

August 2018

**CONFERENCE
ISSUE**



*Photos from our June Conference at The Oxford Belfry
with the Mayor of Thame, Councillor Ann Midwinter*



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Margaret Bowler

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Dr C Turner

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Julie and Mike

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HELLO EVERYONE

Our Annual Conference, 2018 was held at the Oxford Belfry Hotel and was a really great Conference Day, 200 delegates attended. Many people have made favourable remarks about the hotel and the willingness of the staff members.

The Mayor of Thame, Councillor Ann Midwinter accepted our invitation to join us at the start of the day. In her address to the delegates she said how much she was looking forward to sharing part of the day with us and learning more about Myotonic Dystrophy. Lynne Ormandy presented the Mayor with a bouquet of flowers.

The varied programme was well received. The many medical consultants who give their time and skills in relating to us, the MDSG members, in such an understandable non medical jargon way!

People travelled from all areas of the UK, including the Isle of Man.

The willing helpers are of great importance, stall holders, facilitators, and all preparation for the day by office staff Julie, Mike and myself.

Tables and stalls were prepared with information, sweatshirts, bring and buy and some very appealing Teddies.

We did miss Janet and Phillip Walker, who for many years have helped us all in a manner of ways, always with a smile and friendly word. It is good to know that

Janet is recovering well from her recent operation. Best wishes Janet.

Our alternative programme led by Elycia Ormandy was fully occupied by doing various crafts and hearing about how to exercise, a talk given by Dr Margaret Phillips. At the end of the day the group provided thank you cards for the Conference.

Our youngest workshop helpers were the trainee Paramedics Nick and Rohan from Brooks Oxford College, who demonstrated resuscitation under the watchful eye of Dr Ian Bowler. I don't think we say thank you enough to our Speakers. The best in their field and they give our families their time and concern.

Next year the Myotonic Dystrophy Support Group will celebrate 30 years of having an Annual Conference. We will have many memories from 30 years of conferences. It will be great to share them together.

**Margaret Bowler
National Co-ordinator**



Luke Justin Appleby 17th July 1976—18th June 2018



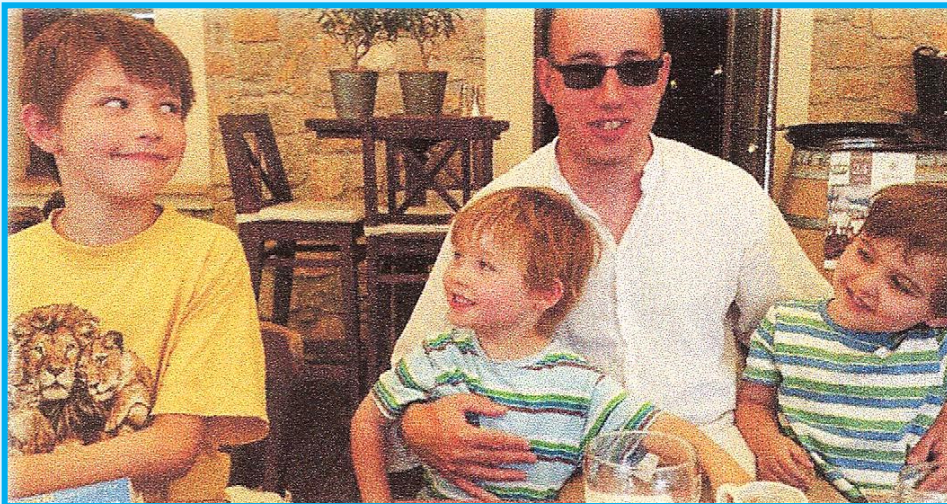
We received the news that Luke Appleby was very poorly on the morning of our Conference Day. We learned with great sadness of his passing the following Monday.

Many of our members will remember Luke from his willingness to advise them on legal matters and in particular, his talk to delegates about Trust Funds at our Peterborough Conference. He understood all too well the difficulties of having family members with a long-term medical condition, and the need to prepare for the future.

