



**Jubilee  
Conference  
Centre,  
Nottingham;  
venue for this  
years  
Conference.**

**May  
2017**

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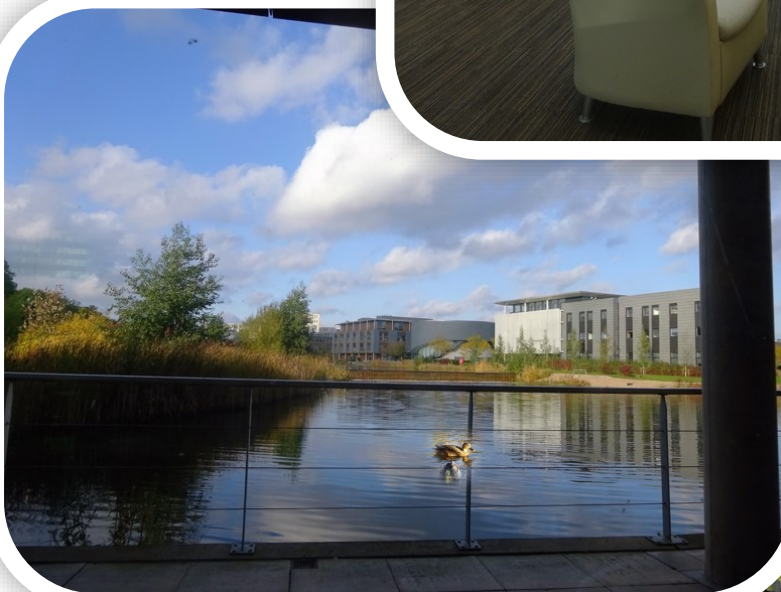
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Margaret Bowler

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## Letter from National Co-ordinator Margaret Bowler

Hello Everyone

This newsletter is being sent as an extra one to families that are on our mailing list, and not just to members as in previous years, (members are people who have paid their annual subscription to MDSG). The sun is shining in Nottingham, but it is cold.

It has been good to hear of the area meetings that have taken place. We are still trying to have a Contact person in each County, but haven't managed it yet! You will find the list of Contact people on the back of the newsletter.

We are looking forward to meeting many people at our Annual Conference in Nottingham on June 23<sup>rd</sup> – 24<sup>th</sup>. Details are printed in this newsletter. We have more information about Research and several different topics for Workshops are planned. If you are at the AGM on June 23<sup>rd</sup> we will have a meal and encourage people to sit with the people in "their area" to get to know who lives near to them.

The Jubilee Conference Centre has Bed and Breakfast accommodation in the same building, above the Conference Suite. There is plenty of car parking and the venue is fully accessible. If you haven't been to a conference, pluck up courage, many people attend each year.

See you there! **Margaret Bowler**

## Letter from Editor Elycia Ormandy

Hello Everyone,

This Newsletter brings lots of Conference information for you to read. We do hope that you will feel able to consider joining us this year, or at least follow what is on offer on our exciting Conference programme of Speakers for

all the delegates to hear, and Workshops for smaller groups. The workshops enable delegates to make the choice of topics that are of greatest interest to them. Some delegates like to stay together as a family for these sessions, others decide to attend different sessions then share whatever they have found helpful afterwards. Either way we do ask that once you have returned your choice to the office you do actually keep to it. The day is structured and to assist the staff at the venue we carefully plan room allocation and seating.

Likewise with the seating for the meals. We try to follow your requests, but sometimes the limitations of the restaurant and tables limits our options too. We really do want you to enjoy the time together, and we do our best to ensure this. If you are only able to be with us for either morning or afternoon please advise us, and tell us if you *do not* require a meal.

I was very pleased to be invited to attend the MDUK Neuromuscular Meeting in April for families with Muscular Dystrophy, arranged by Sam Power in Llandudno. Sam is the Neuromuscular Care Advisor for North Wales. She has regular contact with families who have Myotonic Dystrophy across this geographically challenging area. The chance to meet up with other families as well as enjoying hearing updates on Research, Assessments, Neuromuscular Centre at Winsford, Benefit changes, Technology and Adaptations, and other related topics from speakers made for a good day together. There was also a range of wheelchairs on display with expert advice available, and the chance to try them out.

It is important for families to have these opportunities to share time together, and to meet some of the leading research and clinical experts other than in a clinical setting.

I look forward to meeting you again soon, Best wishes. **Elycia.**

## Trustees

Would you like to be more involved with MDSG? Why not come along as an observer to a Trustees meeting and see what is involved. Ring the office or speak to one of the Trustees at the Conference for more information.

### **28th Conference and Annual General Meeting 23 and 24 June 2017**

We are keeping the same format as last year, as from the returned evaluation forms, the majority of those that attended, appreciated the three sessions of workshops. This gave a wider scope of topics for people to attend and glean useful information. Many of the speakers will be familiar faces, who give their time and expertise to MDSG and the Conference.

