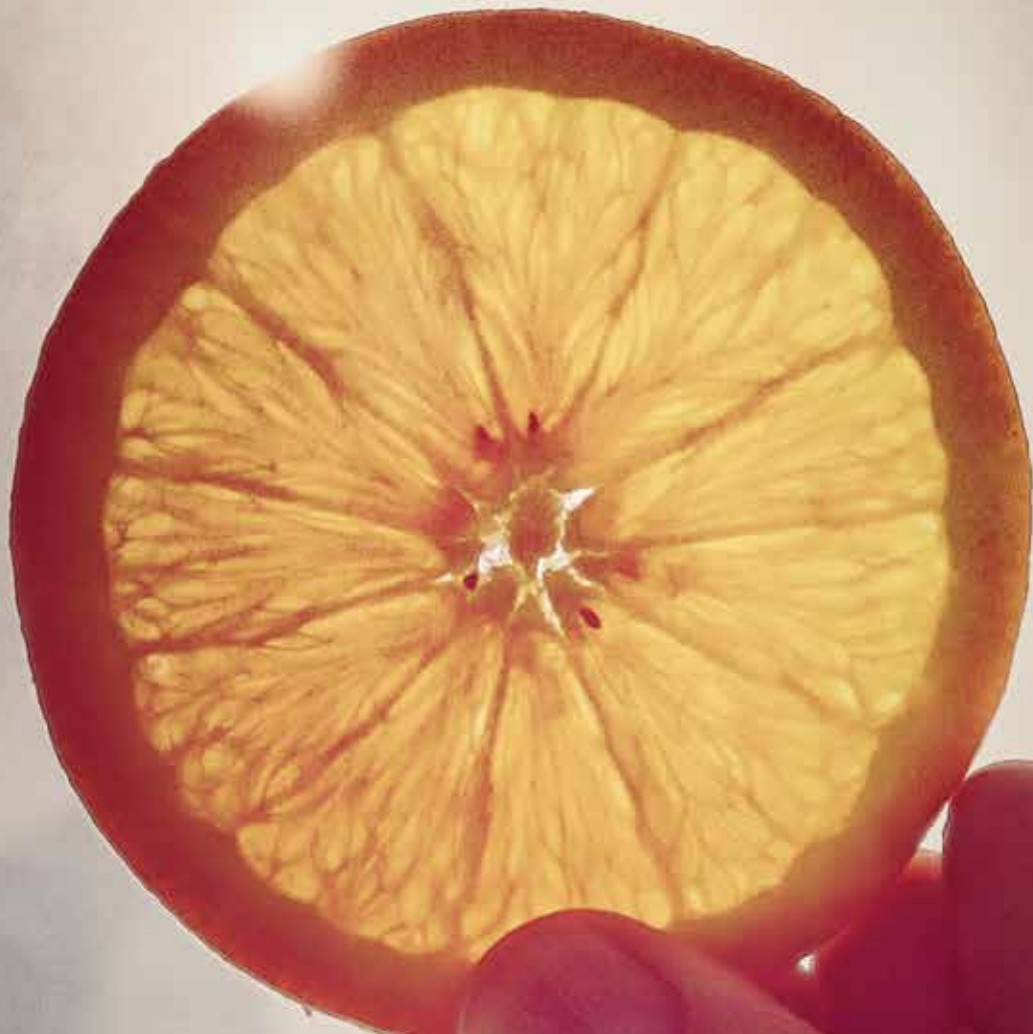


MSA

NEWS



MSA Trust Members Magazine | ISSUE 47, 2016 | www.msatrust.org.uk



Food for Thought

DIET AND MSA

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The Trust is financed entirely by voluntary donations.

Registered Charity Number 1137652
Scottish Charity Number SC044635
Company Number 7302036

MEMBERSHIP AT OCTOBER 2016

Current MSA members 1,288
Carers, relatives & friends 2,198
Healthcare professionals 2,374

Total 5,860

MSA NEWS CONTENTS

Multiple System Atrophy Trust

Information, support, education and research. Free services for people with MSA, carers, family, health and care professionals. **Our Vision is a world free of MSA.**



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We endeavour to ensure the accuracy of articles in *MSA News*. Please note, however, that personal views and opinions expressed are not necessarily endorsed by the Trust. Designed by Base Media www.base-media.co.uk. Printed by INQ Design 020 7737 5775.

WELCOME TO MSA NEWS



The Trust's CEO Karen Walker gives an update on what's been happening, and what's planned, at the MSA Trust.

Welcome to your latest edition of the MSA Trust magazine. We have seen plenty of activity since the last MSA News, not just here at the Trust but with many of you participating in events and fundraising for us during the last few months. Thanks to all of you who are helping in whatever way you can.