Luke had studied both British and French Law, and in his capacity as a Myotonic

Dystrophy Support Group Trustee he used his professional skills to give guidance about some of the more complex issues that arise from time to time in the life of MDSG. He made a truly valuable contribution to the committee, and we will miss him greatly at our meetings.

As fellow Trustees, we appreciated Luke's ability to lighten the mood with his quick wit and dry sense of humour. He was a man who lived life to the full, enjoying the challenges of work and play.



For all of that, Luke will be remembered by us as a Family Man. He loved family life with all its ups and downs and delighted in the achievements of his wife Alex and their three sons, William the eldest and the twins Jonathan and Marcus. He was a proud and devoted husband and father.

We send our heartfelt thoughts, love and prayers to Alex and the boys and to Luke's parents. We cannot imagine their sense of loss. Luke was so talented, so young and so brave.

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Hello Everyone, and welcome to this summer issue of our MDSG Newsletter. We have put together a wide variety of Reports for you so that our Readers can find out about recent events and highlights in the busy life of our Support Group. We hope that these accounts of some of our activities helps to make you feel part of the wider picture.

Once again our Conference drew together a wonderful team of Consultants and workshop leaders, so that delegates had a wide choice of topics. We deliberately avoided giving out Feedback forms on the day. In a busy Conference it is almost impossible to find time to fill in another form! However it would be great if some of the attendees on the day could spend just a little time to let us know how well the programme and the day(s) suited them. An e mail, short phone call, even a short note would be really helpful now that the dust has settled and we have had time to think, (these newsletter

accounts may jog your memories). Please do let us know. Next month the Trustees will be meeting to discuss plans for our 30th Conference in 2019. Your thoughts could form part of our forward planning.

Did you manage to catch up with Carer's Week events during the week of our June Conference? This is held annually to highlight the invaluable contribution Carers everywhere make to our communities.

I would like to share these words (below) from one of **CarersUK** flyers this year. I found them very moving and thought provoking when looking around the hotel on June 15th and 16th.

Thank you to all the care-givers who made it possible for others to attend the 2018 MDSG Conference. Enjoy the rest of the summer. Keep safe, keep well and keep reading. Best wishes,
Elycia Ormandy, Editor

Carer (noun) /'ke r (r)

Washing bodies. And laundry. And dishes.
Keeping appointments. And records. And tempers.
Giving medicine. And time. And hugs.
Filling forms. And fridges. And silences.
Dealing with doctors. And nurses. And pharmacists. And social workers
And benefits agencies. And care workers. And a lack of sleep.

THANK YOU to all our readers who kindly returned the DATA PROTECTION FORM we sent to you with our last issue of the Newsletter. We do appreciate your prompt response. This now enables us to move forward with the MDSG database, so that we comply with current requirements.

SUBSCRIBING MEMBERS who returned the Data Protection Form will continue to receive our Newsletters throughout the year.

A POLITE REMINDER

We currently have a number of people on our database who have NOT RETURNED a completed Data Protection form to us, *(we have included one with this newsletter for those who may have forgotten or mislaid it)*

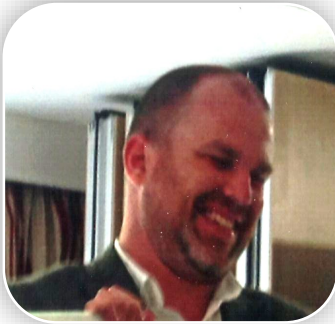
Are you currently a subscribing member? Cost £15 per year for all family members living at the same address.

Have you returned the form to us? Only subscribing members will receive Newsletters throughout the year. Non subscribing contacts must CONFIRM CONSENT for us to keep your personal details on our database.

If there is a problem with this, please contact the office ASAP to discuss. We do want to include you on our database even though you are not a subscribing member, and will only receive the first copy of the Newsletter each year. CONTACT MDSG NOW.

Reflections from the Chair Dr Mark Hamilton

It was a great pleasure and honour to chair this year's MDSG annual conference at the Oxford Belfry Hotel in Thame.



Over 200 delegates from throughout the UK joined us for the main day of the conference, representing a mixture of familiar faces and newcomers to the MDSG. As the following reports will attest, it was a day packed with learning, socialising and laughter ... as well as occasional outbursts of singing!

