NEWSLETTER

Our Patron, Professor David Brook, along with Margaret Bowler and Michael Walker, hosting the visit of the new Gedling Member of Parliament, Mr Tom Randall to the MDSG offices on Friday 2 October 2020.
Mr Randall born and educated in Nottingham, has a special interest in rare conditions.

October 2020

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Hello Everyone

I do hope you have been able to stay well and safe.

You will find a fantastic photo of me on Page 11!

Following a deep clean of our office, I decided to clear out all the unwanted papers from the filing cabinets. MDSG is now over 30 years old, and we had papers, magazines etc dating back to those early years. Once I have checked that they are really no longer needed, they will go for recycling. Of course I ***have*** to read them all, just in case they are ***really*** important. Reading these documents brings back many wonderful memories and some sad ones too. I am still plodding on with the sorting. This photo taken by Michael W shows me busy working in a corner of the Post Room.

I have also been busy photocopying articles to bring our MDSG history for the last ten years into printable chronological form.
I hope the complete history of MDSG will be available before long.

I would like to thank people for the generous donations that have come in with subscription payments. The charity is most grateful. We will meet again……one day, keep safe.

Margaret Bowler

Letter from The Editor

Dear All,
Here is our Autumn Newsletter. A little later than we hoped, but then over the last year almost everything appears to take that bit longer, whether it is hospital appointments or postal deliveries.
Last weekend I took an outing to a local park to enjoy what was probably the last mild sunny afternoon for this year. As I quickened my pace, I remembered that MDSG had missed out by not being able to take part in the Robin Hood Marathon and Mini Marathon this year. This fun annual event was, like so many others, cancelled for 2020. Over the years it has brought Friends of the Support Group together. Carlton Brownies with their families, alongside Students and Researchers from Nottingham University, wearing the MDSG T-shirts made a lasting impression as they approached the finish line. It wasn't just about fundraising, though that was great. It was an opportunity to spread awareness of Myotonic Dystrophy to the wider community and to meet up together. Some families travelled a long way to be there and do their best for MDSG. I guess Dr Helen Brownlee and Margaret Bowler really, *really* missed filling out the dozens of registration forms for participants this time…..but we do have some very happy memories.
Now we are thanking some of those same Friends and others for making time to produce articles for this edition of the newsletter. We do appreciate all your contributions. We are sure that everyone will enjoy a good read.

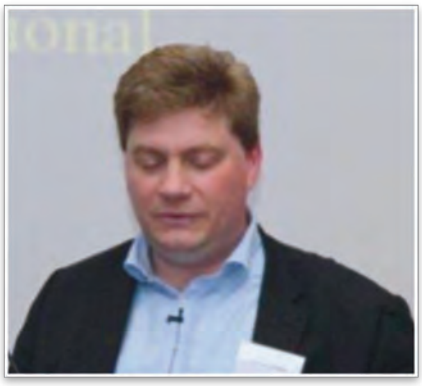
NB, 'Flu is NOT cancelled this year!!
It is time to repeat the message about the importance of having your 'flu jab this year. It may be more difficult to get a convenient appointment at your surgery because of the need to observe social distance and avoid queues, but there are many chemists offering appointments. This may be an option worth considering. If in doubt about access, have a word with your GP receptionist who may be able to make alternative arrangements for you. This year more than ever, it is really important that people with Myotonic Dystrophy and their Carers are protected. If you haven't yet had a pneumonia jab discuss this with your GP.

Keep safe, keep well and keep smiling, even behind your mask. Your eyes can still be seen. Smiling eyes radiate a positive message of Hope and encouragement. My warmest wishes to you all.

Elycia Ormandy

Working around Covid

Dr Chris Turner



The Covid-19 pandemic has had a profound effect on all staff at The National Hospital for Neurology and Neurosurgery, London and on the Neuromuscular Complex Care Centre (NMCCC) which supports many people living with myotonic dystrophy. So much had to change in a very short space of time to protect patients and staff from the spread of the virus.