Sadly, over the summer we had to say farewell to a couple of members of staff. Joan Smith, our interim Head of Fundraising, retired and Melissa Tindle, our Events and Community Fundraiser, moved to a new job that is about an hour and a half closer to her home! We wish them both all the best and thank them for all the wonderful work they did for the Trust. At the time of writing our new recruits are not yet in post, so we will ensure they introduce themselves via email and at events long before the next MSA News is due. In the meantime, however, we have been very fortunate to welcome Tanya Mitra, who has been volunteering with us for the last six months, onto our fundraising team. She will ensure communications and information keeps flowing between the Trust and our amazing supporters.

With autumn upon us it's not too early to start thinking about Christmas, is it? We are very excited to have details of our new Christmas cards in this edition. As they are all rather gorgeous, do get your orders in early and encourage other family and friends to get theirs from us too. We have decided to mix things up a bit this year so we will not have a Christmas raffle. Next year we will be marking 20 years of the MSA Trust, so there will

be a summer raffle with wonderful prizes – more details in the next edition of MSA News.

Finally, I don't want to miss any opportunity to share with you our ongoing plans for the 20th Anniversary of the Trust. We have always been clear our mission is to find the cause and ultimately a cure for MSA. That mission remains as important today as it did 20 years ago when Sarah Matheson first set up our charity with the help of her family and friends. We are planning a varied calendar of events to mark the occasion, alongside some challenging targets including raising enough funds to recruit a fourth MSA Nurse Specialist. Please look out for information on events marking the 20th anniversary in your February edition of MSA News and on our social media channels (we're now on Instagram too).

I very much look forward to meeting lots of you in the coming months and to hearing about your ideas and activities helping us mark this important milestone. **MSA**

Karen Walker, CEO



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www.twitter.com/MSAtrust

MEMBERS STORIES

“It is as it is”

One of our members taking part in a research study run by AstraZeneca reflects on their journey as the study comes to an end...

It was 7.30 on a cold, windy Tuesday morning last August, the clouds dark and menacing. When I found myself huddled, red nosed in my wheelchair on draughty platform two at Salisbury train station at the start of my unknown journey with the AstraZeneca research programme in Kings College Hospital, London. I gripped my Costa coffee in its non-recyclable container and smiled tightly at my ‘**it is as it is**’ husband, admiring but at the same time resenting him for not showing the same anxiety.

The research suite was a discrete, calm unit just a short walk, or in my case a short push, away from the frenetically busy entrance and corridor of the hospital, packed with practitioners, staff and patients from a multiplicity of nationalities and backgrounds, a microcosm of cosmopolitan London. Indeed the team itself comprised consultants from Italy and nurses from Goa, Sri Lanka, Brexit England, Malta and Portugal. The researchers work from leased offices, ascertaining physical and psy-

chological wellbeing and laboriously completing the necessary reams of paperwork. The ‘torture’ room with its corresponding machines is operated by the nurses.

A year on and the journey is over. In fact, it finished six months ago with my last PET scan (what a cute sounding ac-

“

I was reassured that I had added value.

”

ronym for a 90 minute ordeal) and I’m not any the wiser. To date, the results have not been circulated even to the researchers. Since it is a worldwide project, I must be uncharacteristically patient. Not for one moment have I regretted taking part. The blood taking, the scans, the urine samples, the ECGs, the weight and blood pressure monitoring and the twice daily tablets have not made me think differently,

thanks to the consultant and her team of highly competent, really lovely nurses. They made me laugh, feel valued, and reassured that I had added value to the research.

There has been no effect of the myerloperoxidase inhibitor where I am concerned; no miracle cure, no curbing the onslaught of MSA. I remain as expected. I can’t walk even with my tried and trusty Tri-Walker, now relegated to the garage on its way to the dump along with the grass cuttings. My speech is slow, ponderous and at times schlurred! Imagine how it sounds after a glass or three of wine!

“**It is as it is**”, says my husband as he brings the chilled Chardonnay. **MSA**

ON TOP OF THE WORLD

Our **Where Are You Wearing Your MSA Orange** challenge already looks hard to beat!

David and Mary March along with their family took on the daunting task of going up and over the O2 (the Millennium Dome) in London last month. This would be an amazing achievement at any time but it just so happens the family completed the climb on the hottest day of the

year! David who has MSA did the ascent in his wheelchair. The O2 staff (who were also marvelous) used ropes to help David over the top with him being in control of the steering. Thank you so much to all of the March family for completing your climb of the O2 and raising over £2,000. **MSA**

YOUR NEW GIFT AID DECLARATION FORM

giftaid it

Gift Aid allows you to boost your donation by **25p** for every **£1** donated to the MSA Trust. In order to qualify for Gift Aid you need to be a UK tax payer.

Since April 2016, HMRC states that if you pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed then it is your responsibility to pay the difference. The Gift Aid Declaration wording has slightly changed to reflect these changes. We now have new declaration Gift Aid forms stating this. You can download this form from the **"Donate"** section of our website or ask us to send one to you. These changes will not affect any past donations given before 1 April 2016. **MSA**

THE ROLE OF THE DIETITIAN



Alia Torreadrado writes about how it's her role as a dietitian to help people with MSA live life to the fullest...

