MDSG stand at the Association of Anaesthetists Winter Conference held at Queen Elizabeth 11 Conference Centre, Parliament Square, London.
Hello Everyone

Welcome to the newsletter for 2020. Many thanks for the Christmas greetings we received at the office and also at home. Thank you on behalf of families with myotonic dystrophy for the many donations we receive. We do send a ‘thank you’ to people and I hope we do not miss anyone out.

Thank you to all our medical advisors. We do appreciate the time and knowledge they give to MDSG. The researchers are amazing people, Professor Darren Monckton, Glasgow University; Professor David Brook, Nottingham University and Dr Jeremy Rhodes at East of England University. They are all supported by a team of dedicated researchers. Thank you all!

Very soon it will be Rare Diseases Day 29 February. Many areas have meetings now, and we do ask their organisers to arrange a meeting either on or near that date, to discuss more about myotonic dystrophy. Myotonic Dystrophy is registered as a rare disease (not as rare as some conditions).

I am trying to arrange a gathering in Nottingham of rare condition groups, but nothing definite yet.

There is an international document that has been discussed called ‘Care Consensus in Myotonic Dystrophy’. Dr Mark Rogers of Cardiff genetics was very involved with its formation and later Dr Chris Turner of London Neurological Hospital has also been involved, inviting many other specialists in myotonic dystrophy to elaborate on subjects that they have a special interest in. The document will help us all.

More area meetings
It is encouraging to hear of more area meetings, especially along the south coast of England and also Ireland.

Thank you to Mike Walker and Ruth Harrison for organising these meetings. I was able to help in some areas.

For several years I have suggested that families with myotonic dystrophy have an outdoor activity holiday. The Calvert Trust in Devon and Northumberland are prepared to help with the cost. Two DM families (mine and the Vice Chair) enjoyed these holidays for nine years on the run. Whatever your disability you are helped one to one—enjoying boating, abseiling climbing, archery—and joy of meeting other families with a challenge, meals are great.

Margaret Bowler
National Co-ordinator

Letter from The Editor

Hello Everyone,

Welcome to this first issue of the newsletter for 2020.

Already the MDSG Awareness Programme is underway. (see front cover) For details read following accounts of what is planned for the next few weeks and beyond!

Recently I have been concerned by the number of telephone calls to the helpline that cannot be returned because the details are incomplete or inaccurate or because no message is left on the answerphone. If you have been wondering why you have not had a call returned by us, do please call again.

From time to time we have queries that you, our readers, may be able to help with. One family is trying to plan for ‘The Future’. Read our article where a family is looking for a house-share solution.

Continued over
Have you already put a plan in place? Do share your thoughts on this with us. It is a question that we should all be asking ourselves so that options can be explored together with family, and choices considered. The alternative is to wait until decisions have to be made in a crisis situation.

Another recent caller asked about the need for flight assessments prior to a long-haul flight, as recommended by a neuromuscular consultant. If you are planning a flight, do discuss any assessment needs well in advance of the date, so that staff at your nearest Lung Function Clinic can arrange tests to be completed and reports sent. Better safe than sorry!

Keep well, keep safe and keep reading. Best wishes, Elycia Ormandy

31st Conference and Annual General Meeting
19 and 20 June 2020
at Radisson Blu Hotel
Herald Way, Pegasus Business Park,
East Midlands Airport, DE74 2TZ, Derby
Telephone: 01509 670575

We are currently putting the programme together for the 31st Conference, which will be held at the same venue as last year, The Radisson Hotel, East Midlands Airport.

Please see booking form with this newsletter.

Dr Margaret Phillips will be our Chairperson for the day.
Jodie Allen Highly Specialist Speech and Language with one of her Dietician colleagues will talk on swallowing and diets.

There will be updates and workshops on the latest developments on research.
A number of our regular speakers will be presenting workshops. Professor Darren Monckton, Professor David Brook, Dr Chris Turner, Dr Mark Rogers, Dr Ian Bowler and others not yet confirmed.
We are exploring the possibility of having a workshop on DM2.
Sky Dive

Hello, my name is Kayleigh. I took part in a 15 thousand foot sky dive in order to raise money for Myotonic Dystrophy.

