

MSA NEWS



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SPRING FORWARDS INTO MSA

Awareness month

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MEMBERSHIP AT FEBRUARY 2016

Current MSA members 1,214
 Carers, relatives & friends 2,172
 Healthcare professionals 2,244

Total 5,630

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Multiple System Atrophy Trust

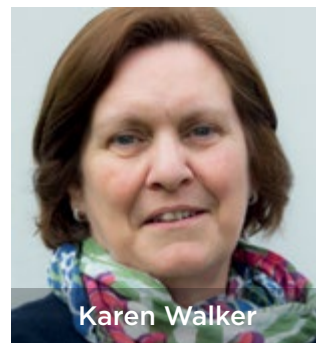
Information, support, education and research. Free services for people with MSA, carers, family, health and care professionals. **Our Vision is a world free of MSA.**



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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



Karen Walker, our new CEO looks ahead at what the next year holds...

I think it is still appropriate to wish all our readers a very happy and peaceful New Year, even if it is February already. I sincerely hope not too many of our MSA community were affected by the terrible flooding we experienced in late December and early January, but if you were, I hope you received the help you needed.

As always at this time of the year we look ahead to what the coming months will bring. There is an interesting article on our research meeting on page nine. It was a great pleasure to see so many of our researchers come along to report to our scientific advisory panel on the progress of their research. As always I am amazed at the intelligence we are gathering on MSA, which will hopefully lead to a breakthrough in the not too distant future.

This year more Support Groups are planned, we will continue developing our information resources and our new website and we will seek more ways of communicating with you. As well as launching our ideas for MSA awareness month in this issue of MSA News I also hope that you or a loved one might wish to support the charity through some of the amazing events planned for the rest of this year. You will have seen the orange ribbon enclosed with your magazine, see page 18 for how this can be used during MSA Awareness Month. We will continue to make your voice heard where we feel the support for people affected by MSA can be improved. NHS England has an interesting Community Neurology Project developing across eight clinical networks,

which we shall watch with interest and there is also a commissioning toolkit being developed in an attempt to ensure better commissioning for care of neurological patients.

As always, discussions with the NHS and other statutory agencies involves considering the costs of everything, so I believe our duty will be to ensure that the concerns of people with MSA, and those who support them, have a voice. The Trust will try to provide that voice, so please keep your comments and information on the good, the bad and the ugly about your experiences of care, treatment and support coming in to us so that we can ensure you are heard and acknowledged.

I very much hope you enjoy reading this issue of MSA News. **MSA**

Karen Walker
Chief Executive Officer

LAST REMINDER - TRUST PHONE DETAILS

Following our office move last year, our old phone number is no longer in use. If you need to phone us you will need to call **0333 323 4591**. Please update this in your phones and phone books.

MANAGING TOILET NEEDS



Many people with MSA will have issues relating to toileting. In this brief article Jill Lyons our MSA Nurse Specialist looks at some options that may be available to help you.

Issues relating to bladder and bowel function are very common for people living with MSA. In fact, they may become apparent before any other symptoms occur. Understandably it can sometimes feel embarrassing to talk about this, but you are far from alone and a lot can be done to help.

COMMON BLADDER PROBLEMS THAT CAN OCCUR

- **Urgency**, this is where you need to go to the toilet suddenly and quickly. This is due to the bladder contracting of its own accord. If you cannot reach the toilet in time you may experience what is called urge incontinence.
- **Frequency**, this is going to the toilet a lot (more than eight times in 24 hours) but only passing small amounts of urine. This can either be due to the bladder's over-activity or because you are not emptying it completely.
In both cases you might want to talk to your occupational therapist, GP or continence specialist about equipment and clothing adaptations and to your specialist or nurse about medications that may help.

- **Retention**, this is needing to pass urine again very soon after just doing so. This may be because your bladder did not completely empty the first time and this is sometimes accompanied by a feeling of incomplete emptying.

Discuss this with your GP or nurse as they may want to do a scan to see if retention is the issue here. They can then determine the best treatment for you.

