

**May  
2019**

Letters...2

Conference...  
3 and 4

Meetings...5

Research...6

Fundraising...  
7

Contact  
List...8



*Invitation  
from Professor  
David Brook, Patron,  
Mrs Margaret Bowler  
and the Trustees of  
Myotonic Dystrophy  
Support Group to all  
Members, Family and  
Friends  
to the celebration of  
an **AMAZING**  
30 years of MDSG  
UK Conferences*

## **National Co-ordinator**

Margaret Bowler

## **Directors**

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

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(Patron)  
Dr I Bowler  
Prof P Harper  
Dr D Hilton-Jones  
Prof D Monckton  
Dr M Phillips  
Dr M Rogers  
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Julie and Mike

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## **Hello Everyone**

Welcome to the Support Group Newsletter, that will tell you we are celebrating 30 years of having an Annual Conference.

The Conference information is written in detail in this issue – Do come! If you need help to get to the Conference, please let us know in the office, contact details are on the back of this newsletter.

Throughout the 32 years of MDSG I have met many people who have struggled in their day to day life because of Myotonic Dystrophy, and we have struggled on together! In all these years many people have given their time to be a Contact Person or a Committee member – that comment makes me remember the Conference days when the Committee members came out to the front at the Conference and sang a silly song, composed by Elycia Ormandy. I remember Ken Ford – absolutely hated it!

Today we have 6 Committee members and we would welcome a few more people who would be willing to be a Committee member. If you are interested please talk to one of us at the Conference – one condition is that you have attended an MDSG Conference.

The encouragement I can give you is that Professor Monckton and Professor Brook are busy every day, trying to find treatment for people with Myotonic Dystrophy.

See you at the Conference.  
Bye Margaret

**Margaret Bowler**  
**National Co-ordinator**

## **Letter from The Editor**

Hello Everyone,  
A warm invitation is to be found on almost every page of this Newsletter!

We are busy preparing our Thirtieth, yes 30<sup>th</sup>, Annual Conference for YOU.....

We are looking forward to meeting many of our regulars at the Conference Venue, and we are hoping that we will be able to meet and greet some new faces too.

The Conference details are all here, so please seriously consider attending. We have something for everyone and delegates and Professionals mingle and have opportunities during the day to offer Presentations, Workshops and Talking time. We are the only condition specific Annual Conference for people affected by Myotonic Dystrophy, their families and friends.

In this issue we are pleased to have some news about the research currently being done by the Nottingham team of Researchers, led by our Patron Prof David Brook.

There will be opportunities to have the latest updates on Research at the Conference.

Just worth a mention, I recently spent an overnight with my daughter Lynne at the Radisson Blu Hotel. The accessible room was fine for our needs, and once inside the building we were totally unaware of any aircraft noise. Fantastic soundproofing!!  
Best Wishes

**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



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## Conference Day

*At time of print and may be subject to change*  
These are some of the workshops you will be able to choose. We are working to make more available.

Paediatrics...**Dr Chow**  
Diabetes...**Dr Saam Sedehizadeh**  
Anaesthetics...**Dr Ian Bowler**  
Research...**Professor David Brook,**  
**Professor Darren Monckton,**  
**Dr Mark Hamilton**  
Living with myotonic dystrophy...  
**Dr Gillespie**  
Cataracts...**Dr Stead, Dr Jeremy Rhodes**

## Young Peoples Group

**It is essential that places are pre-booked.**

This will be running alongside the main programme (ongoing presentations/workshops etc 2 sessions).

1) Before Lunch 2) After Lunch  
We meet in a room opposite the main auditorium. Parents/carers are

welcome to come and meet Elycia Ormandy and the team of helpers for the day. \*

We have an 'open door' which will be closed simply to 'contain' any noisy activities.

\*NB. Please collect Y.P. for lunchtime (and other breaks if you wish). Any queries please ask Elycia either on 0161 445 5844 or 0808 169 1960.

## Annual General Meeting

A short legal side of the MDSG.

Three of the Trustees have completed their three year term and all are willing to continue. They are Margaret Bowler, Peter Ferrari and Michael Walker. In accordance with our M & A's (Constitution) and Charity Law, each person requires over 50% of those attending and eligible to vote.

