

The 27th Annual Conference is almost here

Are you coming?

FRIDAY AND SATURDAY 23/24 JUNE 2016

EAST MIDLANDS CONFERENCE CENTRE  
UNIVERSITY PARK, NOTTINGHAM NG7 2RJ



Fun, socialise, learn, listen to the latest research and medical information here in Britain and across the World.

A choice of ten different workshops offering advice and help in all aspects of Myotonic Dystrophy

Come and JOIN US

**May 2016**

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Margaret A Bowler

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## Letter from Margaret Bowler National Co-ordinator MDSG

Dear Members and Friends of MDSG. It is good to say 'Hello' through this newsletter. I have been able to speak to many people through the telephone helpline and the office phone.

To meet people at the conference, and put faces to names is a real joy.

The area meetings are continuing. I joined a meeting in the Sheffield area a few weeks ago and sat near a young man who I hadn't seen for many years. Alan was a young man who presented our Patron with a cheque, but Alan was only an 11yrs old then, now he is 20 years older!!

Thanks to his mum for taking me to the railway station.

We are arranging a Contact Persons meeting, probably in July. Look at the list of Contact people on the back of the newsletter. Is there one in your area? Would you like to be one? You need to be a paid-up member. Let me know if you would be interested in coming to the meeting. It will be in the Midlands. All expenses will be paid.

There are several people who I know are interested in joining this merry band.

One more thing before I go; the Robin Hood one and a half mile walk. SEPT 25th IN NOTTINGHAM. It is time to register. It does cost £7.50 to register and then we can send you sponsor forms or you can make a Virgin Giving page. Contact Helen Brownlee, via the office. Hope to see you at the Conference in June. It's an event not to be missed!!

All good wishes to all who read this Newsletter. Margaret Bowler

## Letter from Elycia Ormandy Editor and Vice-Chair

Hello Everyone,  
It is time for the MDSG office to shift into Conference Mode. So far we have had an encouraging response, and many of you booked very early. That's great! The venue really does offer us an excellent base for the weekend, and we are subsidising each delegate place so that

the charge to you as members is just £5. We may not be able to offer you this fantastic delegate rate again.

There is an exciting programme, and once again we have invited experts in the field of Myotonic Dystrophy to share the day with us. It is a special event designed for you to increase your personal understanding, learn from the Professionals and to spend time with other families. We aim to make the Conference Day an accessible, worthwhile and informative time for everyone. We look forward to meeting the delegates who come regularly each year, but it adds so much to the day to also welcome first timers.

Erich Maurer from Switzerland has booked his flight to join us at our Conference. Inspired by Margaret Bowler and others he met at the IDMC 10 meeting in Paris last June, Erich is at the beginning of the journey to establish a Support Group for patients in Switzerland. It will be good to meet up with him again and exchange ideas. (He speaks excellent English, so do please make him welcome.)

We have selected a menu to ensure that we will have a substantial meal after the AGM on Friday and for Saturday lunchtime. Many of you tell us that mealtimes provide welcome opportunities to share time getting to know one another. If for medical reasons you are unable to share these mealtimes, please do let us know in advance.

Wondering whether or not to join us on June 24<sup>th</sup> and 25<sup>th</sup>? Why not have a word with one of us on the **Helpline, 0115 987 0080**. We would be delighted to answer any queries you may have.

**Advance notice for all delegates travelling to the Conference Centre / Orchard Hotel:** Nottingham University has advised us that there will be extra traffic travelling to the Campus. Please allow extra time for your travel both to and from the area during the weekend.

Pens at the ready?

Please fill all the forms and let us have them back by TUESDAY 7 JUNE. We would love to have your booking forms in the next few days, and hope to see you soon.

Best wishes, Elycia.

# 27th Conference and Annual General Meeting

## Friday Evening 24 June

### ANNUAL GENERAL MEETING

We realise its a more formal aspect of the weekend, but 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 of the weekend, where you can hear and ask about what is happening with your Support Group — our aims and objectives, what plans for our future, what happens to your generous donations to the running of MDSG and to Research. So, please come along.

Once again, we are offering Bed and Breakfast at reduced rate; *(please note, you need to pay the Hotel in full, give or send us the receipt 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 for the nominations to join the Board of Directors. This year there are four standing for re-election; **Mrs Margaret Bowler; Dr Helen Brownlee; Mr Luke Appleby; and Mr Michael Walker**

We also have one new nomination from **Mr Peter Ferrari**. Peter is a retired Bank Manager (the old-fashioned sort). He has been two Board meetings as an observer and feels he can make a useful contribution to the running of MDSG. With his wife Pauline, they have been having regular contact meetings in the Wakefield area. The Board considered his application and recommends he be accepted. All candidates must receive more than 50% votes of those attending and eligible to vote. *Please note only paid-up members over 18 may vote.*

## Saturday 25 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. **Please fill in young adults programme form with this newsletter and return to the office.** Any queries or not sure if this is for you? Please contact Elycia Ormandy on 0161 445 5844.

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## Conference Day-Saturday 25 June

(Subject to change)

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8.30am...Registration

9.45am...Welcome  
Chairman...Professor Hanns Lochmüller

10am...Research by Prof David Brook, Dr Tetsuo  
Ashizawa and Professor Hanns Lochmüller

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 7 June.