In working with you to improve your diet, dietitians can help improve your wellbeing, help you manage your symptoms and help you enjoy your food better. They can also provide advice, support and reassurance to loved ones and carers to make life easier and help them in their caring role, as food is such an important part of this. Dietitians will also work closely with other invaluable local voluntary and NHS services such as neuro physiotherapists, occupational therapists, speech and language therapists, GPs, specialist nurses, hospices and community nurses.

With nutrition being a basic foundation for wellbeing, there are few features of MSA that can't benefit from some dietetic involvement or consultation. If you've been diagnosed with MSA, you may benefit from seeing a dietitian if you need advice for autonomic problems such as postural hypotension, postprandial hypotension (drop in blood pressure after meals) and constipation, which can all be helped through changes to your diet and drinks.

You might also see us when there are changes to your swallowing and you have to adapt the texture of your meals and drinks. If this is a problem, we will work closely with your speech and language therapist with the aim of helping you to continue enjoying your favourite foods and drinks, but maybe in a new way.

Sometimes getting all the nutrition and fluid you need can take longer and may become a struggle, so your dietitian will come armed with a selection of options for you based on your favourite foods and taste preferences. This might mean adding cream to your porridge, cheese in your sauces or having more 'naughty' puddings and snacks. The plans you come up with together might sound simple and hopefully fun and appetising (that's the goal!), but these strategies are very effective and thoughtfully calculated by the dietitian to give you the extra nutrition you need. Your dietitian might also ask you to try samples from a selection of prescription nutritional options, which might be juices, milk-

shakes, pudding-style products or powders you add to your food or drinks. These sometimes have a bad reputation, as everyone knows someone who had them and didn't like them, but there are so many of them that there's usually a great product for everyone. Luckily your dietitian knows them all and can advise you and if you find one you like your GP can prescribe them for you.

Some people do gain weight because of their reduced mobility or because they have come to rely on high calorie foods they perceive as easier to prepare and consume. If this is a problem for you, your dietitian can help you lose weight in a sensible way which may allow you to mobilise better and be more independent whilst still having an enjoyable diet that meets your particular needs. They'll often do this by working closely with occupational therapists and this might involve choosing recipes, aids for cooking and ways of transporting food and eating in a way that suit your needs and preferences better.

If meeting your nutritional

needs is still a struggle or if you would like to think about planning ahead should this happen, then a dietitian can talk you through what options are available, such as artificial feeding, which despite people's initial concerns can be a great relief and comfort to those who need it. This will usually involve discussions with your neurologist and speech and language therapist and will be a 'team decision' with you always at the centre of it. I always say to my patients who could benefit from it, that tube feeding is a bit like a walking stick for nutrition – some people will choose not to use a walking stick when they need it, but that may also mean they don't live their daily lives as fully as they might otherwise. Family and loved ones can find it very reassuring to know that someone they care for, who is struggling with their nutrition and hydration, are finally getting their needs met and feeling better for it – although the decision is always yours. When a feeding tube placement is being considered, it is usually preceded by long conversations with your dietitian to help you explore the pros and cons of taking this step – as well as explanations to dispel some of the myths of tube feeding, of which there are many! Tube feeding doesn't have to stop you from eating and drinking what you want. If however, this isn't something you wish to consider, you will always receive as much support and guidance from your dietitian as needed.

If your nutrition suffers due to difficulties with MSA symp-

toms, a dietitian's support could help to minimise these issues. Support can improve your sense of wellbeing, improve your mobility and reduce your risk of falls, reduce your risk of urine infections, improve your hypotension, improve your sense of fatigue, improve bowel symptoms and can help you preserve your muscles and strength. It's amazing what food and drink can do!

My patients (jokingly I hope!) often call me a variety of names such as the 'cake lady' or the 'poo lady' (probably because I talk about it so much and carry a 'poo chart' with me!). They're all alright by me, because in getting to know each other and what you need, we can make life better.

Thanks to Sally Darby for peer-reviewing this article.

MSA SPECIALIST GUIDE FOR SPEECH AND LANGUAGE THERAPISTS BY LAUREN GRAY, SLT

MSA is a condition that continues to require more awareness and research to help support those diagnosed. Specialist guides are designed as a free resource to help with this process and will hopefully continue to evolve as research and therapy practice changes.

In March 2016 an MSA Trust commissioned guide for Speech and Language Therapists (SLTs) was published. It is well documented in research that early access to SLT for people with MSA can significantly help with the management of communication and swallow impairments. SLT input can also en-

sure that the impact of MSA on social participation is not forgotten and receives appropriate intervention.

The guide should not only be useful for SLTs but for other Health and Medical Professionals who wish to understand more about our role when using a multi-disciplinary team approach. It is important to remember that no two people with MSA are the same. They may present with different communication or swallowing symptoms which is why specialist SLT input is key.