- **Urine infections**, these can become especially common if you have incomplete bladder emptying. Urine infections often make people feel very unwell and can make other MSA symptoms, particularly low blood pressure, worse.

Whilst in general it's important not to use antibiotics inappropriately, if a person with MSA has signs of a urine infection the early prescription of antibiotics is essential. MSA doesn't deteriorate rapidly, it changes over months or years. If you notice a sudden change in your symptoms, such as your mobility or speech worsening over a few days, always suspect that you may have an infection, either in your urine or chest and see your GP. People with MSA don't always show signs of infection due to their autonomic dysfunction, so may not have a raised temperature or other obvious signs.

- **Nocturia**, this is needing the toilet during the night time. It is common with age to need the toilet in the night but if you frequently

have disturbed nights needing to pass urine this is nocturia.

Your occupational therapist can advise about commodes, urine bottles, pads or urinary sheaths and your specialist can discuss what medications can help

COMMON BOWEL PROBLEMS IN MSA

- **Constipation**, as many people with MSA become constipated there is a need for regular medication in addition to diet adaptations to help manage this.

Diets high in soluble fibre, good fluid intake and maintaining as much mobility as is safe and possible will all be beneficial. Discussing potential medication with your doctor is also important as constipation can make urinary symptoms worse.

- **Loose stools causing incontinence**, can also occur in MSA. You should talk to your nurse or doctor about this if it doesn't settle.

Not everyone with MSA will experience all these symptoms, and they may come and go over time.

The major lesson here is that there are people, medications and aids that can help you, so use these to the full.

If you are having any of the above problems talk to your specialist, Parkinsons nurse, community matron, occupational therapist, district nurse or GP. These professionals are used to assessing these symptoms and will explain ways to help manage them and offer

advice around products to help you. They may in turn refer you to a specialist doctor (urologist), for further tests and to the local continence advisory service. The continence service are nurses and occupational therapists with specialist training and knowledge in bladder and bowel issues. The Bowel and Bladder Foundation will have details of your local continence service.

The Bladder and Bowel Foundation provides information, advice and expertise to anyone with bladder and bowel problems. Telephone: 0845 345 0165 (Nurse Helpline) or visit their website at: www.bladderandbowelfoundation.org.

MSA

The MSA Nurse Specialists are also happy to discuss any questions you have. There is also more information in our factsheets available on our website.

The advertisement overleaf is from Coloplast. They are a leading manufacturer of continence solutions, and their stated goal is to help you lead the life you want, whilst managing your condition. For more information on the products and services they provide please go to www.coloplast.co.uk, where you can find lots of advice and support, and sample the latest products in continence care.

Meet BRAD

- Gregarious 52 year old, fun loving gentleman
- Media technology consultant
- Enjoys DJing with vinyl and can “scratch just like Grandmaster Flash”

“I can boogie with the best of them!”



Brad Francis
SpeediCath® Compact Set User

BRAD'S LIFE CHANGED AT 29...

“I was 29, happily married, great career – incredibly happy. And then I had my stroke. I went from being an independent, fun loving guy – to all of a sudden being vulnerable and needing help.”

AND THEN HE FOUND SPEEDICATH COMPACT AT AN EXHIBITION...

“Oh my god – it's fantastic! The first thing I noticed is they came in this compact little box – usually my catheters come in great big boxes.”

BRAD TOOK A WHILE TO COME TO TERMS WITH THE CONCEPT OF ISC...

“I found previous catheters messy and difficult to use – so I chose not to catheterise at all. I would frequently have episodes where I would wet myself. Social occasions, parties. It was really pretty embarrassing.”

BRAD NOW FEELS THAT SPEEDICATH COMPACT HAS CHANGED HIS LIFE FOR THE BETTER...

“It really promotes confidence. The freedom to catheterise while out at a bar, or a friend's house, or at home is amazing!”

For more information on our SpeediCath range and other continence solutions -

Go to www.coloplast.co.uk/msa - where you can find the right one for you and request a free sample. Alternatively please call us on **0800 220 622** where you can speak to one of our advisors.