Life was never going to be the same the moment the roads, trains and streets became eerily empty and beautiful in their silence. At Queen Square we knew we would need to prepare ourselves for the likes of which we had never experienced. Neuroscience intensive care units and recovery units became Covid ICUs. Neurology and Neurosurgery wards became Covid wards. Outpatient departments and therapy gyms were empty. Neuroscience doctors, nurses and therapists became Covid doctors, nurses and therapists. Initially there was palpable uncertainty and sometimes fear in the teams, uncertain of what to expect.

However, in a matter of days we changed from an internationally renowned neuroscience centre to a full scale Covid-19 treating hospital. The patient-focused dedication by all the teams in delivering this change cannot be underestimated and I am immensely proud of the whole division. Even when we were pushed to our limits, there was always a great sense of solidarity, humour in the face of adversity and every challenge had a solution. It was an example of humanity at its best. Throughout this, we were able to maintain a core facility at the NMCCC for this that were in most acute problems but we also needed to protect patients from Covid-19.

We are currently restoring our services to support our patients, but we know that we cannot return to previous practices. The Covid-19 outbreak was tragic, but it gave us an opportunity to create change for the benefit of patients.

For example, the move towards virtual (telephone and video) clinics which was rapidly developed during the height of the Covid outbreak. We are now conducting over 2500 virtual consultations per week which has made a positive impact on many of our patients who found the commute to London challenging and unnecessary.

As for the NMCCC, it is highly unlikely to return to its original location and is temporarily housed in the oldest part of the hospital, ironically, with more space. The NMCCC is now back up to six beds and remains Covid protected but we understand the anxieties around patients returning to London.

Continued over page

Working around Covid-continued

Looking to the future, plans are already being drawn up for a newly expanded and refurbished NMCCC with more beds, more facilities and more space. Hopefully every cloud does have a silver lining!

The Covid-19 outbreak was very tough for staff, patients and relatives but has brought the best out of our teams and improved how we deliver care. As we face a possible second wave of the Covid outbreak, there is a sense of experience and expectation but also a realisation that we all may need to be adaptable in how we deliver healthcare for the foreseeable future.

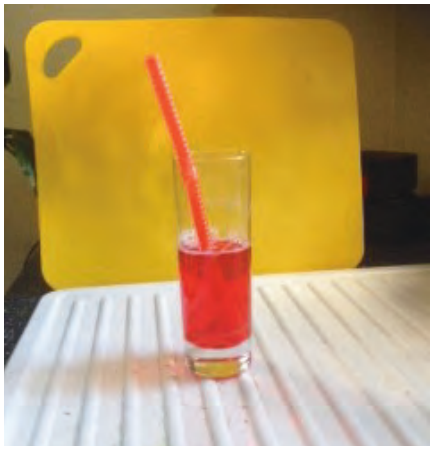
Many thanks for all the support from MDSG and families with DM who have been patient and understanding throughout the pandemic. We all commit to working with you to provide a brighter future for people living with myotonic dystrophy. **Dr Chris Turner**

Balloons to staff at the main entrance to The National Hospital for Neurology and Neurosurgery

Lungs and Breathing

With Autumn and Winter approaching, Margaret has asked me to write something helpful for the news letter about 'Lungs and Breathing'.
As everyone knows, many body systems can be affected if you have Myotonic Dystrophy, including lungs and therefore breathing.

Whether your lungs are good and you just want to keep your lungs as fit as possible, or weather you do have issues with phlegm or have regular chest infections, the following tools can be helpful.



Bubble PEP - (see photo on this and next page).
You will need a very clean/sterilized empty 1 pint milk bottle, a straw and a tray or washing up bowl to catch the bubbles.

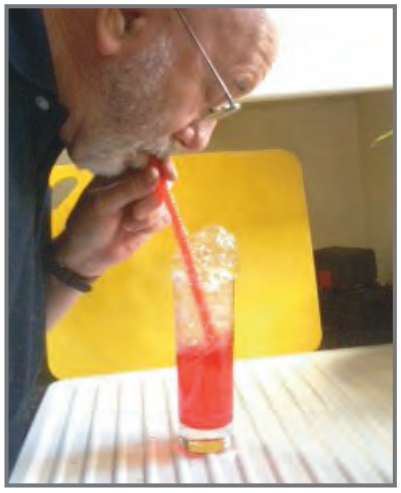
Fill the bottle with approx 10cm (that's 4ins to us older folk) with cold water.
Add a squirt of washing up liquid or liquid soap.