My mother and my grandmother have myotonic dystrophy as do my uncle and some of my cousins.

Robin Hood Marathon

Carlton St Pauls Rainbows again raised money for MDSG by joining in the Robin Hood mini-marathon in Nottingham on 29 September, well done girls.

Association of Anaesthetists Annual Conference

This was held at the Queen Elizabeth 2 Conference Centre, opposite Westminster Abbey for 3 days.

Mike Walker took all the displays and leaflets and set up on Tuesday night. The conference Wednesday/Thursday/Friday he was joined by Margaret Bowler, who stayed at the Premier Hub near the conference centre. Mike travelled by train each day. The anaesthetists are interested in our information.

The very interesting factor is that MDSG are given a display area free of charge, because the management know how important for the anaesthetists to know about myotonic dystrophy. Thank you to the Association of Anaesthetists. (other national medical conference charge is £1200 to £1500 for display space). On the first day we had spoken to 60 anaesthetists.

Bereavement

We are grateful to all those who remember MDSG for donations in memory at the loss of a loved one. A large proportion of our income is raised from this source.

Sarah Dingley sent in donations from the funeral of her daughter Verity Gray, who passed away on 3 September 2019. Thank you.

Personal Independence Payment (PIP)

Member, Laura Hayward from Milton Keynes works for the local Benefits Agency and is willing to help answer any questions regarding claims for PIP. Please direct your question to the office where it will be passed on to Laura. She will answer directly to yourselves.

Car Stickers

We have some new car stickers, priced £1. Contact the office if you would like to buy.
What is happening?

Meetings

Sussex
23rd November.
A date for memorable events...........
The assassination of JFK…
The first episode of Doctor Who…
…and our first attempt at organising a get-together of MDSG members for Sussex.

The venue was booked, the invitations went out and the catering organised. The day arrived rather damply and folks converged from all over Sussex on The Hastings Centre, in 1066 Country, for an afternoon of chatting, getting to know one another, and refreshments. You’ve got to have refreshments—especially if cake and mince pies are involved!

Photos courtesy of Rita Clarke

For a ‘rare’ condition, it was surprising how many folks are either affected themselves by Myotonic Dystrophy or by a family member having it. Hopefully by the end of an all too short gathering, it was realised that you are not alone! Michele Wilmshurst, Graeme Wilmshurst and Rita Clarke.

Get togethers were also held in
Northampton on 28 September,
Somerset/Wiltshire and
Croydon, South London on 12
October, Kent on 30 November,
Devon on 23 November and
South Birmingham on 7
December.

Margaret Bowler and Mike Walker both went to Dublin on 4 October and Belfast on 5 October. The Dublin meeting was held at the Muscular Dystrophy of Ireland office and people came from all over the Republic of Ireland.
Dr Ian Bowler joined us in Belfast and gave a talk on Anaesthetics.

Croydon
Saturday 12th October 2019

On a very wet and wintry day in October, around 30 of us met in our usual Croydon venue to be mesmerised by Professor Anton Emmanuel (Professor of NeuroGastroenterology at Queen Square/UCLH who works closely with Dr Chris Turner).
He shared his inestimable knowledge of the gastro problems he encounters at the NMCCC (Neuro Muscular Complex Care Clinic) and, in a quiet and professional way invited us into his world of ‘taboo’ language when discussing gut problems related to Myotonic Dystrophy.
The group was fascinated by his openness and down-to-earth approach to the subject and responded with a plethora of personal questions to which he replied in an equally personal way.

Our next meeting will be in Kingston on 4 April 2020.

Penni Cotton
Hi there,
My name is Robin and I am looking for someone to share accommodation with me, don’t worry I’m house trained!!

I live in a semi-detached bungalow in Leicestershire with three bedrooms, and all mod cons. After two years my current housemate is moving on to a flat, so there is a vacancy arising for YOU. The bungalow has been adapted for all abilities with level access throughout. It consists of a bathroom that is a wet room, with a fantastic closomat toilet that does everything apart from make you a cup tea. It has a second w.c. for when the bathroom is occupied; kitchen/diner and a large sitting room with a TV. Oh I forget to mention the vacant bedroom has a TV point too. There is small back garden that is manageable.