Highlights included welcome wishes from the Mayor of Thame, and an overview of research progress from MDSG Patron Prof David Brook (after receiving his balloon to mark a special birthday). We were particularly privileged to welcome Prof Eric Wang and his wife Beth, from the University of Florida. Eric gave a wonderful talk about his own family's experiences of myotonic dystrophy, as well as a very clear account of his research group's efforts towards new therapies. Elycia Ormandy gave an excellent, practical guide to personal independence payment applications, and Dr Mark Roberts rounded off the day with a highly informative overview of respiratory health and ventilation.

The main talks were interspersed with a wide choice of workshops from the MDSG's loyal band of expert researchers and healthcare professionals, and the lunch and coffee breaks were, as ever, very well catered!

We are all extremely grateful to all the trustees who worked so hard to make the day run smoothly. In addition, I would also like to thank again all of the delegates whose warmth, good humour and willingness to join in set the perfect tone for the day.

Thank you again for having me as your chairman, and I hope to see you again next year!
Mark Hamilton
University of Glasgow

An Overview from 'First timers'

Me and my wife Lynne attended the conference in Oxford this year for the first time. We arrived early on the Friday and thought we would stay an extra night and make a weekend of it. We received a very warm welcome from Mike Walker and Margaret Bowler.

It was so nice to finally meet everyone and we found everyone at the conference so friendly and helpful.

I particularly enjoyed how light hearted and humorous the meetings and workshops were. We were also very impressed with the food on the day and how much thought had gone into the menu, taking into account that some people like myself who have trouble swallowing.

We also liked the fact that there were doctors, specialists and a host of other people with a wealth of experience attending who we could talk with, discuss and share our own experiences with and often get ideas and information we were unaware of. Needless to say we will be attending next years conference.

Thank you **Joe and Lynne Cocker**



A further overview

My wife Barbara was diagnosed with MD in 2003 after her brother, who lives down south, had been firstly diagnosed. My two sons were tested and my younger son Martin was also diagnosed positive when he was 29. We had very good support from our GP, who at first knew nothing of the illness, and also from our neurologist and cardiologist who he referred Barbara to, coupled also with help from Margaret and the MD Support Group. Barbara was coping reasonably well and therefore we have never chosen to attend the Annual Conference before.

Although prior to attending we had an idea of what was wrong with Barbara, this presentation gave us far more information about why and how things were not right, and the ongoing research into it.

We were also impressed by the guest speaker, Dr Eric Wang, whose own family is affected by MD, who spoke about his background in America, and his current work researching MD at the University of Florida.

The workshops we attended, we found to be most informative and helpful, and the presenters, all specialists in their



This year we particularly noted that the conference was covering a number of topics which were now becoming more relevant to her, so we decided to attend for the first time.

The conference was opened by Margaret and we were impressed to see almost 200 present.

This was followed by a presentation by Prof David Brook who gave a most clear and detailed insight into how the mutant gene is formed and then how it prevents the immune system from combatting it. Much to the delight of those who had been before he explained this more clearly with the on screen display of 'the fried egg', which clearly explained the formation and development of the mutant gene.

respective fields, were all willing to answer questions from the floor. You were even encouraged to approach them outside of the workshops if you felt they could help you further.

It is fair to say that from initially being apprehensive about attending, we came away at the end having thoroughly enjoyed ourselves and far more enlightened about MD.

A special word of thanks to Margaret Bowler, and her willing team of support workers, who all made us feel most welcome.

All being well we will be attending the conference next year, probably with my son Martin, who has been most interested in all we have told him.

David & Barbara Wright.



*More photos from our
29th Conference at the
Oxford Belfry.*



*Above:
Dr Margaret Phillips who ran one of the workshops on Exercise*

*Below:
Our closing speaker, Dr Mark Roberts*







Top Right: Judith, Linda and Rob on registration.

Middle Left: Jackie buying a sweat-shirt

Middle Right: Bring and buy stall

Bottom Left: Peter and Pauline on the pens and Information table



Young People's Report

We met as a small group, and although there were some comings and goings we averaged six throughout the day. The allocated room included access to the Conservatory, and beyond that, a lawn area. This gave us space to spread, and spread we did!

