msa news

MSA Trust Members Magazine | issue 51

Breathe free, *breathe* easy

Flying high *for* MSA

FUNDRAISING STARS - PAGE 14

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Welcome to issue 51

A warm welcome to MSA News from our CEO, Karen Walker

Over the last months much has been going on, with our fourth Nurse Specialist, Emma Saunders fully operational, our first MSA Study day and the funding of our first ever cross-continental research proposal. We were delighted to welcome Carole Ferguson-Walker to the Trust's Board and said a very fond farewell to Clare Powell, who has given us nine years' fantastic service.

Looking forwards, we are changing the format of our Service of Light event, renaming it "MSA Candlelight". It will be held in Leeds on Saturday, 19th May (details on page 8).

With new data protection regulations from May we need to update our processes. As you know we always take security of personal data extremely seriously. The changes are outlined on page 11. If you contact us in the future you may find we need to ask you some basic questions to check you are happy for us to keep in contact.

We can now take donations and payments for shop orders over the phone, something which many of you have been wanting. Just call and we can help you with this.

In these pages, we have news about projects for children, research news, advice from our Nurse Specialists and I hope lots more to keep you engaged. Please get in touch if you have any suggestions for MSA News, we'd love to hear from you. msa *news*

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NEWS ROUNDUP

Communication Matters

Some of our staff recently attended "Communication Matters" Roadshows. These demonstrate a wide range of communication aids and new technology that is soon to be released. We found these to be very informative so if there is one coming to your area you may want to attend. These Roadshows are held all around the UK and people who are interested in finding out more about how such equipment might help them can register at a reduced rate of £5.00. For more information visit their website - ***www.communicationmatters.org.uk/page/road-shows***.

Benefit assessments

Over the last few months we have been active in looking at an issue that impacts all people affected by MSA, that of benefits to support the extra costs incurred through life with MSA. We have updated our factsheet on basic benefits but have also been in contact with the Department of Work and Pensions and the organisations they contract to do disability benefit assessments. We have provided information to them about MSA and its impact, which they were previously unaware of. We hope that, over time, any assessments that are done regarding Personal Independence Payment, Attendance Allowance and Employment and Support Allowance will be based on an improved knowledge of, and sensitivity to, the needs of people affected by MSA. We are always interested to hear of any experiences you have, good or bad, relating to benefits assessments so do let us know and we can use these to support our work in this area.

Our nurse's award

You've all said it but now it's official! In October last year our MSA Nurse Specialist team won an award, presented by the Parkinson's Disease Nurse Specialist Association, recognising and celebrating the amazing support offered by our Nurses. We are extremely proud of their achievements and that their work is recognised by other health professionals – Well done Team!

msa *news*

MSA NURSE SPECIALIST AWARD

New volunteers please, please help!

Support Groups are crucial to many of our members, providing you with information, friendships and support. These Groups, all around the UK and Ireland, are run through the kindness of our volunteers. Due to new group development and changes to the circumstances of some of our existing group leaders, we are in desperate need of supporters to help run some of our meetings. We don't want any of our groups to fold due to lack of support but this may unfortunately be the case in some areas. If you could spare just 3 hours, 3 times a year, we want to hear from you! We will provide you with all the help you need, as well as training, and we can give you initial support with the Groups so you know the ropes. Contact either Emma or Louise in the office if you might be interested in finding out more and they'll be happy to talk it through with you.

Explaining to children that a family member has MSA

MSA is a complex condition which is sometimes hard for children to get their heads around. We look at a new initiative aiming to provide resources for children and young people to help them understand the impact of MSA on their loved ones. Your help can make a difference...

Here at the Trust we regularly get requests for information that will help children to better understand MSA. Although MSA only affects adults, its impact is felt by the whole family. In our last edition of MSA News we mentioned the book that had been written by Claire Williams for her children to help them understand their grandfather's MSA – 'The Secret'. Our Trustees felt that this issue was something that we should be dealing with, so have allocated some financial resources to develop this.

Right from the start we recognise that we need the input of children and young people themselves. We also need to be honest about how MSA can affect someone and the changes a child might notice in a loved one. Therefore, as an initial step, we are developing a book for children aged 4-11 which will contain activities for them to work through with an adult. It will aim to identify the most common symptoms of MSA and explain these, whilst also exploring how the child might be feeling themselves. The resource will also include suggestions about how they might be able to help, talk to and share experiences with their family member who has MSA - as well as encouraging them to help around the house (which can be challenging for children of any age!).

Before we get deeper into development we would like to show our initial ideas to parents and grandparents to ensure we're on the right track. At a later stage we will try ideas out with a small group of 4-11 year old children so that anything we produce is helpful and meets their needs. Please get in touch on the details below if this is something you would be happy to help us with.

For older children, 11-17 years old, we are considering setting up a website forum that can only be accessed by young people within this age group. This site would be moderated by an MSA Nurse Specialist and, given the fact that users would be under 18 years old, parental consent would be required.

For support in the meantime, as mentioned, one of our supporters, Claire Williams has written a book for her children to explain about their grandfather's MSA diagnosis. You can read more about this and how to get a copy in issue 50 of MSA News. As always, our MSA Nurse Specialists are on hand to talk to anyone about concerns or questions around supporting children through a loved one's MSA diagnosis. You can find all their contact details on our website **www.msatrust.org.uk** or by calling our office on 0333 323 4591.