Not all SLT service provisions will be the same, but the guide directs clinicians to areas that should be considered and appropriate therapy or management options that may apply based on the most up to date evidence. **MSA**

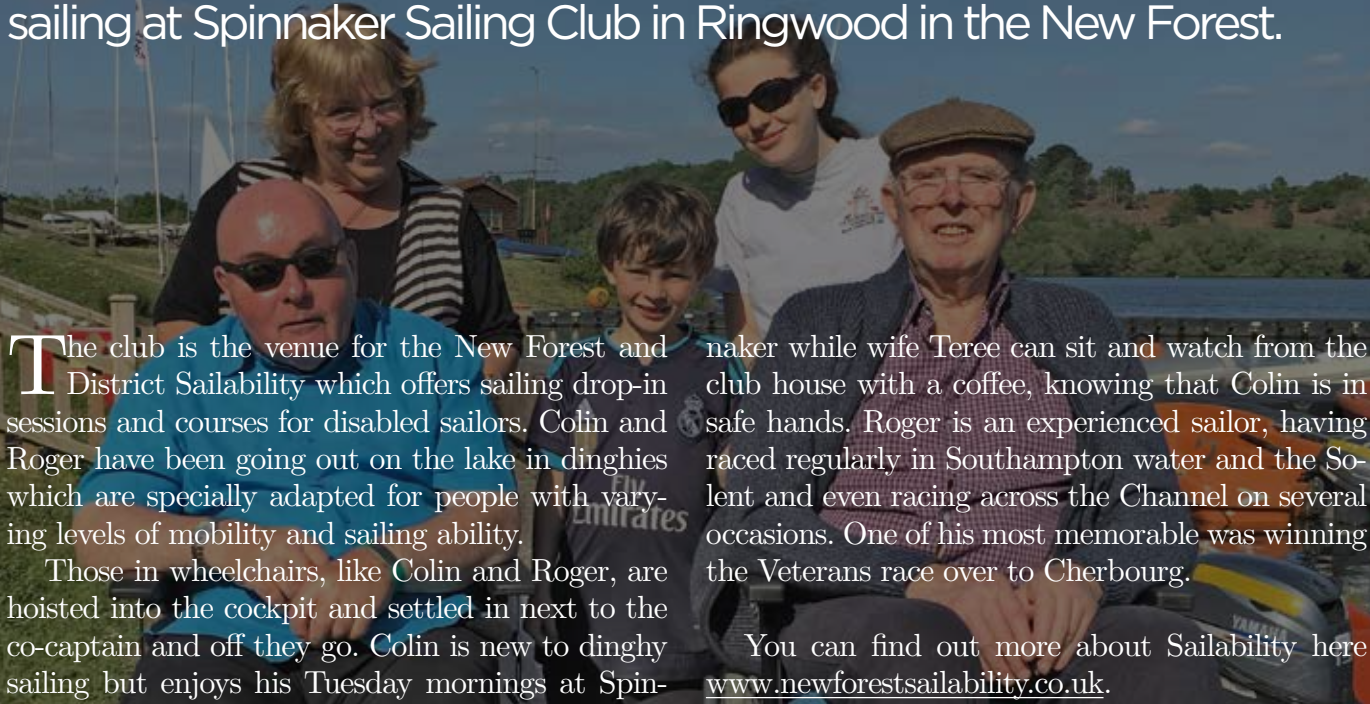


Lauren Gray

You can download the SLT guide from the website www.msatrust.org.uk or if you would like a printed copy please call the office on 0333 323 4591.

MEMBERS STORIES

Colin Allen and Roger Lockett, two members of the Dorset MSA Support Group have been taking to the water lately to enjoy some sailing at Spinnaker Sailing Club in Ringwood in the New Forest.



The club is the venue for the New Forest and District Sailability which offers sailing drop-in sessions and courses for disabled sailors. Colin and Roger have been going out on the lake in dinghies which are specially adapted for people with varying levels of mobility and sailing ability.

Those in wheelchairs, like Colin and Roger, are hoisted into the cockpit and settled in next to the co-captain and off they go. Colin is new to dinghy sailing but enjoys his Tuesday mornings at Spin-

naker while wife Teree can sit and watch from the club house with a coffee, knowing that Colin is in safe hands. Roger is an experienced sailor, having raced regularly in Southampton water and the Solent and even racing across the Channel on several occasions. One of his most memorable was winning the Veterans race over to Cherbourg.

You can find out more about Sailability here www.newforestsailability.co.uk.



MILK, SUGAR AND TEA PARTY IS BACK!

3rd October 2016 was World MSA Day but there's still time to join us in hosting a **Milk, Sugar And Tea** party to raise vital funds in aid of the MSA Trust. Whether it's you and a few friends at a family gathering or at your work or school, it's a great excuse to get together. Get started and order your pack today! Email us at fundraising@msatrust.org.uk or complete this tear-off and send back to us.

I would like to host a Milk, Sugar And Tea party and order my pack

Name:.....

Address:.....

Postcode:..... Telephone:.....

Email:.....

Where will you host your tea party: Home Work

School/University Other.....

When will you host your tea party: World MSA Day

Other.....