In recent years we have had a speaker from overseas and this year we are pleased to announce a researcher from France, Dr Mario Gomes-Pereira has accepted an invitation to come and speak at the Conference and take part in a workshop.

Dr Faraz Mughal, a GP from Solihull, West Midlands, who wrote a case study dealing with a case of myotonic dystrophy which was recently published in the British Medical Journal. We are delighted he has accepted our invitation to the Annual Conference.

**Lisa Smith and Becky Smith, Play Specialists at City Hospital Campus, Nottingham Hospital Trust, have offered their services to run a crèche, (ages 0 to 10).**

**Places must be pre-booked.  
We cannot take bookings on the day. To book contact the office on 0115 987 5869**

## Forms

**Membership forms** are now distributed annually from the date you first became a member. If you have received one with this newsletter, that means your annual membership subscription is now due. Please re-join as your membership is important. The membership fee is the same as last year, that is £15 per family address.

### **Conference Booking form**

Time is short, now is the time to fill the Conference Booking form. Please send in by **Tuesday 6 June**. Thank you, look forward to meeting you once again.

### **Menu**

Please fill in and return by **Tuesday 6 June**. Ring the office if you have any questions regarding the menu.

### **Workshops**

Choose your three workshops, fill in the form and return by **Tuesday 6 June**.

**It is important that you return all the forms by this date. This enables us to plan the day with staff at the Conference Centre.**

If you have never been to a Conference because of travel costs etc, please ring the office, telephone 0115 987 5869.

Other things of interest:

On the day there will be a Bring and Buy; a name the Teddy; items for sale, sweatshirts, T shirts, pens; lots of information brochures on all aspects of Myotonic Dystrophy; and information on Clos-o-Mat toilets and Motability.

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## 28th Conference and Annual General Meeting

Friday Evening 23 June  
START 7.30PM

### ANNUAL GENERAL MEETING

This formal part of the weekend is very important. As MDSG is a Charity and a Company, we are obliged by law, to hold an AGM. It is the only time during the weekend, where you can hear about and ask questions regarding your Support Group. The aims and objectives, what plans for the future, what happens to your generous donations towards the running of MDSG and Research. So, do come along to find out how your Support Group is managed.

Once again, we are offering Bed and Breakfast at a reduced rate; *(please note, you need to pay the Hotel in full, give the receipt to Michael Walker or send it into the office and we will reimburse you).*

A meal will be provided, after the AGM giving time to mingle in a social atmosphere. **Please fill in the menu forms with this newsletter and return to the office**

Registration will be open for those attending Friday Evening. This is a good time to mix, socialise and relax before a busy Saturday.

One important item on the AGM Agenda is voting to elect nominees to join the Board of Directors. This year **Mrs Elycia Ormandy** is standing for re-election and two co-opted members; **Mrs Ruth Harrison** and **Mr Euan Cumming**

are standing for election.

All nominees must receive more than 50% votes of those attending the AGM and are eligible to vote.

**Please note, only paid-up members over 18 may vote at the AGM**

### Saturday 24 June

See overleaf for programme and list of workshops. **Please fill in the workshop form with this newsletter and return to the office.**

### YOUNG ADULTS PROGRAMME

for ages 11 years upwards. Alongside the Sessions for delegates we also offer an Alternative Programme for young delegates who would benefit from an informal time with other young adults. Over the years this has proved to be a valuable social time as well as offering a variety of accessible activities for all. We have a small team of adults who, as carers, have a sound understanding of young people who have myotonic dystrophy. They will be there to give reassurance and guidance as we have a positive, relaxing and fun time together. It is a 'come as you are' day!

N.B. Young adults will spend the lunch break with accompanying families and carers.

**Places must be pre-booked, to book contact the office on 0115 987 5869**

Any queries or not sure if this is for you? Please contact Elycia Ormandy on 0161 445 5844.

## Conference Day-Saturday 24 June

(Programme and timings subject to change)

8.30am...Registration

9.30am...Welcome  
Chairman...Dr Ian Bowler

9.45am...Research by Prof David Brook,  
Dr Mario Gomes-Pereira

10.45am...Viewpoint of a GP, Dr Faraz Mughal

11.00am...Refreshments

11.30am...Workshops Session One

12.45pm...Lunch  
Please fill in the Lunch menu with this newsletter  
and return to the office by 6 June.