Speaking of children's understanding of MSA, the poem opposite by Diane Ball gives a unique take...

msa *news*

POEM WRITTEN BY OUR SUPPORTER, DIANE BALL

Who has got Grandad's controller?

Who has got Grandad's controller
Somebody must have, I'm sure.
No, not the one for the TV and light,
Or the lift, or his 'up and down' chair

Who has got Grandad's controller
You're all going to have to be searched!
Look in your handbags and backpacks
Without it we're all in the lurch

On Monday he had a real lean to the left
On Tuesday, a lean to the right
On Wednesday his chin was down on his chest
And today sitting here, bolt upright

One day the waterworks run like a dream
The next they're on a 'go-slow'
Sometimes the legs stand up 'Just like that'
Others it's 'Yes? Yes? Yes? .... NO'

I'm sure someone just thinks it's funny
Changing the settings like this
But it's actually driving us crazy
We're all in a bit of a tizz

Someone must have Grandad's controller
So own up - you know that you should
And if by some chance it turns out to be you
PLEASE turn all the settings to 'good'

By Diane Ball

Managing breathing difficulties

Katie Rigg, MSA Nurse Specialist, explores some of the reasons for breathing difficulties and how these may be eased.

If you have MSA, maintaining good posture, being able to move around and the function of your autonomic nervous system may all be impaired. This will compound the chances that you will have some difficulty with breathing from time to time.

The most common change in breathing is during the night. Most people with MSA find it difficult to alter their position once they are in bed. Once asleep your posture may not be ideal to enable good breathing, leading to a form of obstructive sleep apnoea. Put simply, this means that the airway becomes partially obstructed due to the position of your head, neck and upper body when asleep. Apnoea means the intermittent stopping of breathing or inadequate breathing. A sign of obstructive sleep apnoea is an occurrence of snoring when you rarely did before, or an increase in the volume and duration of snoring overnight. Often you will not be aware of this but if you have a partner they most definitely will be!

There are some simple and practical steps you could try. Consider the position you sleep in; could you alter your position

- perhaps to lie on one side more rather than on your back? Do you have a bed where you can raise the head of the bed or have a back-rest support on the bed to help prop pillows up and keep you in a better overnight position to improve your airway?

We know many people with MSA get very warm in bed at night or due to snoring or restless sleep, their partners sleep in separate beds. If this is the case, or you sleep on your own anyway, it is worth asking your Occupational Therapist or District Nurse about having a profiling bed. These beds allow you to alter your position through the night using a hand control button. You can elevate the head of the bed, change the height of the bed for getting in and out more easily and also elevate your feet (these features can also be helpful in managing blood pressure problems).

At night, if you notice increased snoring, strained, noisy and irregular breathing or you have very restless sleep causing you to shout and thrash about, or seem to be acting out dreams (known as REM sleep disorder) then you should mention this to your GP or Consultant. Further signs that suggest your breathing is less effective at night may be morning headaches with increased fatigue. Presence of these symptoms can result in a referral for an overnight sleep study to check how well you are breathing in your sleep. Commonly, the centre will give you something called an oxygen saturation monitor and show you how to use it at home overnight. On its return your results will be analysed and you will be advised if you would benefit from a CPAP machine to improve the effectiveness of your breathing overnight. A CPAP machine is a Continuous Positive Airway Pressure machine that helps keep the airway open and encourages deeper breathing. This can really help reduce fatigue and headaches in the daytime, as well as develop better quality sleep with less restlessness. If the centre recommends this as a good option they will provide the machine and set it up for you. The machine can be used anywhere where there is mains electricity. You will be fitted with a mask, a bit like an oxygen mask, with a soft silicone seal and straps to keep it in place as securely as possible. Many people trying CPAP take a little while to get used to it so only wear it for a couple of hours initially, and over 3-4 weeks gradually build up their tolerance. The more of the night you are able to wear it, the greater the benefit will be.

If you experience any changes to the sound of your breathing, it is important you alert your GP and Consultant so appropriate investigations can be done and any treatable options discussed with you.

For a small percentage of people with MSA, the problems with the autonomic nervous system may cause particular difficulties with the vocal chords. When we swallow the vocal chords should be closed sealing off the top of the airway. Sometimes this function is impaired in MSA and the vocal chords don't work together, so one stays partially closed and the other open when we breathe and swallow. When people try to swallow and this happens, there is greater risk of food or fluid going down the wrong way – called aspiration. Very occasionally the cords can go into spasm causing them to block the airway or only allow a very small amount of air through, which triggers a sudden feeling of being unable to breathe. If this happens call 999. Also if it occurs but resolves very quickly, or you have several episodes, then it is essential you alert your GP and get an urgent referral to have your vocal chords checked.

If you notice you have to make more effort to breathe than normal do consult your GP and check you do not have a chest infection. These are more common with people with MSA and sometimes the normal signs of infection, such as high temperature, do not show in people affected.