Either stand at a kitchen counter (with your back straight) or Sit at a table with your back straight) with the bottle on your tray.

Continued over page

Lungs and breathing continued

Breathe in, then put the straw in your mouth and using long slow breaths, blow out through the straw (which will create bubbles that come up and out over the top of the bottle). To direct the bubbles away from your nose, hold the straw between your straight fingers as a shield.



Try and do 4-6 long breaths, then breathe in and do a big cough or two this is one cycle. Repeat the cycle 3 more times, till you have done 16-24 blows and 3 coughs in total.

The water in the bottle (and the bubbles) provide a resistance to your blowing, and it is this which creates a pressure back up the straw and into your lungs. This pressure helps to open up your airways and the tiny air sacks (alveoli) in your lungs. This 'opening up' facilitates the removal of phlegm from your lungs so that it doesn't store up and accumulate, causing you chest infections.

If your lungs are healthy, do this 2-3 times per week, build up to 10 blows and a cough, repeated the cycle 3 times. Build up the length of your 'blow' by counting and increasing the seconds you blow out for. This is a good 'work out' for your lungs.

If you normally have issues with chest infections, or phlegm or coughing, you could do this daily, which will help to prevent so many chest infections for you and help to remove secretions from your chest. Breathe out as long as you can, counting how many seconds the bubbles blow, over time, try and increase the number of seconds you can blow.

NB - Asthma - if you also have Asthma, this tool is not for you.

Best Wishes to All, from
Lynn Hewitt MCSP SRP Dip.Th.p
Snr Specialist Physiotherapist.

Zoom! Zoom! Zoom!

On a Thursday evening in July, Margaret organised an online meeting for the local contact persons using the zoom system, inviting everyone to a 'virtual' get together. Margaret had enlisted the help of a friend who was able to work her magic on the technology, and who could check everyone into the meeting using the video screen process.

Having missed out on the Conference this year, it was great to see everyone and to hear their news and how they organised their local get togethers. From a personal point of view, it also gave me the opportunity to meet some people that I had not met before.