A variety of craft activities allowed the group to engage with one another while using their imaginative skills.

We began the day by hand washing, before modelling marzipan into a variety of shapes for decorating with assorted sprinkles.

This activity enabled us to chat together and find out some likes and dislikes.



The group had four large 3D letters, MDSG, to paint with green paint. This was done with great care before sprinkling them with sequins for added sparkle!

These letters were presented to Margaret Bowler at the end of the day along with various handmade Thank You cards.

Painted pebbles with wobbly eyes, and soon we had created a collection of Bugs.

Later we went on to make Bug Houses by packing natural materials into plant pots. We used pine cones, sticks, twigs, dried leaves and flowers, with long grasses, to stuff the pots as tightly as we could. No right or wrong way. String was threaded through the plant pot bases so that they could be suspended from a tree branch, garden shed or placed in a sheltered outdoor space, to provide luxury accommodation for any passing bugs to make a home.

Dr Margaret Phillips kindly shared some of the afternoon with us. She opened up the topic of exercise, and encouraged everyone to 'have a go'. This small group discussion and motivational talk was helpful to us all. Exercise can and should be part of our daily lives.

We took time to get out into the fresh air for a game of Boule. Everyone took part, and we had fun.



Young people continued

There is something for everyone, regardless of ability. We don't need to reserve exercise for a day at the Gym! Helpers on the day, Jan, Rebecca, Lynne, and Elycia along with Ellie, Greg, Liberty, Jackie, Sarah Hannah, Helena and Grandma spent a busy and enjoyable day together. Thank you for your company. It was good getting to know you. Elycia.

Margaret tells me that the MDSG that you made survived the journey home to Nottingham.

The letters MDSG now have pride of place in the office window for passers-by to see. I wonder how many bug houses had to be rearranged before they got to a good outdoor space!

Annual General Meeting Friday 15 June

This year, we had no election taking place. There were no new nominations for Trustees. None of the existing Trustees were up for re-election. If you think you could help MDSG, by serving on the Board, there are vacancies. Please contact the office for more details. All three officers, Margaret, Elycia and Michael were re-elected.

During the year Helen Brownlee resigned.

Thanks to Helen were expressed for her contribution to MDSG.

We also received the news that Luke Appleby was seriously ill.

The accounts for the year ended 31 December 2017, were presented and approved. If any member wishes to view a copy, then please contact the office.

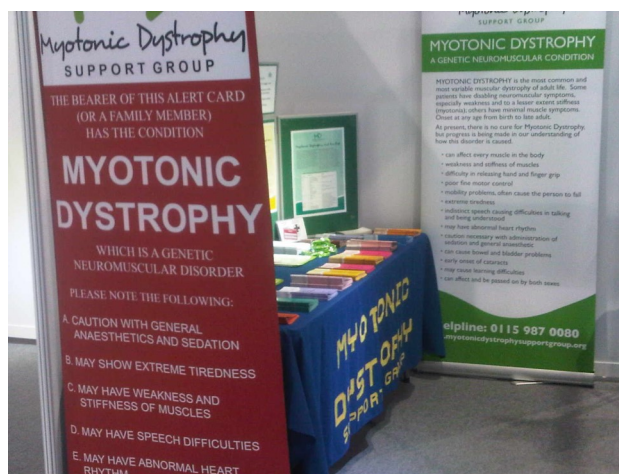
Money designated for research has been donated on your behalf to research teams led by, Professor David Brook, Professor Darren

Monckton and Dr Jeremy Rhodes. We were also pleased to financially support individuals from the Research teams to go to IDMC 11, along with paying for Dr Ian Bowler and Margaret Bowler to attend. This is in addition to the £5000 to help the IDMC Committee put on the event.

Steadily over the years we have been increasing awareness amongst the health professions with information stands at various exhibitions and conferences.