People with MSA should be offered free flu vaccinations each year. If you are over 65 years old and have not had a vaccination for pneumococcal infections previously then it may also be beneficial to have this one-off injection as well. If you are under 65 years old you can request the pneumococcal vaccination as you only need to have it once. However, MSA and other neurological conditions do not automatically qualify you to receive it, so it will be at the GP's discretion. You can have the flu jab in one arm and the pneumococcal jab in the other arm at the same appointment though many people prefer to separate them out by 2-4 weeks.

Often physiotherapists can give you some guidance about how to improve your breathing and cough. Speech Therapists can also advise on this, both in terms of diaphragm and breathing control to enhance speech and also in relation to good swallowing techniques to reduce the risk of little bits of food and fluid going down the wrong way.

MSA is very individual in that it affects everyone differently and not all people experience all of the symptoms. Individual symptom management can be discussed at any time with your specialist team or with our MSA Nurse Specialists. msa *news*

In Memory

Malcolm Gray
Michael Morgan
Frank Goodwin
Alan Patis
Kathleen Widdop
Philip Rutter
Malcolm Hooley
Senan Kelly
Yvonne Dews
Ian Brown
Stephen Taylor
Stuart Fisher
Gerald Mills
Kathleen Thompson
Dennis Woodward
Joyce James
Mary Parmenter
Wendy Radford
Margaret Corbett
Anne Roberts
Stanley Archer
Brenda Stone
Edward Charles Roberts
John Money
Grahame Corke
Georgette McCrystal
Arthur Supple
Malcolm Woods
David Courage
Bernard Wade
Geoffrey Rough
Jean Frazer
Lynda Jones
Ian Rawlins
Sandra McFarlane
Elizabeth Craig
Malcolm Elder
David Livermore
Harry Rodney Elliott
Jackie Faker
James Patterson
Marion Griffiths
Allen James Daniels
Peter Neil
Linda Kail
Christine Kennedy

MSA CANDLELIGHT

MSA Candlelight, formerly Service of Light, is our memorial event for family and friends to remember loved ones lost to MSA.

MSA Candlelight will be an opportunity to bring our community together for a message of hope – that one day soon research into MSA will find its cause and its cure. On the day, there will be music, poems, readings and an update on our research work. In advance of the event we will be accepting dedications to your loved ones that will be entered into the Book of Remembrance and presented to you on the day. Everyone will also be able to make a candle dedication. The details for MSA Candlelight are as follows:

Saturday, 19th May 2018

Oxford Place Centre, Oxford Place, Leeds LS1 3AX

2.00 – 4.00pm

We would love you to join us for MSA Candlelight, followed by afternoon tea and the chance to chat to our Trustees and staff about our work. To cover our costs and to fund research into MSA, we are asking for a minimum donation of £10 per attendee. If you cannot attend, with a minimum donation of £10, we will light a candle on your behalf and ensure your loved one’s name is published in the Book of Remembrance. Please let us know if you would like to attend and the name you would like mentioned by **13th April 2018**. We will post this to you after the event.

To register for MSA Candlelight or to donate visit ***www.msatrust.org.uk/msacandlelight*** or call 0333 323 4591. Keep checking this site for updates as we finalise the order of the afternoon. msa *news*

Member Stories

ARTICLE BY RICHARD DAVIES

My mum, Susan Davies, was diagnosed with MSA in 2013. She currently lives in a care home and this is the story of her move.

Mum's mobility was significantly deteriorating and it was becoming obvious that her ability to continue living at home was becoming more compromised by the day. The decision to look for other options was not taken lightly and involved numerous conversations with family members and health experts. Initial thoughts lent towards altering the house she lived in with her husband and one of her sons - I was living at the other end of the country at the time. With her first assessment flagging up as Parkinson's, the alterations to the house weren't required immediately and therefore funding couldn't be granted. A few short months later however, these alterations proved to be of a necessity with a revised diagnosis of MSA. What followed could be deemed as a sad and testing time but we knew the reality of moving into a care home was fast approaching.

> *Mum moved into 'Kings Lodge Centre for Complex Needs' just outside Nutfield, Surrey for a two week assessment and a bit of respite care. Those two weeks very quickly turned into a month, then two, then six and before we knew it mum had been living there for a year. I think it was fairly obvious to all of us that when mum went into the home this is where she would be staying.*

I've never had any experiences with care homes before so didn't really know what to expect and was a little bit nervous about mum going into one. I just wanted to make sure she was getting the best help and care.

The home itself has been a complete godsend and I think without it mum wouldn't be here today. Mum frequently goes on days out and activities that would be difficult were it not for the care home. She has become one of a number of residents who see the care home as their home and that is a real credit to the staff and management.

The staff are kind, thoughtful and most of all passionate about giving my mum the best possible time. Considering all this, visiting her in the home is great fun and no two days are the same. Whether it is 'Saturday bingo' or 'music man Tuesday' (don't come on this day if you aren't accustomed to some out of tune singing), these are just some of the activities that mum enjoys and loves about the care home. She's definitely made a few friends in the home as well both residents and the staff, everyone is so happy to be there. I try to visit mum as much as I can but with work commitments it isn't always easy. No matter what time I do visit the staff always make me feel welcome and are happy to help.

I think the best way to sum it up is that without the care home mum wouldn't be here anymore. She really is getting the love and support that she needs.