(Please complete and return to MSA Trust, 51 St Olav's Place, Lower Road, London SE16 2XB)



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WORLDWIDE RESEARCH



London, UK Battla et al

To look at young onset MSA cases and find clinical clues that may help in early recognition of MSA. This study has looked at cases from London, Germany and Italy to consider if diagnosis can be supported by looking at young onset Parkinson's. The study found a number of similarities, including the initial response to the drug levodopa.

London, UK Kiely et al

This study is looking into alpha-synuclein degradation in MSA. This study is funded by the MSA Trust and more details will be shared in later editions of MSA News as the study reaches its conclusions.

San Francisco, USA Olson & Prusiner

This study looked at small molecules that might prevent alpha-synuclein formation. This could potentially lead to a new drug to prevent build-up of alpha-synuclein in the brain. The project leaders believe this is a promising approach to the discovery of drugs for MSA and other neurological conditions.

A world map with a dark blue background and orange landmasses. Three callout boxes are overlaid on the map, each pointing to a specific location in Europe. The boxes are white with blue text and have a blue border. The first box is in the top left, pointing to Munich, Germany. The second box is in the center, pointing to Innsbruck, Austria. The third box is in the bottom left, pointing to Belgrade, Serbia. The map shows the outlines of continents and countries.

Munich, Germany

Schuberth et al

In this trial the investigators studied a catechine (plant extract) which prevents proteins binding together (this occurs with alpha-synuclein in MSA). Initial findings are that individual cases of liver toxicity could be controlled by blood tests that check liver function. This study is still in its early stages and the data reported related to safety only.

Innsbruck, Austria

Eschlboeck et al

This study aimed to identify the characteristic presentation of MSA and key changes that indicate progression of the condition. It also aims to clarify the usefulness of 'red flag' symptoms currently believed to be significant in making the diagnosis of MSA. 170 historical records of people with MSA are being analysed, looking at the clinical features they presented with throughout the course of their disease to assist in identifying whether there are particular features that will help us understand and predict better how each person's MSA may progress.

Belgrade, Serbia

Kresojevic et al

The aim of this study was to estimate which demographic and clinical factors were the main contributors to the health-related quality of life (HRQoL). The study also compared HRQoL between people with MSA-P and those with Parkinson's. The researchers conclude that autonomic dysfunction is an area that should be focused on.

We are pleased to bring you this world map of MSA studies, to highlight how important collaborative working is within the rare disease community.

The information was gathered after our MSA Nurse Specialist, Jill Lyons, attended the Salerno MSA symposium in April. We hope that you will find this selection interesting and that in coming editions we will be able to select several studies for more detailed updates.

Our thanks to the Chair of our Scientific Advisory Panel, Professor David Burn, who selected the studies he felt were of the most interest to people affected by MSA into the causes and ultimately the cure for MSA.

LULU WONG TAYLOR



George Taylor writes about someone well known to people in our MSA community.

Lulu Wong Taylor grew up in Sarawak, Borneo, training as a teacher of art. She married an Englishman (myself) and eventually settled in Jericho, Oxford. She continued to paint exotic scenes, publishing greetings cards and prints, exhibiting during Art weeks and once at the Edinburgh Festival. Her hot chocolate and soup runs – on her bicycle – to the homeless made her a familiar figure in the streets of Oxford. She was an exuberant, passionate and generous person.

This year sees her second Christmas card for the MSA Trust (see back page). Last year's had to be reprinted because it 'sold like hot cakes'! Lulu drew the designs some years ago when, with hindsight, a range of MSA symptoms were already starting to appear.

However, it wasn't until September 2013 that she was diagnosed. By then painting and drawing had become difficult, but Lulu was a committed Christian and this didn't quench her spirit. 'I can't think of her without smiling and seeing that mischievous twinkle in her eye. It's rare in my line of work to have someone with a long term condition who was such fun to work with,' commented her occupational therapist. She died at home peacefully in her sleep earlier this year.

At the celebration of her life at the King's Centre, Oxford, attended by around two hundred people, over **£1,200** was donated to the MSA Trust. Lulu would have been pleased to give another card design to the Trust, too. **MSA**

In Memory

George Mitchell
Robert Allen
Maureen Davenport
Lynette Nardone
Philip Jones
Marilyn Corkill
Chris Lightfoot
Jennifer Forward
Alan Campbell

Roger Spires
Frank Cross
Helen Hughes
Mark Rumbelow
Robert Piper
Angela St. Clair-Clarke
Christopher Rumford
Diane Harrison
Brenda Nathanson

Jacky Ward-Panter
Norman Kingston
Mary MacLennan
Paul Pennington-Edwards
Chris Yoell
Maurice Coates
Kelvin Rumming
Ernest Woollett
Ian Whittaker

Valerie Brocklehurst
Peter Maitland
Charles Chetta
Huw Jermine
Raymond Ireland
Lucy Ruse

GREY MATTERS

Louise Sizer, the Trust's Administrative Assistant was invited to Queen Square Brain Bank to learn how they use donated tissue to better understand neurological conditions such as MSA.