Visit us on   

or see Brad's full story at www.coloplast.co.uk/thailaseries

THIS SPORTING LIFE

Most of us got a buzz from the recent Rugby World Cup. For former amateur rugby ace John Cann, it had special significance and brought back memories of his own career “rugbying” around the world.

John started playing at 11 and remembers, “in our first years at the school we used to dread coming up against the teams from Devonport High School and Plymouth College, who would always beat us by over 40 points.”

By the age of 15 however, his team had emerged as one of the best in the region with John, amongst other schoolmates, playing for his county.

After leaving school he joined the RAF as a chef. Although pitch locations changed as postings took him to Germany, Sri Lanka and the Far East, his passion for the game remained resolute. Posted in one of the most serene locations, RAF Gan, cooking up a storm with exotic ingredients, swimming in clear blue waters full of sharks and playing rugby with crews of naval ships, John was living his life to the full. However, a seri-



John Cann

ous injury to his vertebrae was to lead to a heart breaking and premature end to his rugby career at the age of 27.

Although John couldn't go back to the pitch, he has always supported his team, Wasps. He is proud of the fact that unlike other games, rugby support-

ers are respectful even when their team is losing.

He reveals that as a young player, sporting an immaculate hairstyle made him feel like a ‘cool dude’. Whenever he went onto the rugby field he carried a comb in his shorts’ pocket, “in case I botched my hair tackling an opponent—as you never knew if anyone on the touchline had a camera or what girls might have been watching”.

Recently diagnosed with MSA, his sense of adventure and sport gives him the strength to stay positive. “When you’ve been active all your life it’s hard to deal with and

I have to face the fact that I might not see out my seventies. But something inside prepares you. I’ve had a good life and have been all over the world with rugby - the sport which has given me, and so many others, so much enjoyment.” **MSA**

TO *our* MARVELLOUS SUPPORTERS

Looking back over 2015 it's clear that, yet again, you excelled yourselves with your generous and committed support. And in consequence, the Trust was able to support thousands of people affected by MSA. For example, we increased our support to people living with the devastation that MSA brings, by starting two new Support Groups - our first group to take place in Cardiff, Wales and Weston Super Mare, Somerset. We could not have achieved this without the funds you so kindly donated.

But as the demand for our vital services increases, so does the need for us to raise even more funds. The introduction of the Milk, Sugar And Tea Party fundraiser, together with some old favourites such as Christmas cards and our raffle, enabled you to contribute significantly towards the total income raised in 2015. Our nurses Samantha, Katie and Jill were very pleased with the response to their letter, asking you to host a Milk, Sugar And Tea Party. Following the success, they said:

“As always, our members got involved with the Tea Party fundraiser with great gusto and we would like to thank each and every one of them for their involvement. Here's to even more Tea Parties in 2016!”

We also said goodbye to some amazing members, who sadly passed away. Even at a time of sadness and loss for so many people, you dug deep and raised much needed funds in memory of your loved ones. We are extremely grateful for your support. We look forward to our Services of Light in London and Manchester, where we will remember and celebrate the lives of all those we have lost over the years. Please see the back page for more information about the Service of Light events.

Thank you for your continued support, commitment and fundraising.

Joan & Melissa

In Memory

Bryan Attwood

Trevor Jones

Susan Laughlin

Jean Bartlett

John Duke

Alistair Smith

Noel O'Donoghue

Moti Bazaz

Patricia Lake

Carol Reed

Peter Shardlow

Mary Phillips

Michael Wilkinson

Mary Stewart

Sylvia Platten

Fredrick Sharp

Bob Blackaby

Anne Mitchell

Violetta Gregowska

Melvyn Hancox

Antony Bates

Migs Probert

Peter Cox

Peter Postlethwaite

Philip Allen

Victoria Smalley

Robert Hall

Sheila Ashcroft

Daphne Field

Jennie Tait

Margaret Wicks

Peter Robjant

Richard Lee

Jan Wastell

Victor Boczkariw

Stephen Harber

Eileen Cranston

George Brooker

Malcolm Todd

Margaret Minall

Angela Mills

Roy Coulthard

Kenneth Hallam

Margaret Smith

Wayne Grahame

Raymond Neville

Wendy Dyer

A MEETING OF (GREAT RESEARCH) MINDS

In November the chair of our Scientific Advisory Panel (SAP), Professor David Burn, convened a meeting to review the current research funded by the Trust. This is part one of a report prepared by the Board of Trustees Chair, Professor Clare Fowler.