The Trust's MSA Nurse Specialists can give basic advice around adaptations around the home and things to think about when choosing a residential home which can best support people with MSA. msa *news*

EMMA SAUNDERS VISITS QSBB BRAIN BANK

What goes on at a brain bank?

As part of her induction, Emma Saunders, our new Nurse Specialist, visited the Queen Square Brain Bank in London. Here she explains what she found and why it, and other brain banks, are important to people with MSA.


JANICE HOLTON, DIRECTOR AT THE QSBB

The Queen Square Brain Bank (QSBB) is a research resource that 'aims to provide the highest possible quality of brain tissue for neuropathological studies and for scientific research in the United Kingdom and Worldwide' (quote from the QSBB website).

The Queen Square Brain Bank for Neurological Disorders opened in 1984 and since then has collected over 2000 brains affected by neurological conditions such as Parkinson's, Progressive Supranuclear Palsy, Corticobasal Degeneration and Multiple System Atrophy. They also collect the brains of people unaffected by neurological disease, known as 'controls', for use in research into these conditions.

Research carried out includes seeing whether the symptoms experienced by the person with MSA match the damage seen in the brain when looking at tissue in the lab (the correlation of clinical and pathological features). Genetic studies also look for gene mutations or risk factors, and genome-wide association studies. The aim of such research is to better understand the effect and cause of MSA and other neurological conditions. At QSBB, protocols for banking and research have ethics committee approval and tissue is stored under a licence from the Human Tissue Authority. Tissue donated from donors, and their medical records, are stored in accordance with the Data Protection Act 1998. QSBB staff undertake high-quality research to produce studies that contribute to clinical and research training globally. Research findings are regularly presented at both UK and international conferences. They organised and hosted the second UK MSA research meeting, and have contributed to the Global MSA research roadmap meeting, which developed questions for MSA research globally, and shaped the direction of current and future research into MSA.

At the QSBB, Professor Janice Holton, Director of Neuropathology, and a number of her colleagues have a special interest in research into MSA. To date, over 200 brains with confirmed MSA have been donated. This makes it the second largest collection of MSA brains in the world, with only Florida having more. Many 'control' brains have also been donated by family members of people with MSA. Control brains are used to compare and contrast brains affected by disease to those not affected by disease, and are absolutely key to understanding how the brain works.

There are several brain banks across the UK and Ireland, and people can choose to register as a donor with any brain bank facility they feel they would prefer (for example their most local brain bank, or one with a particular interest in MSA research). Restrictions may be in place around the transfer of tissue (e.g. from Ireland to England) due to requirements of laws and legislation and practical aspects may need to be considered, for example geographical and time-limited constraints on the donation process. Further information about individual registration requirements and processes can be obtained from each brain bank. Contact details for these can be found in our factsheet 'Guide to Brain and Tissue Donation'. If someone is interested in brain donation, this factsheet is available on our website, **www.msatrust.org.uk/brain-and-tissue-donation** or by contacting the Trust office on 0333 323 4591. Further information about QSBB can be found on their website at **www.ucl.ac.uk/ion/departments/molecular/themes/neurodegeneration/brainbank/donors** or by telephoning 0207 679 4024. msa *news*

Lasting Hope

Sarah's Wood – Sapling Plantings

Following the launch of Sarah's Wood (our lasting symbol of hope for everyone affected by MSA) we've been working hard with the foresters at its location, Thoresby Estate, Sherwood Forest, Nottinghamshire.

We have held three tree planting days this winter, in November, December and January, with 80 young Sherwood Oak trees planted in total. We planted saplings in to pots at our summer Launch Event and during the winter the young trees have been planted into the ground in Sarah's Wood.

It's wonderful that so many people have helped us to create a lasting symbol of the strength, support and hope for all of the MSA community. Special thanks go to Hugh and Ranji Matheson, staff at Thoresby Estate and the Rotary Club of Sherwood Forest for all their support. Our next tree plantings will be in the winter of 2018/19 and further details will be available in upcoming issues of MSA News and on our website.

We will be holding a symbolic sign-unveiling event at Sarah's Wood on 21st July 2018 when we will also be planting more saplings in pots ready for winter. We look forward to welcoming people with MSA and their family and friends to the afternoon. If you would like more information about this event, please email ***fundraising@msatrust.org.uk***. msa *news*

Your Information Security

General Data Protection Regulation (GDPR)

At the MSA Trust we will always take data protection very seriously.

We do not, and will not, share personal details with other organisations or sell on details of personal information. The only instances where we may pass on basic information is to fulfil our legal responsibilities for example, for HMRC and Gift Aid, or to provide address information for sending MSA News by post only.

New rules are being introduced from May and these will require us to ensure that people are aware that they can request to have no more contact with us. Going forward, we will also need to make sure that we record your consent for us to contact you, and how you prefer contact, be that by email, post or phone.

Our data protection processes will remain secure so please bear with us if you contact us over the next few months and we ask you a couple of extra questions to record consent.