The BBC recently filmed a fascinating documentary presented by Angela Rippon highlighting the research that the Queen Square Brain Bank (QSBB) is undertaking on dementia. With my interest piqued, I arrived at the Brain Bank and was greeted by Professor Janice Holton, the Neuropathology Director at the Brain Bank and Dr Aoife Kiely, Research Fellow – both members of the MSA research group at QSBB. They explained the importance of brain tissue in their research and showed me the difference between a healthy brain and one affected by MSA under a microscope.

The team relies on post mortem brain donations from people with MSA alongside those from healthy donors in order to make accurate comparisons. So far their work has shown that the immune system of the MSA-affected brain may not be functioning properly resulting in over-activity known as 'neuroinflammation'. The team uses state-of-the-art tech-

nology to look closely at a large number of indicators of inflammation in brain regions typically affected. This has given them a unique opportunity to find several new targets for future studies that may be valuable in developing treatments for the disease. Dr Kiely's work is paid for by the MSA Trust and she explained to me how essential this funding is in order to continue in their research.

I also met with senior research technician Dr Sandrine Wauters who has created a database detailing over 200 MSA cases – the largest collection in the UK. This is a remarkable resource for scientists studying the condition.

On the way to the lab I was taken through a corridor lined with artwork from the Artist in Residence at QSBB, Dillwyn Smith. He created beautiful works using images of the brain in order to engage the public with brain donation. The lab itself was an extraordinary place with many scientists hard at work on their

own projects. I was shown samples of brain tissue that had been sliced thinner than the width of a human hair and delicately preserved for future use.

Finally, I met Lynn Haddon who manages donors' journeys from the initial enquiry through to the careful delivery of the brain and tissue itself. She acknowledged that organ donation can be a difficult and sensitive issue to talk about but for those people who are interested they can rest assured that their brain will be handled with the utmost care and their legacy will play a vital part in the on-going research into MSA research at QSBB. **MSA**

For more information on brain and tissue donation please contact the Queen Square Brain Bank on 020 7837 8370 or email l.haddon@ucl.ac.uk.

FUNDRAISING ROUND-UP

Our fantastic community fundraisers from Wales, Rebecca Edwards and Kelly Greenough, put on a MSA Family Funday and raised close to **£2,200!**



Family Funday

Simon Breslin ran the Edinburgh half marathon with his cousin Amanda in memory of Simon's mum, who had MSA. Between them they raised **£2,843.**

One of our running events, the British 10k raised close to **£8,000** and participants included Janine and Ethan.



Janine and Ethan after completing British 10K

Thanks go to our Trustee, Al Loehnis who raised an amazing **£8,000** in his triathlon event in May. He describes the agony and triumph in his blog post on our website – www.msatrust.org.uk.



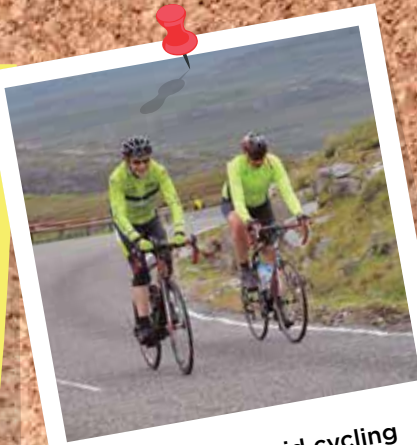
Anita Shellum after completing Ride London 46

We had an incredible 14 riders in Ride London cycling 46 or 100 miles each. They all completed the course which was an amazing effort and raised a fantastic **£11,000** and counting.



Neil Crawley in Ride London 100

Another challenging ride was undertaken by Peter Cormack and David Lindsay in the Outer Hebrides, covering 305 kilometres of the Isle of Lewis. What an endurance test that was and they raised close to **£2,000**.



Peter and David cycling 305km

Over in Copenhagen, Neil Tempest was competing in an Ironman Triathlon, supporting his uncle who has MSA and at time of print raised over **£2,000**.



Neil Tempest in the Ironman Triathlon

Have you spotted the MSA Trucks yet? They are covering lots of miles around the country, raising awareness and funds. Let us know if you have seen them anywhere unusual!



MSA Truck

The amazing team at KPMG undertook the Three Peaks Challenge this year and raised a whopping **£25,000** in the process.

LAST CHANCE TO REGISTER FOR THE LONDON MARATHON 2017

We have very limited Gold Bond places available for the London Marathon. If you have been unsuccessful in the public ballot please get in touch with us. Please note we only allocate our Gold Bond places to those who have a direct connection to MSA. The closing date for applications is 24 October 2016.



MEMBERS STORIES

“Baby B’s” letters to granddad

Baby Beatrix was born in October 2015, and her mum Amanda started writing a blog about what they had been up to together. Here’s their story...

Dad has been living with MSA for around about five years now. From an initial appointment with a neurologist in September 2011 it took almost two years to get a diagnosis. In July 2014, Dad decided to try some gymnastics in the garden and fell and broke his hip... His recovery has been good though, he uses his rollator to walk and has a nurse come in to see him each month. He also has a speech therapist, who he saw every week to begin with, but now they call on a monthly basis, or if he is having issues with swallowing.