I live in supported living where carers come in to help with cooking, cleaning and so on. The carer on duty has their own bedroom for overnight support. They are a friendly group of people who I have got to know very well and I’m sure you could do too.

I am 38, have a great sense of humour, love music, support Leicester City (sorry), like board games and quizzes. I am also a great conversationalist I’m told I never stop talking!

If you, your parent or carer is interested I’d love to meet you with my mum and dad (who live next door) for an informal chat and look around the gaff.

Please telephone Margaret Bowler at the Myotonic Dystrophy Office, who will pass on your interest to me Thanks, Robin.

Margaret Bowler, Elycia and Lynne Ormandy represented Trustees and Members at the funeral of former Committee Member and friend of MDSG, Colin Mason. Until recently Colin lived in Kenilworth Warwickshire. Colin’s funeral was held at Inkpen, West Berkshire on January 17th.

Colin and his late wife Bridget were Committee Members, and Colin was very much the driving force in organising all the administration that was involved in drawing up the MDSG Constitution prior to applying for charity status. We all owe a great debt of gratitude to Colin for his dedication and sheer hard work that laid the foundations to place us on a firm footing for the future of MDSG. He never failed to express his appreciation for the way the Support Group grew to be recognised nationally and internationally.

We send love and prayers to Colin’s family and friends.

Colin had contributed much time and interest to the world of Snowdrops. He was a Galanthrophile, whose passion for this tiny flower gave him much pleasure every Spring. How appropriate that they were coming into flower at the time of his passing, and featured at his funeral. Any donations to: colin-mason.muchloved.com
Prizes will also be available. The first correct answer drawn out of the hat will win a High Street voucher. Five runners up will receive a prize.

The deadline is Rare Diseases Day 29 February 2020.

Please check the word search on the very important topic of research.

Here is a word search on the very important topic of research.

Thirty of the thirty-one words shown below 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 deadline is Rare Diseases Day 29 February 2020.

The first correct answer drawn out of the hat will win a High Street voucher. Five runners up prizes will also be available.

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### 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?

<table>
<thead>
<tr>
<th>Region</th>
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<tbody>
<tr>
<td>Aberdeen</td>
<td>Jenny Watt 01224 580559</td>
</tr>
<tr>
<td>Cardiff</td>
<td>Margaret Ware 02920 869277</td>
</tr>
<tr>
<td>Croydon</td>
<td>Lesley Smith 020 8777 6587</td>
</tr>
<tr>
<td>Cumbria</td>
<td>Neil Braiden 01228 512385</td>
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<tr>
<td>Devon</td>
<td>Josephine Holmes (contact office)</td>
</tr>
<tr>
<td>Dorset and Hampshire</td>
<td>Ruth Harrison 01425 626133</td>
</tr>
<tr>
<td>Glasgow</td>
<td>Ann Cobburn 01389 381246, Michael Kneafsey 01360 311440</td>
</tr>
<tr>
<td>Kent</td>
<td>Kirsty Blount and Amanda Scott 01622 764824/01622 764347</td>
</tr>
<tr>
<td>Kingston-upon-Thames</td>
<td>Penni Cotton (contact office)</td>
</tr>
<tr>
<td>Manchester, North West and North Wales</td>
<td>Elycia Ormandy 0161 445 5844</td>
</tr>
<tr>
<td>Northampton / Milton Keynes</td>
<td>Michael Walker 07831 347143</td>
</tr>
<tr>
<td>Northumberland, Tyne and Wear, Teesside</td>
<td>Peter Bodo 01740 620707</td>
</tr>
<tr>
<td>Nottinghamshire</td>
<td>Margaret Bowler 0115 987 5869</td>
</tr>
<tr>
<td>Sheffield</td>
<td>Rachel Reeson 07544 353076</td>
</tr>
</tbody>
</table>

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

**Sussex**
- Michele Wilmshurst 01424 421013
- Rita Clarke (contact office)

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