The meeting was, in terms of MSA scientific research, a stellar gathering. Between the members of SAP and the Principal Investigator's (PI's), we had a group which included many of the most influential and promising investigators in scientific understanding of MSA **anywhere** in the world. The Trust and all those who have raised money for research have good reason to feel really proud of what has been achieved so far and what this may lead to in the future.

Dr Viorica Chelban is working on the UK MSA network, collecting clinical details and biological samples from people diagnosed with MSA. Now procedures are in place it is hoped that ten new cases and control samples will be added each month. Biological specimens will include, when possible, CSF (cerebrospinal fluid) and small skin biopsies. Discussion took place on how this database could relate to international databases and the problems of sharing data with countries outside the EU. There was also discussion between Trust staff and the scientists as to how people registered with the Trust could be linked to Professor Houlden's database. This would obviously be of great importance in recruiting people with MSA who wish to take part in this research, but also where there may be other pharmaceutical trials of possible treatments.

We were particularly honoured by the presence of Professor John Hardy, fresh from receiving an award in the USA in recognition of his research into Alzheimer's. Professors Hardy and Houlden have been working on a very difficult experimental technique to induce pluripotential cells from fibroblasts taken from skin biopsies of people with MSA. This Nobel Prize winning technique, from Korea, is both complex and time consuming. The selected cells are cultured in a dish with factors that regress them to their foetal state, then treated with other growth factors which push them towards developing into cortical neurones. Professor Hardy reported slow but steady progress and there is little doubt that, if the technique can be made to work, it has enormous potential for future investigations. He was also hopeful that collaborations with Cambridge University would also help progress the project.

Everyone at the meeting was excited by the research progress to date, much of it funded by the Trust. The scientists clearly have many new ideas for future work and we in the office felt inspired to try our very best to raise more money in the coming years. It is only through research that we are likely to achieve our Vision of 'a world free from MSA'. **MSA**

HOW HOSPICE CARE CAN HELP YOU



The following is a special feature on the benefits of hospice care. First off is a piece from Melanie Hodson at Hospice UK.

“**A** hospice can show you there is a lot to live for – and that they help you do just that. I often say that the hospice ‘saved’ me and it has.” For Allison in Surrey, a referral to Woking and Sam Beare Hospice soon after she was diagnosed with MSA has not only provided vital physical and emotional support, it’s also shown her how hospices help people to live life as fully as they can.

From the point of diagnosis, hospice care can help to improve quality of life and wellbeing amongst people who have a life-limiting illness – including MSA. Hospices provide care that is personal and tailored to your needs, as well as care and support to those close to you, such as friends and family.

Since coming under the care of her local hospice Allison has benefitted from home visits by the counselling and clinical nurse specialist team, visits to

day care for therapies to help challenge her muscles and improve her breathing, and has also been referred for hydrotherapy sessions which are really helping to keep her mobile. As the condition has developed the hospice has worked with her to adapt her care plan. For example, Allison spent a week of planned respite and intensive physiotherapy at the hospice’s inpatient unit. Allison said “Some may see this as delaying the inevitable; I see it as making sure that I am able to properly enjoy whatever life that I have left. I cannot fault the hospice, nothing is too much hassle. It is all those little human considerations shown to me that makes the hospice experience so very different from what happened to me in hospital in the early days. Alongside the physical care, the emotional support has also proved vital to us. My husband and I have both received professional counselling and my

husband participates in carer support programmes.”

Each year hospices across the UK care for 120,000 people and those close to them. Hospice care is freely provided and it is available in a range of settings such as hospice outpatient and drop-in centres, inpatient units and people’s own homes, where the majority of hospice care is provided.