We went to visit my parents for a week in the February, after Mum had a shoulder operation and needed some help. Mum asked Dad to get his speech therapy pack out and a book of short stories, to show Beatrix what a good Granddad he was, doing his exercises. It was immediately obvious that Dad wasn’t too keen on them - I can see why, there

are only so many times you can read the sentences about Gary flying to Chicago for his “vacation” before it gets a little tiresome. We also discovered he didn’t speak as clearly as we know he can sometimes because



he felt like he was shouting (even though he wasn’t). This is where the idea for the “letters to Granddad” came from.

“Dear Granddad...” This is how we start each Wednesday, publishing a roundup of what Beatrix has been up to that week. Initially, I suggested we wrote an actual letter each

week and put it in the post (real mail!). Mum suggested it would be nice if we e-mailed it instead, as then Dad could keep up some of his computer skills too. I thought we could do one better and decided to add a section to my blog. Dad looks for the blog website and then reads the letter out loud for Mum. We try and keep it fun and it serves a few purposes: 1) It gets him to speak clearly at least once a week and I hope, gives him a laugh 2) Mum and Dad get to keep up with what Beatrix has been doing, and 3) We bring MSA into the spotlight for all of the normal blog readers and hopefully a few more.

MSA

All of Beatrix’s letters can be found here at www.bootiesandbunting.com/letters-to-grandad.

COENZYME Q10 (CoQ10)

We have many people asking us about the possible benefits of the supplement Coenzyme Q10. Katie Rigg, MSA Nurse Specialist explores this further...

We regularly hear of people with MSA who take the supplement CoQ10, in the hope that taking this will reduce fatigue and improve function.

Coenzyme Q10 (CoQ10) is an antioxidant that is made in the human body. CoQ10 is needed for basic cell function.

Currently CoQ10 is not a medication that can be prescribed. This is because the evidence is poor as to whether it provides any benefit; and although it can be bought as a food supplement it is quite expensive.

It is made by most of the body's cells and is key to energy production for all the cells in the body. Some people with Parkinson's Disease and some elderly people may have lower levels of bodily CoQ10, but unless we are born with a genetic deficiency to absorb CoQ10 most of us will ingest enough from a good, balanced diet.

Foods that are a good source of CoQ10 are meat – especially offal; fish – particularly oily fish; soya beans; canola oils and nuts. Other sources are fruit and vegetables and dairy produce.

There is limited evidence to in-

form that increasing the amount of CoQ10 through supplements results in an increase within body tissues. Where there is some evidence for this, it relates to uptake in the heart, liver, pancreas and kidneys, but the research undertaken has limitations in terms of robustness.

Although there is some research suggesting that some people who have Parkinson's Disease may have lower levels of CoQ10, there is no evidence that this is a causative factor or that taking the CoQ10 supplement will improve the condition. Two small studies, one led by Shults (2002) and another by Muller (2003), suggested there may be some mild benefits in taking CoQ10 in people with Parkinson's, however the 2006 NICE Guidelines found the evidence not strong enough to recommend this as a treatment.

Studies undertaken have indicated that people can take doses up to 1200mg a day safely for several months with no major adverse effects. The main reported side effects are nausea, diarrhoea, indigestion and abdominal discomfort.

If you choose to take CoQ10

inform your GP and Consultant as it may possibly lower blood pressure and blood sugar and can reduce the effectiveness of warfarin if you take this.

Whilst there is little evidence that there is any benefit to taking CoQ10 supplements if you do try it, limited evidence suggests a daily dose of 1200mg divided into three doses of 400mg may be most beneficial and safe to take for three months, by which point it will be clear if you feel there is a benefit that justifies the cost. **MSA**

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SUPPORTING & HELPING EACH OTHER

Emma Rushton, the Trust's Information and Services Manager reviews some of the topics discussed during our summer Support Groups...

Our MSA Nurse Specialist, Katie Rigg reported a discussion on the use of Continuous Positive Airway Pressure machine (CPAP) in Dublin. Using this supportive breathing device overnight can reduce REM sleep, restless leg problems and daytime fatigue. If you have noisy or changed breathing at night, REM sleep and restless legs it is worth talking to your GP about having a sleep study and breathing assessment. This will show if you are likely to benefit from the CPAP machine, and the assessment centre usually provides these or will advise how to purchase one.

If you're thinking of applying for a grant to purchase items such as speech apps or mobility aids, then a member of the Lincolnshire Support Group shared that it's worth initially checking if your occupation has a benevolent fund. You may be eligible to apply to this and we know some members have been successful. Some examples of benevolent funds include the Help Musicians Benevolent fund and Forces SAFFA. You can also use the Turn2us grant finder on their website www.turn2us.org.uk.

One member of the Greater Manchester Support Group was provided with a piece of equipment called a 'Mangar Camel lifting aid' by their Occupational Therapist (OT). The Camel aid inflates and is used to help get someone off the floor when they have fallen. They have found this to be much easier to use and more supportive than other products. Please speak to your OT if you think this is something that would be useful to you.