2.00pm...Workshops Session Two

3.00pm...Workshops Session Three

4.00pm...Support Group in Switzerland by Mr Erich  
Maurer

4.10pm...Anaesthetics by Dr Ian Bowler

4.45pm...Goodbyes

## Workshop One 11.30am

*(all workshops are subject to change)*

Benefits...Mrs Rebecca Brown-MDUK, Wales

Overnight Breathing and Fatigue...Dr Paul Maddison

Congenital...Dr Gabrielle Chow

Research 1...Professor David Brook and Dr Saam Sedehizadeh

Research 2...Professor Darren Monckton and Dr Tetsuo Ashizawa

Genetics...Dr Mark Rogers

## Workshop Two 2pm

Maintaining Mobility-Orthotics, Aids and Keeping Active  
Mrs Jane Freebody-John Radcliffe Hospital

Benefits...Mrs Rebecca Brown-MDUK, Wales

Questions and Answers...Dr Margaret Phillips

Genetics...Dr Mark Rogers

Heart and Pacemaker...Dr Chris Turner

Speech and Language Therapy...Jodi Allen

## Workshop Three 3pm

Research 1...Professor David Brook and Dr Saam Sedehizadeh

Research 2...Professor Darren Monckton and Dr Tetsuo Ashizawa

Maintaining Mobility-Orthotics, Aids and Keeping Active  
Mrs Jane Freebody-John Radcliffe Hospital

Questions and Answers...Dr Margaret Phillips

Heart and Pacemakers...Dr Chris Turner

Speech and Language...Jodi Allen

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## RAF Cranwell

It was a really pleasant surprise to receive an invitation from Matt Akers to visit RAF Cranwell in Lincolnshire and to be handed a cheque for almost £4000!

Jan, a friend and I went to Cranwell one bright morning. We were made very welcome. I hadn't realised how big RAF Cranwell was. Matt greeted us and introduced us to a gentleman who gave us a tour of RAF Cranwell. A venue that is full of history. Following the tour we were invited to join the fundraising committee to have lunch. Then to our surprise we walked into a room to receive the cheque and found 40-50 members waiting to greet us.

A week later another donation for more than £300 was sent to MDSG from a collection taken at the Passing Out Parade. This was an amazing contribution, huge thanks to all concerned.

### A Gentle Stroll along the River Trent in Nottingham

If you would like to join a small group of MDSG Supporters for a gentle stroll over 1.5 miles in the Robin Hood Mini Marathon on Sunday 25<sup>th</sup> September 2016, please register under the Mini Marathon section on the website: <http://www.robinhoodhalfmarathon.co.uk/index.htm>

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

### Awareness

Increasing awareness amongst the Health Professionals we feel is well worthwhile as a number of you have commented that many of them have never heard of Myotonic Dystrophy. This is why we attended the:

Anaesthetists Conference in London; and the Wales Neurological Alliance in Cardiff in April.

We will have attended the Primary Care Exhibition at the NEC by the time you receive this newsletter and have a stand booked at the GP Conference in Harrogate in October.

### Website

Finally, our new website is live. Please have a look at our new and refreshing website. We would like to thank the designers Foster and Scott for their patience as the Trustees have pondered over various aspects and designs. Alex Appleby is our Editor and Kate Hill is in charge of the Social Media (Facebook and Twitter)



LORD WALTON OF DETCHANT

Walton Muscular Dystrophy Research Centre are deeply saddened to announce the death of our founder, John Walton, Lord Walton of Detchant. With his seminal work 50 years ago at Newcastle, John was a founding father not only of our centre but of the field of myology itself. Over many decades, he has given his brilliant thought and kind support to generations of clinicians, researchers and patients with neuromuscular conditions, inspiring many of us in Newcastle and across the world.

Kate Bushby; Rita Horvath; Hanns Lochmüller; Volker Straub

*The Board of Directors of Myotonic Dystrophy Support Group send sincere condolences to the family of Lord Walton.*

## Unexpected Legacy from the Heller Family

MDSG recently received the sum of £147,000. This unexpected bequest was sent to MDSG by the Heller family with the request that it was used for research.

The Trustees agreed to donate £50,000 to Professor David Brook, £50,000 to Professor Darren Monckton and £20,000 to Dr Jeremy Rhodes

Pictured right is Margaret handing over the cheque for £50,000 to David



Drs Sarah Russell and Jeremy Rhodes

Our Contact Person for Glasgow, Isabelle Munghall, along with her friend, were invited to meet the team and hand over the cheque for £50,000 to Darren



Wonderful news about the Wellcome grant to Prof David Brook's labs. I understand that the outcome of £3million is the work of many years work to apply for the grant, to find a treatment for people with DM.

*To all researchers worldwide as well as in the UK we send a special Thank you.*

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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.

### Bedford

Kath Dixon  
01234 708520

### Leicester

John Langley  
0116 287 9064

### 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

### Cumbria

Neil Braiden  
01228 512385

### Northampton

Michael Walker  
07831 347143

### Wakefield

Pauline Ferrari  
01924 377986

### Dorset and Somerset

Ruth Harrison  
01425 626133

### Northumberland, Tyne and Wear, Teesside

Peter Bodo  
01740 620707

### Wiltshire, Hampshire

Sue and John Kelly  
01725 519233

### Essex

Gwen Mumby  
01245 601343

### 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

### Glasgow

Isabelle Mungall  
0141 883 6934

### Nottinghamshire

Margaret Bowler  
0115 987 5869

### Kingston-upon-Thames

Penni Cotton  
(contact office)

### Pontefract

Jack Lawrence  
01977 705496