Hospice UK is the national charity for hospice care, supporting the work of more than 200 member organisations. For more information about hospice care and hospices in your area visit www.hospiceuk.org, call 020 7520 8200 or email info@hospiceuk.org.

Our thanks to Woking and Sam Beare Hospices for allowing us to share this story.

Now please turn over to hear from Allison herself. **MSA**

THE IMPORTANCE OF HOSPICES WHEN LIVING WITH A LIFE LIMITING CONDITION

“The light of my life went out when I received a diagnosis of MSA. I was filled with despair and despondency and even thought about going to Switzerland. My close friend and ex-nurse was concerned about me and suggested I contact my GP for a referral to Woking Hospice. I was horrified as I thought hospices were places where you went to die. How wrong I was.

In the first instance hospice staff assessed my needs at home. The hospice community nurse, occupational therapist and physiotherapist referred me to other agencies such as the respiratory team, speech and language team and White Lodge Hydrotherapy as my condition changed. I now visit the day centre once a week where I receive wonderful support through complementary therapies, physiotherapy, massage, entertainment and group exercises plus many laughs. Twice a year I receive a week's respite care. I have attended a creative writing course which I really enjoyed and two of my poems were published in MSA News. I have written articles for the hospice magazine and been

the covergirl several times. My photograph was also the poster display on Surrey buses and at bus and train stations. The hospice has been able to supply me with equipment and a hospital bed to assist my needs at home.

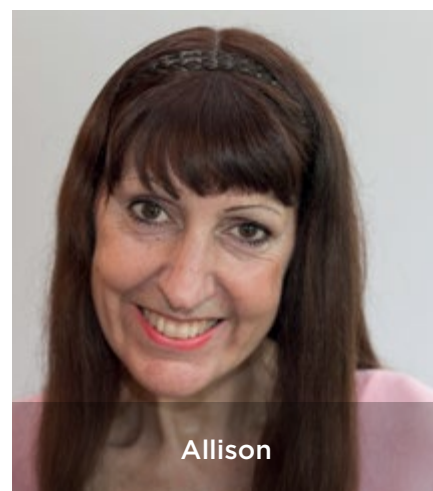
So you can see how the hospice has been an invaluable resource offering me the tools to manage my condition and take back control of my life.

I believe that all people with MSA should take advantage of the benefits offered by these wonderful institutions.”

So having heard how positive and beneficial the services of hospices can be, we sent our intrepid Services Officer Emma Rush-ton off to find out more...

Ever since I started at the Trust over a year ago I have been hearing about the vital role hospices play in the lives of people affected by MSA. I confess that I had always thought hospices were mainly involved in end of life care so wanted to find out more.

As soon as I arrived, the hospice felt like such a warm and welcoming place. Everyone was really upbeat and genuine-



Allison

ly positive. Family and friends come into the day unit after visiting people and you could tell they were able to chat with the staff and felt comfortable doing so.

I came away from my visit with so much admiration for the hospice movement and the staff and volunteers who work there. It's really important that people affected by MSA receive the support they need and hospices can help in more ways than you might think.

If you're nervous or anxious about contacting your local hospice try contacting Hospice UK first, whose details are on page 10, and they will support you through the referral process. **MSA**

NHS CONTINUING HEALTHCARE

The right care at the right time...

When it's required, getting the right care can make all the difference. Samantha Pavey, one of our MSA Nurse Specialists, looks at where care may be provided by the NHS.

WHAT IS NHS CONTINUING HEALTHCARE FUNDING?

NHS continuing healthcare (CHCF) is a free package of care for people who have significant ongoing healthcare needs. It is arranged and funded by the NHS. You can receive NHS continuing healthcare in any setting, including in your own home or in a care home.

WHO IS ELIGIBLE FOR CHCF?

If you need care, primarily because of your health needs, you will be eligible. You will be assessed by a team of healthcare professionals as having a 'primary health need' for care.

This includes looking at:

- the type and particular characteristics of your needs
- how intense and severe they are
- the complexity of your needs
- how unpredictable your needs are.

Eligibility is always based on these needs, rather than any particular diagnosis or condition. If you have a diagnosis of MSA it doesn't mean you automatically qualify for CHCF.