For further information about our processes and policies please go to our website or telephone the office on 0333 323 4591. msa *news*

Research Developments

*As mentioned in the last MSA News, the Trust recently opened a call for research applications for grants up to **£150,000**.*

Our call for research applications asked for exceptional projects to further our understanding of MSA. The closing date has now passed and we were pleased to receive several applications. These are currently in the process of being independently reviewed and they will be assessed at our next meeting of the Scientific Advisory Panel (SAP) in Spring. Recommendations will be made by the SAP Chair, Professor David Burn, to the Trustee Board for approval of the awards. We will let you know more about the successful projects in the Summer edition of MSA News.

In the meantime our Research Fellow, Viorica Chelban, remains busy working on her MSA project identifying biomarkers in blood and cerebral-spinal fluid to give an earlier diagnosis. She will also give us an update in the next edition.

We know how important research is to you so this year, as a special initiative, our Trustees agreed to fund some research projects being undertaken worldwide.

The MSA Coalition is based in the USA. They have selected and seed-funded innovative projects which will provide a better understanding of MSA. We feel the synergy of being able to use worldwide expertise to work collaboratively towards a better understanding of MSA, and its causes, symptoms and possible treatments, offers optimum benefits for those with MSA in the longer term. Following our contribution, the Coalition has published their projects and we are able to highlight some of them here:

- ***Supporting the Global MSA Registry which will collect data from MSA patients worldwide and link to our Prospect study in the UK.***
- ***A study in the USA and Sweden which is seeking to establish new and improved models of MSA, which will help future research.***
- ***In Germany and Austria more than 800 genetic samples from MSA Patients around Europe will be studied to understand the genetics of MSA.***
- ***In France, USA and Italy a study is being funded to develop a simple blood test (biomarker) for MSA.***
- ***A study in Denmark will look at new strategies for effective immunotherapy in MSA.*** msa *news*

ARTICLE BY MSA NURSE SPECIALIST, SAMANTHA PAVEY

Coping with coat-hanger pain

Samantha Pavey, our MSA Nurse Specialist, looks at a common symptom...

> *“The pain usually starts around the back of the neck and may radiate to the back of the head and the shoulder muscles. The overall shape of the area of the body where this pain occurs resembles a coat hanger.”*

What is it?

It is often described as a tightness in the neck and shoulders, that progresses to an ache, then pain. The muscles of the head, neck and shoulders are involved, where you might imagine a coat hanger would be if your shirt was still on one.

What causes it?

Postural (sometimes called orthostatic) hypotension is a sudden significant drop in blood pressure when someone stands from a sitting or lying position. This leads to a decrease in blood supply to the brain, causing a person to feel dizzy or light-headed and may cause a person to faint.

When blood pressure drops the body prioritises the major organs - brain, heart, lungs, kidneys and liver. Large muscle groups, such as those in the neck and shoulders, may then have to cope with less blood supply than is ideal. Pain in these muscles is a response to this poor level of blood supply. The severity of the pain appears to correlate with the degree of postural hypotension.

How can it be treated?

Pain relief alone is not effective as this does not address the cause of the problem. Correcting the low blood pressure is the most effective way of treating your pain. Your Neurologist or Parkinson’s Nurse Specialist will monitor your blood pressure in clinic. If it is low, you may be asked to record your own blood pressure at home as this can be helpful in the management of coat-hanger pain. We have factsheets on postural hypotension and how to record your blood pressure which are available to download from our website, or we can send these to you.

The pain is often relieved by lying down as this increases the blood pressure to the affected areas, and the pain worsens when sitting upright.

Other methods to raise low blood pressure are:

- ***Drinking adequate fluids - aim for a minimum of 1.5 litres a day, ideally 2 litres a day***
- ***Adding salt to your food at the table (cooking with salt means some will evaporate)***
- ***Using elastic stockings (full length, not knee high) available from your Community Nurse as these are measured to fit***
- ***Abdominal binders - available through your Physiotherapist or Occupational Therapist and can be modified for use with a Peg feeding tube***
- ***Sleeping with the head of the bed raised to a 30 degree tilt. Discuss with your Occupational Therapist about getting bed blocks or a wedge to go behind your pillows (this can also help to reduce the number of times you need to get up at night to pass urine)***
- ***If you feel lightheaded when you first stand from a chair or get up in the mornings, try some ankle rotations and foot pumping exercises for five minutes before moving or standing. Have a large glass of water prior to getting up***
- ***Avoid getting dehydrated, avoid hot steamy bathrooms or hot showers***
- ***Try to avoid constipation and straining on the toilet.***

Medications that may be prescribed:

If none of the these measures are effective your Neurologist or Parkinson’s Nurse Specialist may suggest trying some medications. Medications that can be helpful include Fludrocortisone, Midodrine, and Ephedrine. Side effects can include swollen ankles and your GP will need to check your blood electrolytes regularly if you are prescribed these medications. Many of the Parkinson’s medications that we use in MSA can lower blood pressure, so this will be taken into account when your specialist reviews you.