Institute of Physicians Annual Conference, Manchester in March
Neurology Seminar for GP's, London in March
Primary Care Exhibition NEC, Birmingham in May
Trainee Anaesthetists 50th Conference, Cardiff in July
Speech and Language Annual Conference, Glasgow in September
GP Conference, Liverpool in October
Royal College of Midwives, Manchester in October.

At these larger meetings we have many interesting conversations. The majority of people we talk to are genuinely interested, and wish to know more and take away the brochures. *We have attended several already this year, including the Royal College of Paediatrics and Child Health.*



The Masons, Margaret and Me

(The 'Me' being the MDSG Patron Professor David Brook)

On Wednesday 2nd May, Margaret and I had a big adventure. On behalf of the Support Group we were invited to attend a presentation by the Hope Valley Lodge of the Masons at the Dore Masonic Hall. The evening started badly. I got held up in traffic as I went across Nottingham to pick up Margaret. When I arrived in Carlton, Margaret was waiting. I knew immediately that she was different; there was less of her than there had been previously. In fact, Margaret was one toe less than a full set. Turns out it's a genetic condition in which one toe becomes very painful because it twists under another. Surgery was the only option and sadly it means her ballet career is probably over.

We left Carlton and headed towards junction 26 of the M1. The traffic was horrendous! but Margaret used her knowledge of the backroads of Nottingham to good effect. Nevertheless, we had to stop en route to let our contact Tony Le May know that we were going to be a bit late. Tony is father-in law to Shona Davison (who many of you may know from her time on the MDSG committee). We followed the directions provided, turning left just before the railway station onto Dore Road and then left again at the very large sign "Dore Masonic Hall Car Park". Finally, we had arrived. Journey time 2hrs 15 minutes, distance travelled 37.9 miles.

From the car park we proceeded to the lounge area as directed, where we met around a dozen ladies. The chaps were downstairs in the Temple transacting business and participating in things masonic. Tony appeared, dressed in a suit with black jacket and grey and black striped trousers, light blue apron and sash, and a pair of white gloves. He escorted us along a corridor, past a collection of briefcases and downstairs into the Temple, which was occupied by around 25 similarly clad gentlemen. I was struck by the age distribution, as I was one of the younger people present. Not sure about Margaret. The room was wood paneled with pews on all sides, a bit like a small chapel, and a man in the corner played tunes on an organ. We were brought to attention by the Worshipful Master and three different people banged gavels from high chairs on two sides of the room.

One gentleman gave a long speech about numerous fundraising activities that had generated large sums of money for good causes over the past few months and then Margaret and I were called forward to say a few words about myotonic dystrophy and the Support Group, before being presented with a cheque for £2,000. **Smiles all round.**



Masons continued

The non-masonic guests, as we were called, retired back to the lounge, passing the briefcases and a large picture of the Duke of Devonshire with several hundred Derbyshire Masons, whilst the chaps in the Temple conducted the rest of their business.

Margaret and I mingled and after about 20 minutes we were joined by the gentlemen who had completed their meeting.

I was befriended by a very nice man called Barney who bought me a glass of lemonade and showed me round the outside of the building which had apparently been constructed from material salvaged from the former Sheffield bus station. Barney assured me that most of the stories about the masons were fake news. They did not indulge in human sacrifice, or even the slaughter of goats, unless the brethren were butchers, of course. I asked whether the briefcases symbolized leaving business outside the main proceedings, but Barney said no, it was just where the chaps kept their aprons.

We were then treated to a three course meal with wine. We were not really able to take advantage of the fine Bordeaux as I was driving and Margaret doesn't drink alcohol. Nevertheless, the food was smashing. We were seated separately, with Margaret on the top table, with the Worshipful Master and the Regional Worshipful Master and opposite the master of ceremonies who barked out information periodically in a loud voice. The chaps sang the Lodge song and we toasted the Queen, the Great Architect and the Duke of Kent (I think).

The gents on my table included a retired sales manager, a retired police officer, a pathologist from Sheffield and an engineer. It transpired we had supporters of Derby County, Sheffield Wednesday and Sheffield United in the group. As a Leeds United supporter from Nottingham I felt slightly ill at ease. Nevertheless, the guys were very sociable and we chatted away about a range of issues. All in all, it was a great experience, very enjoyable, and the slightly worrying aspect was that I fit right in.