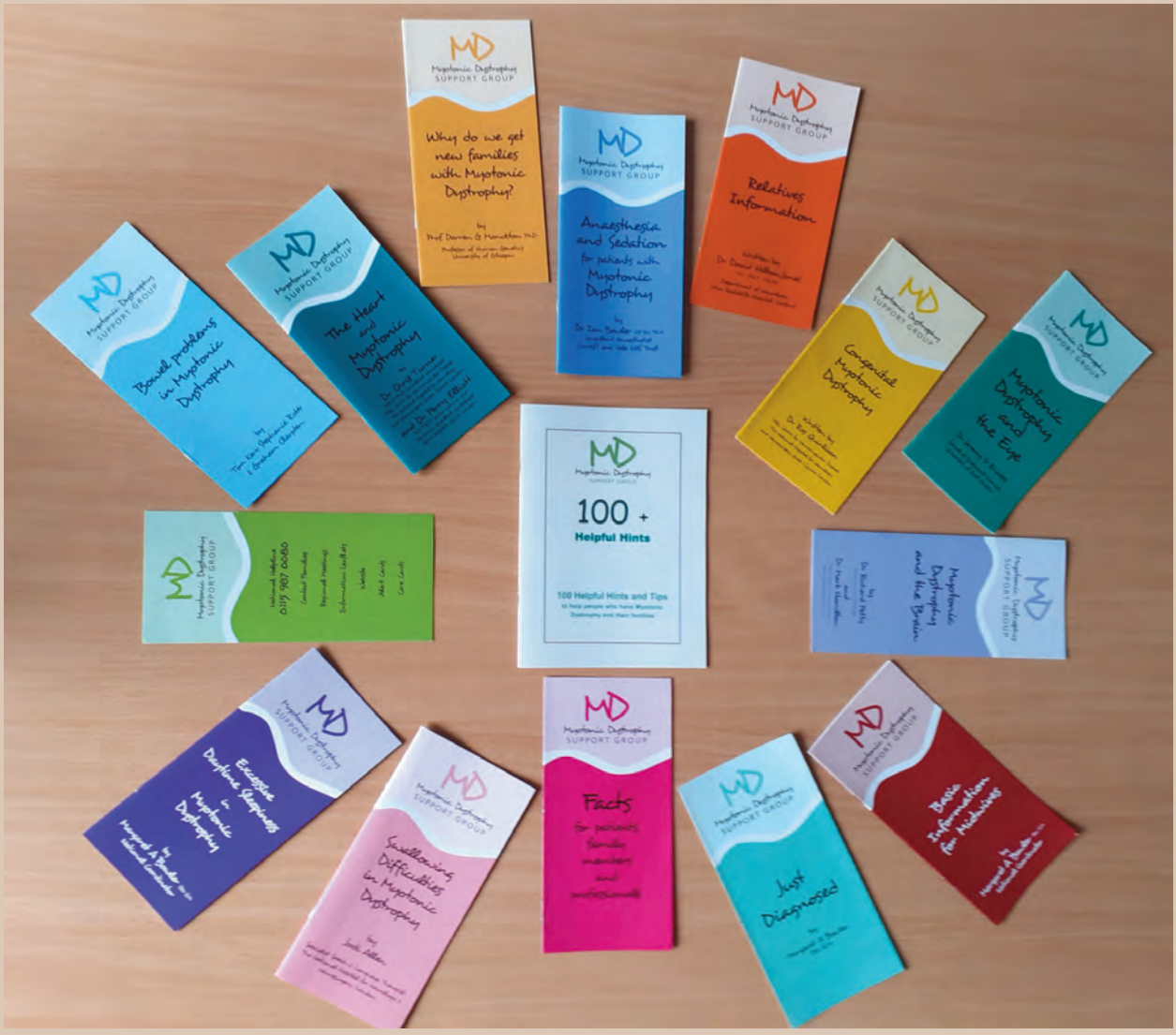
In these difficult and strange times, it is important that we can all stay in touch. Please do remember to call your contact person if you should need any help or advice, or if you would just like a chat. All of the phone numbers are shown on the back page of the newsletter.