If you want to talk about this issue contact your MSA Nurse Specialist, whose details can be found at **www.msatrust.org.uk**. msa *news*

Events up and down the country

To support her sister-in-law who has MSA, ***Natalie Betts*** *teamed up with her work colleagues to complete the mud challenge* ***'Nuclear Blast'*** *in Essex. They raised almost £4,300!*

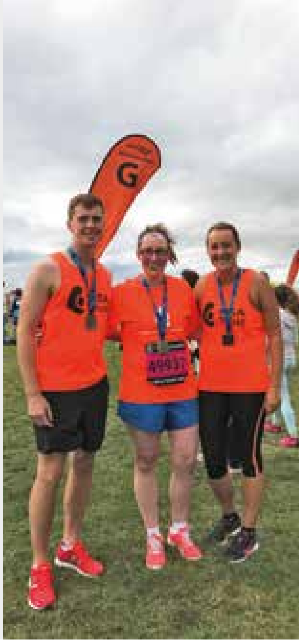
The ***O'Keefe & Foley*** *families first met through our Support Groups as Colin O'Keefe and David Foley both have MSA. They joined forces for a 5k family Ride or Run challenge around the* ***Cardiff Castle*** *grounds. About 100 people took part and raised around £5,000!*

Three siblings, ***Niamh****,* ***Matthew*** *and* ***Grainne Flanagan*** *ran in the* ***Dublin Half Marathon*** *to thank the Trust for the support provided to their father, Tom. They raised more than €5,500 in his memory. Great going!*

Mark Jameson's *sister, Leonie, has MSA so he rode in the* ***London to Brighton cycling challenge****, and his pedal power generated more than £3,500 for our work.*

Kate and Leon Beards *did the* ***Saint Edmund's 10K Run*** *in memory of Leon's father, Trevor raising more than £1,600 – well done both!*

Our fantastic runners ***Kelly, Stephen, Amanda, Elaine, James, Olivia, Robb and Ceri*** *took part in this year's* ***Great North Run****, amassing more than £5,000 in total. This year our MSA Trust cheering team were there to support the runners, cheering them across the finish line!*



Who took up the '20 Events in 20 Weeks' challenge?

__Chloe Pigram__ completed a __skydive__ on her 16th Birthday in memory of her Nan! What a wonderful way to celebrate and she raised £1,200. Well done thrill-seekers!

__Lisa Fitzpatrick__ ran in __Great Scottish Run__ in Glasgow for her mum who has MSA. Family and friends helped her raise close to £2,500 and came to support her on the day as well.

__Andrew__ and __Claire Higgins__ ran the __Cardiff Half Marathon__ in memory of their dear friend, John Money. John's wife, Janet, also coordinated a choir concert performed by the Steventon Choral Society in aid of the Trust. John has donated his brain for MSA research and £2,500 has been raised in his memory.

Tee-off for MSA!

__Yvonne Gibbs__, as lady Captain, nominated the Trust as the Charity of the Year for the __Horsley Lodge Golf Club__ and through fundraising activities throughout the year, raised close to £4,000.

A big thank you to all the Golf Clubs for supporting these fundraising days. As far as the Trust is concerned you are all straight down the middle…!

__Colin and Gill Fellows__ organised a __MSA Golf Day__ at the __Silvermere Golf Course__. They sold tickets and mulligans (ask a golfer!), conducted a silent auction and raffle raising close to £3,500!

__Terry Young__, whose sister-in-law, April Sanford, has MSA organised yet another successful Golf Day at the __Kent and Surrey Golf Club__ in Edenbridge, raising £2,000.

Lots of MSA Trust charity places available for 2018 RideLondon – free registration! **Email fundraising@msatrust.org.uk to sign up!**

PRUDENTIAL RIDELONDON

Supporting & Helping Each Other

As we move into another year jam-packed with Support Groups, Emma Rushton reflects on some of the fantastic tips and information that you have been sharing at Groups over the past few months...

A key conversation in South Yorkshire was around the importance of people with MSA drinking plenty of water throughout the day. This can help with low blood pressure difficulties and allows the body to deal more effectively with drugs and other treatments. The MSA Nurse Specialists recommend drinking a glass of water before getting out of bed in the morning to maintain good blood pressure. You can find out more in our Postural Hypotension factsheet on our website – ***www.msatrust.org.uk***.

The Staffordshire Support Group discussed how difficult it can be for someone with MSA if they have to stop driving. To complicate matters people then often have to sit in the back of the car if using a wheelchair. The Support Group Leader, Bev, suggested considering an accessible vehicle such as the 'Infront Doblo' which is adapted to allow for a wheelchair in the passenger seat. Unfortunately these can be very expensive but Accessible Vehicles do also advertise pre-owned cars. For more information visit their website at ***www.accessiblevehicles.co.uk***. We have also just launched a new page on our website where our members can buy and sell second-hand equipment - ***www.msatrust.org.uk/support-for-you/second-hand-equipment***.

Members of the Scottish Borders Support Group spoke about having an emergency plan in place in case a main Carer becomes ill or there's a sudden emergency. Carer's UK have lots of useful information on their website (***www.carersuk.org/search/planning-for-emergencies***) to help you prepare for these situations. They suggest creating a plan which outlines who needs to be contacted in an emergency, any medication the person you look after is taking and key healthcare professionals that support them. Some local carers centres also provide 'Carer's Card' schemes - a 24 hour response service which can be called in case of emergency. You can find out more about this on the Carer's UK and Carers Direct websites.

