Dystrophy Patient Registry: facilitating and accelerating clinical research" and was written by Libby Wood and Professor Hanns Lochmüller both from the John Walton Muscular Dystrophy Research Centre at Newcastle University, with help from experts, scientists and clinicians across the United Kingdom. 556 patients with a confirmed diagnosis of DM1 (who were all participants in the registry) were included in analysis.

Research:

The registry is now regularly used in research both nationally and internationally, with many different projects ongoing at present.

OPTIMISTIC is an international clinical trial that was funded by the EU, testing if Cognitive Behavioural Therapy (CBT) and increased activity has an impact on fatigue and quality of life.

PHENO-DM1 is an ongoing natural history study in adult DM1 patients that is funded by NIHR. This study uses patient reported outcomes to assess levels of pain, fatigue and quality of life.

AMO Pharma is sponsoring a phase II study testing Tideglusib in people with DM1 aged 16-45 with onset of symptoms before the age of 12.

PREFER is an EU-funded project that aims to establish how patients' preferences should be collected during drug development and how this information can support decision-making by industry, regulators and HTA bodies.

MDSG Trustee/Director

Have you ever considered becoming more involved with your Support Group?

We have vacancies on the Committee.

To become a Trustee, you must be a paid up member and need to have attended an Annual Conference.

We usually have four/five meetings a year, normally in or around Nottingham.
(your travelling expenses are reimbursed)

Requirements: you need to be a Team player with a desire to help and participate in all aspects of MDSG

Not sure?

Why not come as an observer to one of our Trustee meetings, to find out more about running a National Charity.

Contact the office if you are interested and if you have skills to offer MDSG.

Overleaf, you will see a list of contact people.

We need more!

Do you live in an area where there is no contact person.

Would you be interested in becoming one?

Contact the office for more details.

Primary Care, NEC Birmingham 16 and 17 May

This event covers a wide range of Primary Care topics and is attended by 7000 delegates.

The information leaflets are printed and ready to be handed to the Health Professionals as we talk with them about Myotonic Dystrophy.

2018 Conference Guest speaker Assistant Professor Eric Wang



Dr Eric Wang, Ph.D. works in the Centre for NeuroGenetics at the Department of Molecular Genetics and Microbiology at The University of Florida USA.

Dr Wang has always been interested in understanding how biological systems function.

He received his PhD from Harvard-MIT Division of Health Sciences and Technology. There, he trained in computational biology, as well as learned about diseases such as DM, Huntington's disease, and ALS.

Dr Eric Wang has published key work characterising the use of deep sequencing technologies to study RNA species across the entire transcriptome.

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.

Aberdeen
Jenny Watt
01224 580559

Cardiff
Margaret Ware
02920 869277

Croydon
Lesley Smith
020 8777 6587

Cumbria
Neil Braiden
01228 512385

Dorset and Somerset
Ruth Harrison
01425 626133

Essex

Glasgow
Ann Cobburn
01389 381246
Michael Kneafsey
01360 311440

Kingston-upon-Thames
Penni Cotton
(contact office)

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

Northampton
Michael Walker
07831 347143

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

Nottinghamshire
Margaret Bowler
0115 987 5869

Sheffield
Rachel Reeson
07544 353076

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

West Yorkshire
Pauline Ferrari
01977 799565
Jack Lawrence
01977 705496

DM2
Jaine Meridith-Kite
01732 841652