Grateful thanks to Tony Le May and the Hope Valley Lodge for an excellent evening and a very generous donation to a very good cause!
David Brook



Tim and Sam Simpson successfully completed the Manchester 10K run, earlier this year, raising funds and awareness for Myotonic Dystrophy.

Hadrian's Wall in Roman Armour – Sponsored Walk

Steve Welsh walked Hadrian's Wall dressed in Roman armour to raise money for the John Walton Muscular Dystrophy Research Centre in Newcastle.

Steve lived in Jarrow for most of his life and often used to walk parts of the wall when he was younger. Walking the whole wall from Bowness in Salway to Wallsend had been an ambition of his, and he decided to walk it in June in Roman armour and raise money whilst doing so. Steve does Roman days in schools, so finding the Roman armour wasn't a problem. The walk took 6 days and he also managed to arrive in time for his mother's 90th birthday.

Steve met well over a hundred people on the walk. Most were tourists from all over the world – Italy, Germany, Denmark, Holland, Netherlands, Ireland, America, Japan and Australia. All of them were excited when they saw Steve and many photos were taken of him in his armour alongside smiling tourists. The experience of the walk has inspired Steve to think of setting up a charity and doing the walk with people – dressed in armour – as a therapeutic exercise.

Myotonic Dystrophy is a form of Muscular Dystrophy and Steve's nephew, Iain Smith, pictured below, has the condition. Steve raised just over £2,500 for the Myotonic Dystrophy Charity and the money will be given to the research centres in the UK.

The picture shows Steve arriving at the John Walton Muscular Dystrophy Research Centre at the end of the walk to meet the Newcastle team researching into the disease.



From left to right: Libby Wood, Project Manager; Dr Cecilia Jiminez Moreno, Research Associate; Steve Welsh; Cathy Turner, Project Manager; Iain Smith; Professor Volker Staub, Director of the John Walton Muscular Dystrophy Research Centre; Dr Tiago Gomes, Speciality Doctor in Neurology.

Contact: Steve Welsh
Swelsh_ace@hotmail.com
07964 106037

The picture below shows Steve crossing the Tyne on his way to Wallsend.





Miss Scotland finalist

I chose to fundraise for mdsg as my little cousin Mia was diagnosed with this and I had never heard of this before. From seeing the struggles that Mia has had from day one and getting to know more about mdsg I was keen to use my title of being a Miss Scotland finalist to fundraise in order to help Mia and other people just like her.

I started off with arranging a charity night. I really enjoyed the planning and organising, and I was so amazed by all the help that the local businesses have gave me, and all my family and friends coming together to raise a high total. It was a great night with bingo, buffet, dancing and lots of raffles. I



had been in touch with Professor Darren Monckton and we arranged a speaker to come to my charity night on behalf of him to give a speech about mdsg. It was really nice and interesting and gave

people more of an idea as no one had heard of it before.

My next fundraising event was at B&M in Airdrie, my local store. I had a 1 hour slot to help pack bags and raise some money. I raised around £70 in one hour, it was nice when customers would ask a bit about mdsg and I was proudly telling them bits about it.

In total I have raised £2500 towards the research headed by Professor Darren Monckton.

I hope to do more fundraising events in the near future. I am really happy with what I have raised and this has encouraged me to do more.

Gemma McIntosh

Please note:
One of our email addresses mdsg@tesco.net has been discontinued.
If you wish to contact us via email, please use contact@mdsguk.org

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West Yorkshire

The latest meeting of the West Yorkshire local group was held on 2nd June.

Cecilia Jimenez-Moreno, a Research Assistant from Newcastle University, came along to talk to the group about the PREFER project, which plans to gather evidence to show how and when patient preferences should be taken into account when new drugs are developed and licenced



The photo shows the round table discussions

The members enjoyed her presentation and were very interested to hear about the project and a number of people came forward with offers to be involved as the project moves forward.