The Cornwall Support Group was able to secure a representative from Cornwall Healthwatch to come and do a presentation on the work they do. Part of the Healthwatch team's role is to deal with people's complaints regarding an NHS service that is common to several people or one-off complaints which are serious. There are Healthwatch teams all around the country and you can find your local team at www.healthwatch.co.uk.

At the Inverurie Support Group there was a discussion held about swallowing problems and how this can become especially difficult when taking medicines in pill form. Our MSA Nurse Specialist advised that it's important to ask pharmacists for their advice regarding this and to check whether there are different forms of the same drug available that may be easier for some people to swallow, for example in dispersible or liquid form.

If your Support Group discussed something that you think might be helpful to others please let me know and we'll try to include it in the next edition of MSA News. **MSA**

Emma Rushton - Information & Services Manager

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MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people affected by MSA and healthcare professionals that can support you.

Please contact Emma Rushton at the Trust's Office on **0333 323 4591** or email her at emma.rushton@msatrust.org.uk for more details. These groups are subject to change, so please check the Trust's website or ring the Office for up-to-date information.

GROUP	VENUE	DATE & TIME
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 12 Oct - 1.30pm
Cambridgeshire	Barton Bowls Pavilion, High Street, Barton, Cambridge, CB23 7BG	Thur, 13 Oct - 2.00pm
Cheshire & Greater Manchester	Mayo Clinic, Salford Royal Hospital, Stott Lane, Salford M6 8HD	Mon, 17 Oct - 1.30pm
Kent	Room B028, University of Greenwich, Chatham Maritime ME4 4TB	Thur, 20 Oct - 11.00am
Essex	Great Tey Village Hall, Great Tey, CO6 1JQ	Mon, 24 Oct - 2.00pm
Oxfordshire	The Girl Guide Hall, Southern Road, Thame OX9 2EE	Mon, 24 Oct - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 26 Oct - 2.00pm
Aberdeenshire	Community Room, Tesco Store, Harlew Road, Inverurie AB51 4SR	Wed, 26 Oct - 1.30pm
Cornwall	Carnon Downs Village Hall, Tregye Road, Carnon Downs, Truro TR3 6GH	Thur, 27 Oct - 1.30pm
Scottish Borders	Old Gala House, Scott Crescent, Galashiels TD1 3JS	Mon, 31 Oct - 1.30pm
Surrey Carer's lunch	Please contact the Trust office for more details	Thur, 3 Nov - 12.30pm
West Midlands	Moxley People's Centre, 3 Queen Street, Moxley WS10 8TA	Thur, 3 Nov -11.00am
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 4 Nov - 2.00pm
County Durham	Chester Le Street Hospital, Day Room, Front Street, Chester Le Street DH3 3AT	Fri, 4 Nov - 1.30pm
Bristol	The West of England MS Therapy Centre, Bradbury House Clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 10 Nov - 1.30pm
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamstead HP4 3GW	Tue, 15 Nov - 2.00pm
Glasgow	Kilbryde Hospice (inside Hairmyres Hospital grounds), Therapy Room 5, McGuinness Way, East Kilbride G75 8GJ	Wed, 16 Nov - 1.30pm
Lancashire	Grimsargh Village Hall, Preston Road, Grimsargh, Preston PR2 5JS	Fri, 18 Nov - 1.30pm
Northumberland	TORCH Centre, Corbridge Road, Hexham NE46 1QS	Wed, 30 Nov - 11.00am
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 5 Dec - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 8 Dec - 1.00pm
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 14 Dec - 1.30pm

SUPPORT THE TRUST THIS CHRISTMAS

Give a loved one a Christmas card and help raise awareness of **MSA**.



Skating Santa



Angels & Shepherds Nativity
- by Lulu Wong Taylor



Snowy Hands



Sparkling Red Christmas Tree

Our four festive designs have a greeting inside reading:

“Season’s Greetings and Best Wishes for the New Year” or “Wishing you a Merry Christmas and a Happy New Year”

Each Christmas card design comes in a pack of 10 and costs £4.00 plus postage and packing. Please see our cost table for prices if buying multiple packs. Please return the slip below or order online at www.msatrust.org.uk/our-shop. **Thank you for your support.**

Pack(s)	1	2	3	4	5	6	7	8	9	10
COST incl. P&P	£5.00	£9.30	£13.30	£17.80	£22.65	£26.65	£30.65	£34.65	£38.65	£42.65

MULTIPLE SYSTEM ATROPHY TRUST CHRISTMAS CARD ORDER FORM

Please return to us at 51 St Olav’s Court, Lower Road, London SE16 2XB with payment by 9 Dec 2016.

Name:.....

Address:.....

Postcode:..... Telephone:.....

Skating Santa (Qty):..... Angels & Shepherds (Qty):..... Snowy Hands (Qty):.....

Sparkling Red Christmas Tree (Qty):..... Total payment enclosed £.....