Pauline Ferrari

B R E A T H I N G

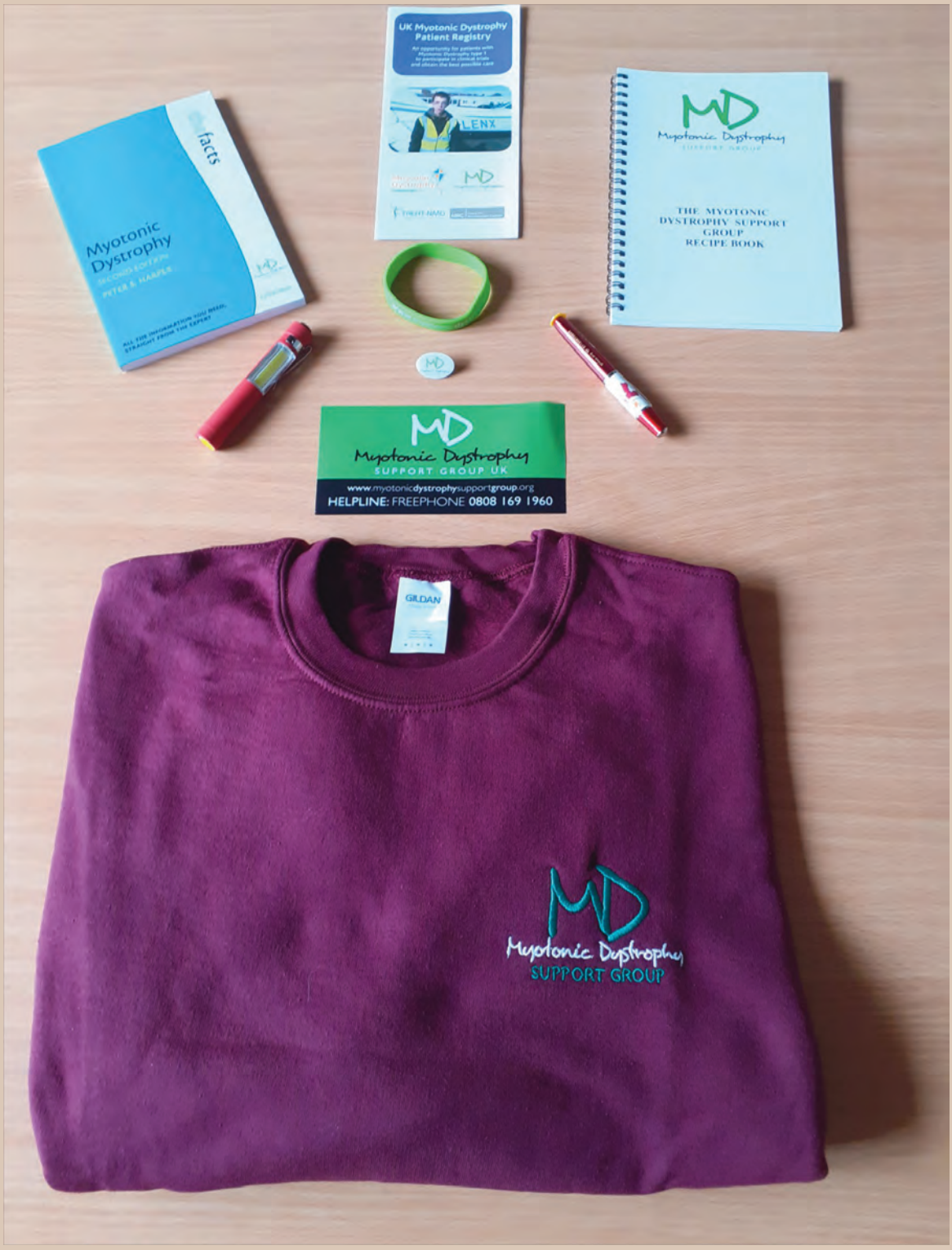
INFORMATION

Below is a display of all the information leaflets that are available free of charge. If you do need any for yourself, a family member or a health professional, please contact the office.



Anaesthesia and Sedation for patients with Myotonic Dystrophy
Basic information for Midwives
Bowel problems in Myotonic Dystrophy
Congenital Myotonic Dystrophy
Excessive Daytime Sleepiness and Myotonic Dystrophy
Facts for patients, family members and professionals
Just Diagnosed
Myotonic Dystrophy and the Brain
Myotonic Dystrophy and the Eye
Myotonic Dystrophy Support Group
Relatives Information
Swallowing Difficulties in Myotonic Dystrophy
The Heart and Myotonic Dystrophy
Why do we get new families with Myotonic Dystrophy

FOR SALE



Above are items for sale and the leaflet about joining the Registry.
Have you joined yet?

Facts Book £5
Recipe Book £1
Lapel Badge, Car sticker, Wristband all at £1
Torch, £3 and Snowmen pens £3
Sweatshirts £10/Polo shirts £8 available in all colours and all sizes
Postage and Packing extra.

W E L C O M E

Dr Stefen Brady Consultant Neurologist and Neuromuscular Specialist

Dr Stefen Brady took over the Oxford Adult Muscle Service following Dr Hilton-Jones' retirement last year.

Stefen studied medicine at Trinity College Medical School in Dublin and trained as a neurologist in Yorkshire. He first came to Oxford in 2010 when he was awarded a Muscular Dystrophy UK clinical fellowship. He went on to become a senior clinical research fellow funded by Myositis UK in 2013. He trained in muscle diseases with Dr Hilton-Jones at the John Radcliffe Hospital in Oxford and with Professors Hanna and Holton at MRC Centre for Neuromuscular Diseases and the Institute of Neurology in London. In 2014. He was awarded a DPhil by the University of Oxford for his work on inclusion body myositis (IBM).

Stefen has worked as a Specialist Neuromuscular Consultant since 2016. He returned to Oxford in 2019 to take over from Dr Hilton-Jones. Earlier this year, he became a council member of the British Myology Society.