It was good to see everyone again, after a break in our local meetings whilst Pete and I moved house. **Pauline Ferrari**

Birmingham, Worcestershire and Warwickshire

I had a contact meeting on 14th July. Although not as many as usual due to holidays and illness, it was a successful meeting where we shared information and experiences and passed on things we had learned from the conference for those who did not go. I intend to have another meeting in the Autumn which will hopefully be better attended. **Gillian Stock**

WE HAVE A **NEW**
HELPLINE NUMBER

0808 169 1960

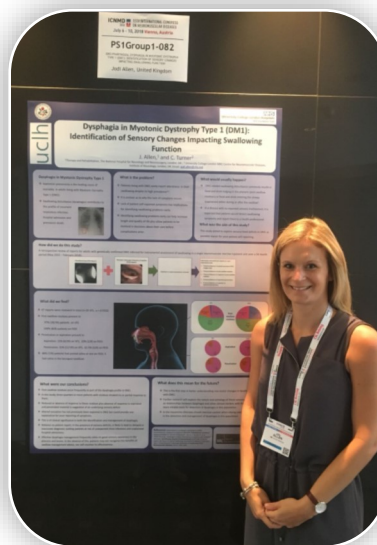
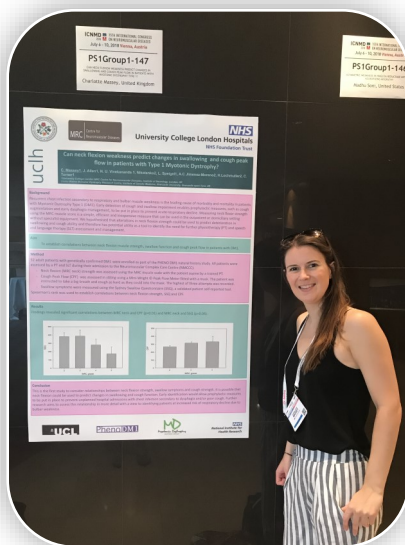
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0115 987 5869

International Congress Vienna, Austria

With the support of the MDSG, Jodi and Charlotte were able to attend the International Congress on Neuromuscular diseases in Vienna, Austria to present their current work, swallowing and cough difficulties in Myotonic Dystrophy.

Jodi Allen (Speech and Language Therapist) and Charlotte Massey (Physiotherapist) are allied health professionals who work on the Neuromuscular Complex Care Centre (NMCCC) at the National Hospital for Neurology and Neurosurgery, Queen Square, London.



They have a keen interest in supporting patients living with Myotonic Dystrophy who have difficulties with swallowing and coughing. Problems with swallowing and coughing can lead to weight loss and recurrent chest infections. Chest infections are the leading cause of death in patients living with Myotonic Dystrophy. Weight loss and poor nutrition can prevent patients from fighting infection and staying well. We are keen to identify problems with swallowing and weak cough early on in the disease to help reduce the likelihood of these problems occurring.

They presented two posters to a large audience of neurologists and health care professionals from across the world. The posters were titled:

Can neck flexion weakness predict changes in swallowing and cough peak flow in patients with Myotonic Dystrophy Type 1 (Charlotte, on the left)

Dysphagia in Myotonic Dystrophy Type 1 (DM1): Identification of sensory changes impacting swallow function (Jodi, on the right)

The work stimulated lots of interest and discussion. Most importantly, it raised awareness of the issues that occur in Myotonic Dystrophy. In sharing the work they hope patients and professionals will identify problems with swallowing and coughing early to prevent avoidable problems. They hope to continue their work to find better ways of managing swallowing and cough difficulties. Jodi and Charlotte would like to thank the team at MDSG for supporting their work.

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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

Kingston-upon-Thames
Penni Cotton
(contact office)

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

Cardiff
Margaret Ware
02920 869277

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

West Yorkshire
Pauline Ferrari
01977 799565
Jack Lawrence
01977 790886

Croydon
Lesley Smith
020 8777 6587

Northampton
Michael Walker
07831 347143

DM2
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01732 841652

Cumbria
Neil Braiden
01228 512385

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Wear, Teesside**
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01740 620707

Dorset and Somerset
Ruth Harrison
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