HOW DO I APPLY FOR CHCF?

For most people, the first step is to have an assessment with a health or social care professional using a screening tool called the Checklist Tool. If this suggests that you may be eligible for NHS continuing healthcare, a full up-to-date assessment of your needs will be arranged, using something called the Decision Support Tool. You can ask your district nursing service to carry out the initial assessment.

A copy of the Decision Support Tool is available here:

www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care.

You should be fully involved in the assessment and decision-making process. Your views about your needs for care and support should be taken into account. If you feel that you need help to explain your views, you may want to ask a friend or relative for support. It also helps to prepare for assessments by keeping a diary or records of when and what sort of care is needed.

INITIAL SCREENING WITH THE CHECKLIST TOOL

The Checklist Tool is used to decide whether you should be referred for a full assessment. It helps health and social care professionals to work out whether your care needs may be of a level or type that indicate you may be eligible for NHS continuing healthcare.

After the initial screening, your local clinical commissioning group (CCG) will write to you to confirm whether or not you will be referred for a full

assessment for NHS continuing healthcare.

FULL ASSESSMENT WITH THE DECISION SUPPORT TOOL

If the Checklist Tool shows that you may be eligible for NHS continuing healthcare, the person who completed it will contact your CCG to arrange a full up-to-date assessment of all your care needs.

The full assessment will be carried out by a multidisciplinary team made up of a minimum of two different health or care professionals who are already involved in your care, to build an overall picture of your needs. In some cases, more detailed specialist assessments may be required from these professionals.

The information from your assessment will be used to complete the Decision Support Tool. This tool is used to assess whether your main or primary care needs relate to your health, by looking at the following types of care need:

- behaviour
- cognition (understanding)
- communication
- psychological / emotional needs
- mobility (ability to move around)
- nutrition (food and drink)
- continence
- skin (including wounds and ulcers)
- breathing
- symptom control through drug therapies and medication

- altered states of consciousness
- other significant needs .

For individuals who need an urgent package of care because their condition is deteriorating rapidly a Fast Track Tool may be used instead. This enables the CCG to arrange for care to be provided as quickly as possible.

WHAT HAPPENS AFTER THE ASSESSMENT?

You will get a decision about whether or not you are able to get NHS continuing healthcare. This may be a full package, elements of support, a joint package, support from local authorities or no eligibility. If you are unhappy with the decision you are given you can appeal, but you might also want to contact your MSA Nurse Specialist who can give you further information.

WILL THERE BE A CHARGE?

There is no charge for the NHS part of a package or joint package of care.

Local authorities are allowed to charge for the services they provide, and most of them do so. If your local authority is part-funding your care package, you may have to pay towards the cost of their part of the care, depending on your income and savings. Some authorities have set maximum amount that you can be charged, which varies from area to area.

FURTHER INFORMATION:

All the documents referred to in this article are available here:

www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care.

CARERS DIRECT

You can call the Carers Direct helpline on 0300 123 1053 if you need help with your caring role and want to talk to someone about what options are available to you. These services are available for people living in or caring for someone in England. **MSA**

For help in Wales

www.wales.nhs.uk/continuingnhshealthcare

For Scotland

www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/NHS-Continuing-Care

For Northern Ireland

www.nidirect.gov.uk/index/information-and-services

For Eire

www.hse.ie

FUNDRAISING ROUND-UP

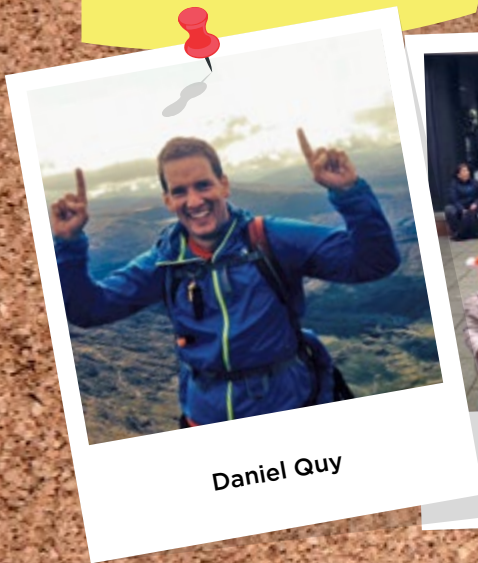
SEPTEMBER

Even after Daniel Quy took part in a Fan Dance in July 2015, his fundraising was not complete. In September he braved the Man Vs Mountain challenge, a 22 mile uphill run raising nearly **£2,500**.