When not in work, he enjoys spending his time (in descending order of importance to him) riding mountain bikes, cooking, and battling with his garden.

Registry

On Friday 18th September the Steering Committee of the UK Myotonic Dystrophy Patient Registry convened for their annual meeting. The Steering Committee comprises of professionals with clinical and genetics expertise as well as important patient representatives. Together they help govern the UK Myotonic Dystrophy Patient Registry and help decide whether it is suitable for the registry to support various new research projects and clinical trials.

The most recent meeting was attended by seven of the eleven members over a virtual meeting. One of the key discussion points was the ongoing Steering Committee membership and there were various suggestions as to which members may want to step down from the Steering Committee and who may be interested in joining.

The meeting also saw discussions take place about the UK Myotonic Dystrophy Patient Registry clinician form, and how it might be possible to amend this and use additional staff to help complete this when clinicians are really busy.

An overview of the current registry progress was presented which has seen the registry support over 25 different research projects since it was created in 2012. The overview also showed how many patients are currently registered which is now over 780, and new potential research projects that the registry may be supporting. The registry is very keen for more participants with myotonic dystrophy to register.

UK Myotonic Dystrophy Patient Registry

If you are interested in joining the UK Myotonic Dystrophy Patient Registry please visit: https://www.dm-registry.org.uk/ or contact ben.porter@newcastle.ac.uk. Thank you and take care.

Ben Porter is the UK Myotonic Dystrophy Patient Registry Project

Lockdowns learning curve

and how it has dragged me into 21st century, kicking and screaming I might add, but very happy now to be there. These last few months have taught me a good few things including being more patient, how to Zoom, how to keep in contact with friends, make new friends. All this without going outside the door. The only thing I regret is that this year I was going to go to our AGM for the first time in years, and it had to be cancelled, like lots of other events.

At the beginning of lockdown I was asked to take part in a Zoom meeting. Help, what was Zoom? Well, I asked Mr Google, and I had no trouble at all installing this app. What a boon it has been.

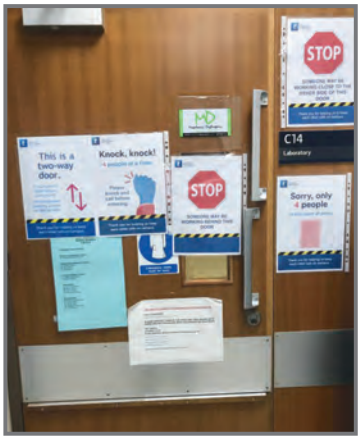
As a Christian I was very upset at the closure of our churches. I could understand the reasoning but it still hurt, a lot. Well not only did Zoom come to the rescue but it has been such a pleasure meeting people from various different Benefice and parishes around Llandaff Dioceses these last months. Sunday 10am finds me in St. Peter's a church in the Vale of Glamorgan (I live in Caerphilly a way away) for a service live on Zoom with usually 40 or more Zoomers, some like me from different parts of S. Wales a few from Sweden too, we are of course all in our own homes. Pentecost Sunday we had the readings in, English, Welsh and Swedish, so appropriate. Sunday evening I zoom into evening prayers at a vicarage in Tonyrefail a village up the valley. Here again I have met lovely people who have welcomed me and made me feel part of their church family. When we are able I intend going to both these churches and meeting the people who have welcomed me over the weeks.

As I intend, all being well, to come to next years AGM in Nottingham. This brings me right back to the beginning. I have learnt how to record and send voice mails, to video chat, although I can't get on with Skype. I've been asked to attend a Teams meeting. Even Mr. Google doesn't seem to be able to help me install this app. Lockdown has been hard, and now we are being allowed more "normal" freedoms, we must be vigilant and keep to the rules. My son has been shielding, as I expect a lot of you reading this have been. He is so looking forward to going out again, but always being very careful. God bless.

Margaret Ware

Update on the Brook Lab

After several weeks of badgering, mostly from Mike, here is an update from the Nottingham lab.



We would have produced it sooner, if only Mike had stopped his anti-Leeds United propaganda.