The AGM is also **your** opportunity to ask the Trustees about any aspect of the workings and running of MDSG. What do we get up to in the office and at our Trustees Meetings?

2019

## Provisional Conference Programme

(these details are correct at time of going to press, but may be subject to change)

### Friday 21 June Evening 7.30pm

Annual General Meeting chaired by  
**Professor David Brook—MDSG Patron**

Followed by evening meal  
(Registration will be open for those attending the AGM)

### Saturday 22 June Morning

8.30am...Registration and refreshments on arrival

9.30am...Welcome by Margaret Bowler, Chair of the Board of Trustees  
Chair for the Day...Dr Helen Gregory from Aberdeen

9.40am...30th celebration  
Cutting the Cake—blowing out the candles  
After the cake, the young people will leave for their activities

9.50am...Research update: Professor David Brook

10.15am...Gastroenterology: Dr Anton Emmanuel

10.45am...Refreshments (during which the auditorium will be partitioned for workshops)

11.15am...Workshops Session One

12.30pm...Lunch

### Saturday 22 June Afternoon

2.00pm...Workshops Session Two

2.45pm...Workshops Session Three

3.30pm...Refreshments (during which the partitions in auditorium will be removed)

4.00pm...Care Plan...Dr Chris Turner

4.30pm...P.I.P...Elycia Ormandy

4.45pm...Closing Talk:...Dr Helen Gregory

5.15pm...Thank you's

5.30pm...Celebrations and refreshments

7.00pm...Finish

## What is happening?

### Meetings

Since our last Newsletter, we have had get togethers in Sussex, Hampshire/Dorset and Kent.

Kirsty and Amanda had their first get together in Kent at end of April (see below) following on from the inaugural meeting last December.

Rita Clarke and Michele Wilmshurst have offered to be Contact People for the Sussex Area.

### Awareness

Margaret Bowler and Michael Walker are attending the Association of British Neurologists Conference in Edinburgh in May. Whilst there, we are arranging a get together for those in the Edinburgh area.

Margaret and Michael are also attending and having an Information stand at the Royal College of Paediatrics and Child Health Conference at ICC in Birmingham and the Primary Care Conference at the NEC Birmingham, all in the same week.

### Kent

We had our first meeting Saturday 27 April for Kent. We had about 19 people including us. It was a lovely meeting, people were mixing, eating, swapping details and asking when the next one is, so I think it was a great success.

We are going to see some in June at the MDSG conference and hopefully meet up with many others and the Trustees. **Kirsty and Amanda**

### Dorset/Hampshire

On Saturday 13<sup>th</sup> April, we had a get-together for those living in Dorset and Hampshire. It was held at a location just off the main highway from

Ringwood, so it was easily accessible, by car, for people from both counties.

Trustees Mike Walker and Ruth Harrison were there to welcome attendees and we were very pleased to welcome 26, including some who had not been to any group meetings before and others who had never met anyone else with the condition.

Once everyone was settled in, Mike explained his family link with Myotonic Dystrophy and expressed the hope that this would be the start of many similar gatherings in future.

Refreshments were available for all and there was a relaxed atmosphere to the occasion, with a good mix of those directly affected by the condition themselves and their family members. We would like to think this event was the start of some good friendships for those attending who, despite being mostly strangers to each other, have so much in common already.

Ruth will be setting up another get together at the same venue in July and invitations will be sent in advance. We look forward to seeing many of you there again then. **Ruth Harrison**

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*Happy Family Wedding  
Tanya Randhawa*



Hello,  
I am Anjani Kumari, a first year PhD (Genetics) student working under the supervision of Professor David Brook. Before starting my PhD at the University of Nottingham I completed my Bachelor's and Master's degrees in Biotechnology in India.

My research interest lies in understanding the role of CDK12 (an important protein which regulates different functions in the cells of our body) as a drug target in Myotonic Dystrophy. It has been established that some drug-like molecules acting on CDK12 alleviate the negative effects in Myotonic Dystrophy. We aim to develop a test to help us analyse the activity of CDK12 when targeted with different drug-like molecules. We

hope this will allow us to identify new targets for myotonic dystrophy therapy to provide a treatment for this condition.