A perennial issue discussed at Support Groups is travelling and MSA. At the last County Durham meeting a member suggested contacting ***www.easy-breaks.com*** who give guidance on disabled facilities when researching for a holiday. The member said they had found the company to be very helpful and reliable. If you're thinking about booking a holiday, in the UK or abroad, you should start planning for this as soon as possible. Lots of members have very good experiences with accessible accommodation, airline support and cruise ship services, but all of these will need to be notified in advance about your particular needs. Our factsheet 'Travelling and MSA' has lots of useful tips and also details some insurance companies which we know are aware of MSA. You can download the factsheet from our website or contact our office on 0333 323 4591 if would like a hard copy sent to you. msa *news*

If you have any questions about anything included in this article please contact your MSA Nurse Specialists at ***support@msatrust.org.uk***.

Local support groups are a great way to meet other people affected by MSA, listen to presentations from healthcare professionals that can support you and meet our MSA Nurse Specialists.

Please contact the Trust's office on 0333 323 4591 or email support@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
County Tyrone/ Strabane	Please contact the Trust office for details	Mon, 12 Feb - 12.00pm
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Tue, 13 Feb - 2.00pm
County Belfast	Marie Curie Hospice, 1A Kensington Road, Belfast BT5 6NF	Tue, 13 Feb - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Wed, 14 Feb - 2.00pm
County Down	Downe Hospital, Primary Care Conference Room 1, 1st floor, 2 Struell Wells Road, Downpatrick BT30 6RL	Wed, 14 Feb - 1.30pm
Cornwall	Carnon Downs Village Hall, Truro TR3 6GH	Thur, 15 Feb - 1.30pm
County Durham	Chester Le Street Hospital, Day Room, Front Street, Chester le Street DH3 3AT	Mon, 19 Feb - 1.30pm
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted HP4 3GW	Wed, 21 Feb - 2.00pm
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 21 Feb - 1.30pm
Glasgow	Alexander Court Nursing Home, 332 Edinburgh Road, Glasgow G33 2PH	Thur, 22 Feb - 1.30pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing BN11 5DR	Thur, 22 Feb - 2.00pm
Cumbria	Burton Memorial Hall, Main Street, Burton in Kendal, Carnforth LA6 1NA	Thur, 1 Mar - 1.30pm
Kent	Room B028 Medway Campus, University of Greenwich, Central Avenue, Chatham Maritime ME4 4TB	Thur, 1 Mar - 11.00am
West Yorkshire	Small Hall, Kirkgate Centre, 39a Kirkgate, Shipley BD18 3JH	Fri, 2 Mar - 1.30pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 5 Mar - 1.30pm
Dublin	St. Francis Hospice Raheny, Station Road, Raheny, Dublin 5	Tue, 6 Mar – 11.00am
South London	St James Church, Thurland Road, Bermondsey, London SE16 4AA	Tues, 6 Mar - 1.30pm
County Sligo	Therapy Room, St John's Community Hospital, 8 Ballytivanan Road, Sligo	Wed, 7 Mar - 1.30pm
County Cork	St Joseph's Church (SMA) Parsh Centre, Wilton Road, Wilton, Cork	Thur, 8 Mar - 1.30pm
Staffordshire	M&S Wolstanton Stoke, Wolstanton Retail Park, Wolstanton ST5 0AP	Fri, 9 Mar - 12.00pm
Dorset	The Grove Hotel, 2 Grove Road, East Cliff, Bournemouth BH1 3AU	Mon, 12 Mar - 11.00am
Scottish Borders	The Old Gala House, 8 Scott Crescent, Galashiels TD1 3JS	Mon 12 Mar - 1.30pm
Cambridgeshire	Barton Bowls Pavilion, High Street, Barton, Cambridge CB23 7BG	Thur, 15 Mar - 2.00pm
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 21 Mar - 1.30pm
Tyne & Wear	St. John's Church Community Hall, West Lane, Killingworth, Newcastle upon Tyne NE12 6BL	Mon, 26 Mar - 11.00am
Leicestershire	Village Hall, Main Street, Swannington, Coalville LE67 8QL	Tue, 27 Mar - 11.00am
Merseyside	St John the Baptist Church Hall, Forest Road, Meols, Wirral CH47 0AF	Wed, 4 Apr - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 4 Apr - 2.00pm
Lancashire	Tesco Extra, Clifton Retail Park, Blackpool FY4 4UJ	Fri, 6 Apr - 1.30pm
Essex	Great Tey Village Hall, Great Tey CO6 1JQ	Mon, 9 Apr - 2.00pm
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	Thur, 19 Apr - 2.00pm
Greater Manchester	St. Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Wed, 25 Apr - 1.30pm
Cardiff	City Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff CF14 7BF	Wed 9 May - 11.00am
County Tyrone/ Strabane	Please contact the Trust office for details	Mon, 21 May - 12.00pm

STORIES FROM TWO FAMILIES RAISING FUNDS

Family Fundraising

In July last year, Ian Walker and Nick Underwood took on a huge challenge in support of the Trust. Alongside Ian's son, Zak, and Nick's brother, Simon, they cycled the length of the Kennet and Avon Canal from Reading to Bristol in just four days raising a staggering £18,512.

They chose to take on the challenge as Ian's dad, Bob, was diagnosed with MSA in 2015. Bob was absolutely thrilled with their fundraising efforts when they told him of their cycling success. Ian's wife, Kim, gave them marvellous support with fundraising and contacted friends and family to ask them if they would donate, but Ian and Nick were also great at updating their Just Giving page with photos of their training and during their ride.