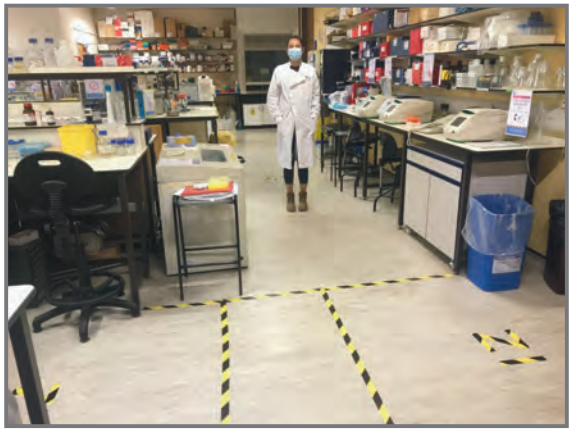
Anyway, we are back in the labs and slightly fearful of a second lockdown, though the Vice-Chancellor says that we cannot afford to damage research with a second lockdown, so hopefully we should be able to keep going even if COVID numbers continue to rise. The lab is a little different. It is decorated with black and yellow tape (we have adopted a zonal approach for 2M distancing) and there are multiple signs everywhere *(see the pictures of our lab door-above and Anjani in the lab, overleaf).*

We can only have 4 people in the lab at any time and we are going to work in shifts so that we have 2 bubbles. This is in case any of us comes down with the virus and the rest have to isolate. The other bubble should be able to keep going (and do everybody else's work in the lab) whilst the other bubble is under house arrest.

Continued on next page

Update on Brook Lab continued

Anjani writes: "When lockdown started, I had to freeze a lot of my live cells, not knowing if they would survive, by the time I was back. The return was bittersweet for me, as my mind kept drifting towards the worst - what if my months of work didn't make it? Would I have to restart? Would I be lucky enough to have another breakthrough? The day we went back I rushed to the freezer like a momma bird rushes to her chicks after a hunt. Unfortunately, I wouldn't know the answer I was looking for immediately. After taking all precautions and following the procedures. I had to wait for my cells to thaw. So, I waited!! When the results came back, it almost felt like a dream - most, if not all, of the cells made it! Lockdown wasn't all that bad after all. Not to get used to talking to others through plastic shields and suffocating facemasks... It's worth the effort."



Sarah says: "Although it was great to spend time at home with my kids whilst being furloughed it felt good to return to work in the lab and to see all my work colleagues. However, it feels very different to how things were prior to lockdown and although many labs are back working in the Medical School it is still strangely quiet. In our laboratory we have had to divide our space into one person working zones and implement new working regimes to ensure Covid-19 safety measures are in place. There has been plenty of paperwork too and I've had to write a lot of risk assessments! Despite all the changes everyone has adjusted to the 'new normal' and have got stuck back into what we like doing best – our research."

Jake comments: "It's been a long process and everyone has been working very hard but we are finally back to a normal (ish) state in the lab. It's great to be back and I'm very glad to no longer be stuck reading papers from a computer screen all day. I'm excited to finally be conducting my first major experiment next week and taking the first big step on my PhD in terms of lab work. Fingers crossed it all goes as planned."

Belle writes "Hiya, this is Belle. We have returned to lab for over 2 months. Everything is getting better and better and our experiments are already back on track. Although the government has relaxed the restrictions about Covid-19, the Uni is still being rather cautious. For example, each room has been organised for certain amount of people to use, even the bathrooms. I appreciate the situation. As there have been over 1500 students affected by COVID, the Uni is not making a mountain out of a molehill. Meanwhile, I am really thankful for our Uni and NHS workers who are trying to keep us safe, I believe if we stick to it, we will defeat the virus one day."

So dear readers that is a brief update from the University of Nottingham. I also went to the MDSG office in Gedling last week, partly to keep an eye on you-know-who, and I can confirm that Margaret and Mike are working hard (It was Julie's day off). We met Tom Randall MP, who represents Gedling. It was a very constructive meeting and Tom (we are on first name terms now) kindly offered to ask questions in Parliament for the MDSG. So, if any of you have anything you would like to raise that is relevant to Myotonic Dystrophy, please tell Margaret. She's on first name terms with Tom too, and I am reliably informed by an unnamed source, that she took a shine to his bearded assistant Sam so Margaret would like an excuse to get back in contact with him. Take care and stay safe.