I am highly grateful to David for giving me this opportunity and to the Myotonic Dystrophy Support Group for providing me with financial support during my study.

Hello, My name is Xiaomeng Xing (aka Belle). I am an MRes student in the Brook Lab. I am currently working on the knock-down (down-regulation) of MBNL1 and MBNL2 in DM1 patient cells. MBNL proteins regulate the processing of genes and have been directly implicated in the causation of DM1. Because they bind to CUG repeats and are sequestered by CUG-repeat RNA foci, which appear as spots in DM patient cells. This affects many genes related to DM and contributes to the cause of DM. We have demonstrated that the depletion of MBNL1&2 results in a dramatic decrease in the number of spots in patient cells, supporting a role for MBNL-mediated rescue of DM1 pathology.



I am sincerely grateful to David and to the Myotonic Dystrophy Support Group for helping me with my funding. This definitely helps reduce my financial burden and provides assistance for me as I continue pursuing my education.

### **IDMC 12**

I am sure all our readers will be interested to know the International Myotonic Dystrophy Consortium (IDMC12) will be held in Sweden in June this year. Approx.250 Researchers from many countries, meet together to share their findings in research. Our own Researchers will be there. MDSG have helped to fund some of the students to attend.

MDSG will be represented and will have a display of all MDSG literature. In the next newsletter there will be a report of IDMC. At our own Annual conference, which follows a few days later, we will be able to hear a little more about IDMC 12.

## MDSG Collecting Boxes

Important Information required please  
ASAP

We are currently reviewing our 'collecting box policy' and would like your help please.

**Do you have a MDSG collecting box?**

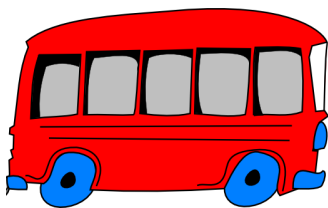
**Have you been responsible for placing a collecting box in a local shop/pub etc?**

**When did you last empty the box?**

If you can answer any or all of the above questions, please contact the office as soon as possible, so that our poor treasurer (aka Mike Walker) and Trustees can audit the information. Once done the Trustees can create a policy for future handling of the boxes. Please let us know, even if 'your' box has been dormant for some time or 'lost' in the mists of time. Thank you for your cooperation.

## Buses

You know the saying, you wait for ages for a bus and then three come along at once. Well we are hoping 20 come along!!



During the last two weeks of July and the first two weeks of August, buses on five bus routes in the Birmingham area,

will carry posters advertising the Myotonic Dystrophy Support Group. These will appear on the rear of the buses. Three of the bus routes go past Edgbaston Cricket Ground. For cricket enthusiasts, the first week of August, is the start of the Ashes series when England will be playing Australia, yes you guessed it, at Edgbaston.

## Online Donations

Recently we have had donations given to MDSG via online banking.

I would ask that if you do use this method, could you please send an email to the office to let us know who has sent the money, so we can send you an acknowledgement.

The money is transferred but we do not always know who has sent it.

The same applies with fundraising sites, Virgin Giving and Just Giving, several donations are added together and MDSG do not know who has made the donations.

We are grateful for all donations and we do wish to acknowledge and say thank you.

## Professor Darren Monckton

Professor Darren Monckton of University of Glasgow receiving a cheque for £2404 from Gemma McIntosh (a Miss Scotland Finalist). Gemma raised funds on behalf of little Mia seen here with her mum Lisa Purvis. Mia has congenital myotonic dystrophy and is cousin to Gemma.



Another member of the family, Stuart Hay, Uncle to Mia, is fundraising through the Rust to Rome event. This is a Banger Rally, covering 4000 miles and hope your 'banger' makes it. His firm are going to match whatever he raises. All the best to Stuart.

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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?

**Aberdeen**  
Jenny Watt  
01224 580559

**Cardiff**  
Margaret Ware  
02920 869277

**Croydon**  
Lesley Smith  
020 8777 6587

**Cumbria**  
Neil Braiden  
01228 512385

**Dorset and Hampshire**  
Ruth Harrison  
01425 626133

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

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

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

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

**Northampton / Milton Keynes**  
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

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

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

**DM2**  
Jaine Meridith-Kite  
01732 841652

