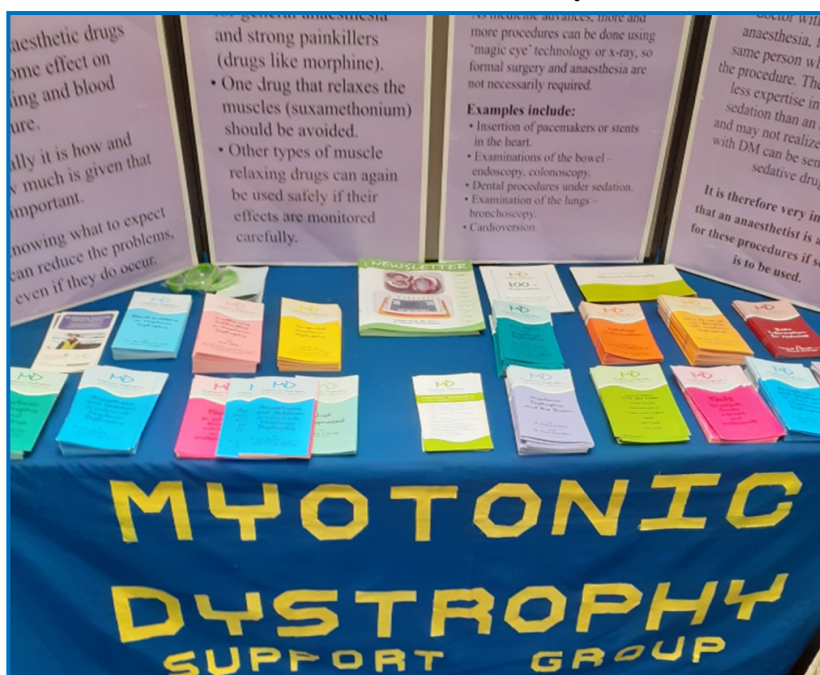




MDSG stand at the Association of Anaesthetists Winter Conference held at Queen Elizabeth 11 Conference Centre, Parliament Square, London



January 2020

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

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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

Continued from page 2

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.

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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 Wilmschurst,
Graeme Wilmschurst 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**

Moving on...An exciting opportunity for the next step in Life's journey

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.

Remembering Colin Mason

25 May 1927 - 30 December 2019

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 and the snowdrops

Colin had contributed much time and
interest to the world of Snowdrops. He
was a Galanthophile, 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

F	G	A	W	T	S	E	T	T	Q	I	T	V	C	Z	K	B	O
N	C	O	V	B	I	I	W	N	U	C	L	E	U	S	T	E	P
X	A	L	W	T	R	R	S	D	E	G	L	H	R	T	N	A	I
B	L	M	I	S	U	R	Z	Y	K	L	P	N	Y	U	A	J	P
U	J	R	P	N	N	E	V	A	L	U	A	T	E	F	R	G	E
E	N	E	Z	D	I	D	B	R	P	A	T	Y	L	O	G	K	T
P	W	P	Q	U	V	C	E	P	N	R	N	R	S	A	S	Y	T
O	S	E	P	J	E	X	A	A	D	D	O	A	F	L	J	R	E
C	G	A	N	E	R	Q	I	L	Z	T	Y	F	B	C	K	O	L
S	B	T	W	C	S	C	A	D	O	F	U	R	E	J	U	T	V
O	E	A	G	S	I	B	L	A	C	I	D	E	M	S	B	A	I
R	F	O	I	N	T	W	U	T	M	G	J	I	X	L	S	R	R
C	T	S	H	E	Y	U	S	A	Y	N	B	O	L	W	C	O	H
I	N	C	P	T	B	D	D	A	S	C	I	E	N	C	E	B	R
M	E	K	L	U	R	T	S	Z	V	J	R	S	W	U	T	A	B
T	M	H	E	B	O	A	R	N	Y	L	A	X	E	K	R	L	N
C	I	R	H	P	W	R	M	O	F	M	U	L	R	J	I	T	R
S	R	T	E	M	X	E	G	I	P	Y	B	H	O	D	A	A	N
A	E	T	B	S	D	N	I	L	W	E	U	B	T	O	L	Y	C
G	P	Y	M	D	E	T	E	C	O	H	R	R	C	L	S	E	D
H	X	U	N	D	W	A	V	K	J	R	Y	E	O	B	A	V	S
C	E	T	R	D	O	I	R	F	W	B	T	L	D	A	W	R	V
S	T	A	T	I	S	T	I	C	S	I	Z	N	K	I	T	U	D
M	N	I	P	U	B	L	I	S	H	F	T	G	O	S	U	S	L
A	S	T	L	U	S	E	R	W	G	U	M	D	A	C	R	P	O

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.

ANALYSIS	EVALUATE	MICROSCOPE	REPORT	STUDY	WHITE COAT
CELL	EXPERIMENT	NUCLEUS	RESEARCH	SURVEY	
CLINICAL	FRIED EGG	PIPETTE	RESULTS	TECHNICIAN	
CONTROL GROUP	GRANT	PROFESSOR	SAMPLE	TEST	
DATA	LABORATORY	PUBLISH	SCIENCE	TRIALS	
DOCTOR	MEDICAL	REPEAT	STATISTICS	UNIVERSITY	

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

Kent
Kirsty Blount and Amanda Scott
01622 764824/01622 764347

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

Cardiff
Margaret Ware
02920 869277

Kingston-upon-Thames
Penni Cotton
(contact office)

Sussex
Michele Wilmshurst
01424 421013
Rita Clarke
(contact office)

Croydon
Lesley Smith
020 8777 6587

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

West Yorkshire
Pauline Ferrari
01977 799565
Jack Lawrence
01977 790886

Cumbria
Neil Braiden
01228 512385

Northampton / Milton Keynes
Michael Walker
07831 347143

Devon
Josephine Holmes
(contact office)

**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