It was a pretty eventful ride too - Ian hadn't cycled since he was 17 and said that he was still laughing after falling off his bike into the canal, but not so much after falling in to a bed of nettles! Zak took a video of a lot of the ride so they can keep and share the memories.

We'd like to say a massive thank you to Ian, Nick, Kim, Zak and Simon for their incredible support. If you feel inspired to 'Pedal for people with MSA' then please do get in touch. msa *news*

If you and your family would like to fundraise for MSA Trust please contact us at ***fundraising@msatrust.org.uk*** or call 0333 323 4591.

The family of Mary Maclennan trekked Ben Nevis last year and raised a fantastic £2,713! In total 16 family members walked to the top of the Scottish mountain in memory of Mary.

However, this is not the only support they have given us. Mary's son, David Maclennan, ran the London Marathon last year raising £4,630 and Mary's GP, Dr Kate MacGregor, won Scotland General Practitioner of the Year last year after being nominated by the family for the support she gave Mary.

We're really grateful to all of you for your fantastic fundraising and awareness raising efforts. msa *news*

Our first MSA Study Day

We know that increasing the awareness of MSA amongst health and care professionals is of great importance our members. So, last October we held our inaugural Study Day in Southampton. Nearly a hundred people, from a wide variety of specialisms attended, including consultants, nurses, therapists and colleagues working in palliative services.

We invited speakers who are leaders in their fields to give presentations about different aspects of MSA and how to improve the lives of people affected by the condition. We were fortunate to have three Consultant Neurologists give talks: Professor Henry Houlden gave an overview of MSA and the next steps for research and trials; Dr Boyd Ghosh spoke about diagnosing MSA; and Dr Luke Massey spoke about Imaging and Management.

Anna Kent, Specialist Neurological Nurse, emphasised the importance of Advance Care planning and how health care professionals can encourage people to look into this. Our very own MSA Nurse Specialists, Jill Lyons and Samantha Pavey, spoke about their roles within the MSA Trust.

Dr Viorica Chelban is our Association of British Neurologists/ MSA Trust Clinical Research Training Fellow and she presented her findings in looking for a cause and cure for MSA. Dr Harriet Bush, Consultant in Palliative Medicine, illustrated key issues around Palliative Care and Symptom Control in MSA; and Lizi Nicholls, Advanced Occupational Therapist at Countess Mountbatten Hospice, ending the day by looking at Therapy Perspectives in MSA.

In designing the programme we knew it was essential to include the perspective of someone who had direct experience of living with MSA and so we invited Will Norman, whose father had MSA, to speak about his relationship with his dad and the challenges they faced. Will had recently been interviewed on ITV News about a film documentary he had made about his dad's life and he showed a selection of clips during his presentation. It was clear that although life had been a struggle for them there was a lot of laughter and love in their family.

Deputy CEO of the MSA Trust, Andy Barrick, said:

> ***"Many of our members tell us that, due to its rarity, their health and care professionals know little, if anything, about MSA and so we hope our study days, and the other information and support we offer for professionals, goes some way to counter that."***

We received incredibly positive feedback from those who attended the Study Day with comments such as

> ***"A brilliant day with fabulous speakers. Please aim to do this every year as it is a valuable way to educate people"***

and

> ***"Fantastic! I will suggest this to my colleagues as it's essential that they come".***

100% of those asked said they felt the event provided them with information to better support people with MSA. **Plans are in place to hold a similar Study Day in the north of England this October.** msa *news*

MSA *Awareness* Month

MSA is a very rare condition and therefore increasing knowledge of both MSA and the work of the Trust is vital. **March** is a great month to get started as it is MSA Awareness Month. There are many ways you can help us, wherever you live, during the month and beyond. **You can:**

1. **Wear our Orange charity ribbon – Contact us to get yours!**
2. **Distribute our MSA information leaflets**
3. **Share our social media posts with your friends and family**
4. **Buy, wear and use the Trust merchandise**

Get your Awareness Bundle for the excellent value of just £10! 1 carry bag with 1 Trolley Key ring, 1 wristband, 1 pin badge, 2 pens, 1 pack of notelets and 1 car sticker. Buy them online at ***www.msatrust.org.uk/shop*** , send a cheque payable to MSA Trust or call 0333 323 4591 to place an order. Or why not use MSA awareness month to set up a monthy donation to the Trust at ***www.msatrust.org.uk/regular-giving***.

We are very grateful to those who continue to work hard to raise awareness of MSA. Thanks to some very courageous members, we've recently had fantastic coverage on national and local radio stations:

Angela Armitage contacted BBC Radio Manchester's Mike Sweeney Show and was invited to share her story. Angela spoke movingly about her husband before and after his diagnosis with MSA.

Douglas McBride from Scotland shared his experiences of living with MSA live on BBC Radio 2's Jeremy Vine Show. Since his interview, we've had many people call our office to find out more about MSA.

If you would like to contact your local newspaper, radio or TV station about a story or event you are planning, we can help you to write a press release and give you tips on how to get your story noticed. Contact the office on 0333 323 4591 for more information.