2.00pm...Workshops Session Two

3.00pm...Workshops Session Three

4.10pm...Neurology Dr David Hilton-Jones

4.45pm...Thank you's and Goodbyes

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## Workshop One 11.30am

*(all workshops are subject to change)*

Gastrointestinal...Dr Mark Roberts

Daytime Sleepiness...Dr Margaret Phillips

Congenital...Dr Gabrielle Chow

Anaesthetics...Dr Ian Bowler

Overnight Breathing...Jonny Smith, Clinical Lead Physiotherapist,  
Neuromuscular Centre, Winsford

## Workshop Two 2pm

Research 1...Professor David Brook

Research 2...Professor Darren Monckton and Dr Mario Pereira

Heart...Dr Konstantinos Savvatis (National Hospital for Neurology)

Practical Anaesthetics...Dr Ian Bowler

Overnight Breathing...Jonny Smith

Benefits...Charlotte Throssel (Disability Direct)

## Workshop Three 3pm

Research 1...Professor David Brook

Research 2...Professor Darren Monckton and Dr Mario Pereira

Heart...Dr Konstantinos Savvatis

Questions and Answers...Dr Chris Turner and Dr David Hilton-Jones

Benefits...Charlotte Throssel

Daytime Sleepiness...Dr Margaret Phillips



**Nathan Walker**  
**26<sup>th</sup> February 1993 - 10<sup>th</sup> February 2017**

It is with great sadness that we have to tell you that Sharon and Michael Walker's beloved son, Nathan, passed away in February following a short illness in hospital. Nathan was the twin brother of Connor and they would have shared their 24<sup>th</sup> birthday together later that month.

Many of you will remember Nathan helping at MDSG Conferences (last year in the orthotics workshop). He was always a willing member of the team and would lend a hand whenever he could. Not only did Nathan help out with photocopying and collating the paperwork for the conferences, but he took an active interest in the preparation of the Newsletter alongside his Dad, Michael.

Family and friends filled the Baptist Church in Olney for the Thanksgiving Service on March 6<sup>th</sup>. The upbeat music and hymns were chosen by the family as particular favourites of Nathan. The tribute by Michael included references to Nathan's take on life and his sense of humour and courage that shone through, even when he faced daily challenges. Connor had prepared a beautiful photo tribute which captured Nathan so well, living life to the full within a loving and caring family.

We will miss Nathan for all that he gave to MDSG, and are thankful to have known him.

We join together in sending our heartfelt love, sympathy and prayers to Sharon, Michael and Connor.

**Flowers**

St Saviours Nurseries in Guernsey, Channel Islands have regularly sent donations to mdsg for many years and have provided complementary bouquet of flowers at our conference. Have a look at their website [www.stsavioursnurseries.com](http://www.stsavioursnurseries.com) for the beautiful displays and gifts and nominate MDSG as your chosen charity with your order, for us to receive a donation from them. Telephone 01481 265521

**Run, jog, walk along the River Trent in Nottingham**

If you would like to join a small group of MDSG Supporters for a gentle run/walk over 1.5 miles in the Robin Hood Mini Marathon on Sunday 24<sup>th</sup> September 2017, please register under the Mini Marathon section on the website: [https://www.sweatshopevents.co.uk/irhm17/entry\\_mini17.asp](https://www.sweatshopevents.co.uk/irhm17/entry_mini17.asp)

For further information please e-mail Dr Helen Brownlee ([h.brownlee@uea.ac.uk](mailto:h.brownlee@uea.ac.uk)).



**Rotterdam**

I attended the final meeting of the 'Optimistic' Committee, held in Rotterdam, Holland. Support groups were invited from UK, Holland, Germany and France. For some time, participants from four countries have been taking part in a Cognitive Behaviour Therapy, to see if it could help people with Myotonic Dystrophy have a better quality of life. The scientists and clinicians gave

talks on various aspects of the Therapy and their conclusions. The Support Groups were asked their opinion on the monitoring and implementation of the scheme. It was obvious from the talks that the Optimistic Team were excited by their results, which will be published later in the year. A big thank you to all those professional who are seeking to help those who have Myotonic Dystrophy, their families and carers. Michael Walker

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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.

**Aberdeen**  
**Jenny Watt**  
(contact office)

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

**Sheffield**  
Rachel Reeson  
0114 230 6177

**Cardiff**  
Margaret Ware  
02920 869277

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

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

**Croydon**  
Lesley Smith  
020 8777 6587

**Northampton**  
Michael Walker  
07831 347143

**Wakefield**  
Pauline Ferrari  
01924 377986

**Cumbria**  
Neil Braiden  
01228 512385

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

**Dorset and Somerset**  
Ruth Harrison  
01425 626133

**North Yorkshire, Knaresborough**  
Roberta Elliott  
01423 868455

Jaine Meridith-Kite who has DM2 is willing to be a contact person for people who have a DM2 diagnosis. Her contact details are 01732 841652

**Essex**  
Gwen Mumby  
01245 601343

**Nottinghamshire**  
Margaret Bowler  
0115 987 5869

**Glasgow**  
Ann Cobburn  
(contact office)

**Pontefract**  
Jack Lawrence  
01977 705496