BW David

Helpful Hint?

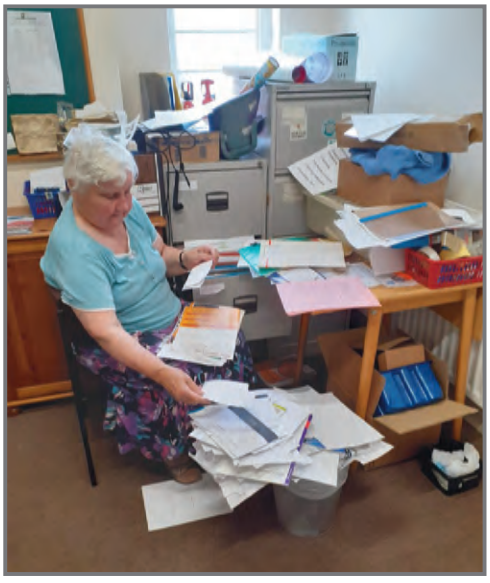
If you take tablets….do you find that sometimes they fall on the floor when you are getting them out of the foil? I have found it helpful to have a piece of kitchen roll at hand on the work surface you are using to get your tablets out of the foil. If you drop one whilst doing this the piece of kitchen roll stops the tablets running away. I put my tablets in containers for the week. Any other ideas? Margaret

My son Ian (Consultant Anaesthetist) needs your sympathy. He has had an emergency operation but is home and being looked after by a trained nurse- his wife Katie. Patients need you Ian and the Air Ambulance need you as soon as you are mended.

Subscription apology

Julie, our secretary has recently sent out reminders to people who have already paid! We apologise for this. When the subs are paid through the website using Worldpay, the bank does not always record the senders details.

We are asking...when you do pay your subs through the website please send the subs form back to the office, so that we have your information. Many thanks, Margaret.



What a view!

Member, Martin Payne, sent us this picture of his daughter, Alisha Moore, age 14 after climbing Cow and Calf rocks, Ilkley, West Yorkshire on 19 September.

Alisha is going into hospital for bilateral Achilles tendon 'lengthening' operation. She will be in casts for four weeks and need rehabilitation. Martin and family are hoping this will improve her walking. *And we hope so too, Alisha*

Annual General Meeting

As has previously been reported, owing to the Pandemic, we have been unable to have our usual Conference and Annual General Meeting. Charity Commission Guidelines have recently been updated, and they do allow us to miss an AGM provided that,

a) We record the fact that it is due to Covid 19
b) We have filed the accounts for our last financial year and
c) We have submitted our annual report.

I can confirm that MDSG has complied with all the above and have thereby met our legal obligation.
If any member wishes to see a set of accounts, then please contact the office for a copy.

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

Devon
Josephine Holmes
(contact office)

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

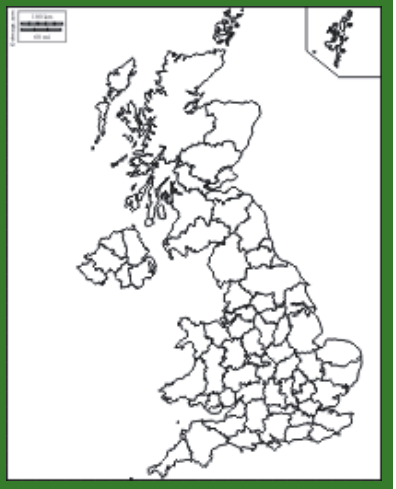
Sheffield
Rachel Reeson
07544 353076

Somerset
Lucy Howard
07748 636122

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



National Co-ordinator
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Helpline: Freephone 0808 169 1960 - Office Telephone/Fax Number: 0115 987 5869

Email: contact@mdsguk.org - Website: www.myotonicdystrophysupportgroup.org

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Myotonic Dystrophy SUPPORT GROUP

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