The MSA Trust Great North Run team of seven runners collectively raised over **£4,000!**

Lindsay Jessett celebrated her 90th birthday in aid of the Trust raising over **£500**.

Repeat fundraiser Matthew Toombs took on the Windsor Half Marathon and raised **£285**.



Daniel Quy



Louise Foakes with her grandchildren



Irish Gala



Matthew Toombs

A very busy month as **Milk, Sugar And Tea** parties were held across the UK. Special mention goes out to the Adam's family who raised **£1,256** whilst combining their tea party with granddaughter Tia's 16th and her grandmother's 98th birthday celebrations.

Louise Foakes and her grandchildren happily cheered on daughter/mother Catherine Tyler in the Great Birmingham Run who raised **£772**. Louise even knitted cute MSA hats to keep out the cold.

Guests at the Black Tie Gala event held at the Grand Ballroom, Europa Hotel Belfast, in aid of the Trust contributed to the fantastic sum of **£16,000** raised on the night. Kiera Davidson, organiser of the event said, "Everyone had a fabulous time and were very generous!"

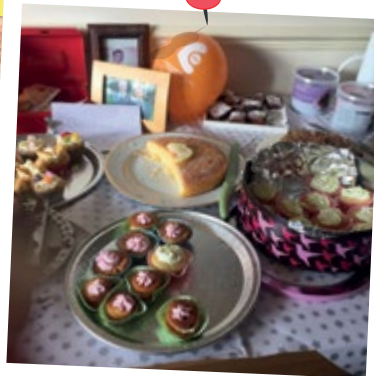
Sabrina Moore tackled the Wolf Run raising nearly **£500** for her efforts.

Our corporate supporters continue to raise funds for us, with Skipton Building Society donating **£1,000** to our Research programme, in the name of Jim Carruthers.

Waitrose and Asda Stores 'Green Token' appeals continue to raise much needed funds for the Trust throughout the UK.



Irish Gala



Katie Holder Tea Party



Maria McLeod raised **£1,790.00** cycling from London to Brighton



Lucy Keenan & friends



Joan Foster, wife of John collecting the cheque on the Trust's behalf

Lucy and Victoria Keenan along with their friends donned Santa suits to help support people affected by MSA raising **£1,080.41**.

Fundraising by our young supporters really took off in 2015 with schools from John O' Groats to Lands End raising funds for the Trust.

Dollar Academy in Clackmannanshire, Scotland raised **£9,000** in memory of John Foster, a much loved teacher; Darren Elder, a pupil of Mearns Academy in Aberdeenshire raised **£400** selling merchandise and Manningtree High School in Essex raised over **£250**. Well done to all our young fundraisers and our volunteers for attending the cheque presentations.



WHERE WILL YOU BE WEARING YOUR **#MSAORANGE** DURING MARCH?

It doesn't seem like two minutes since we had our last slurp of tea at our **Milk, Sugar And Tea** parties in October for World MSA Day. But now MSA Awareness Month is upon us and we need your help again.

This year our big push is to lift the lid on how devastating MSA can be and how so few people have ever heard of it. As we know, this lack of awareness can worsen the isolation often felt by people living with MSA.

To help us change this, we're asking you to wear orange during March, in solidarity with people affected by MSA and our work at the Trust. Tell your family, friends, and work colleagues why you're wearing orange and ask them to pass the message on. We would also love you to share with us and others **where** you are wearing your orange.

For starters, please wear the **orange ribbon** included with this magazine (and ask us if you need more). You don't have to restrict your orange to the ribbon, be creative and show us the different locations where you're proudly wearing our colour!

You might want to wear orange socks, an orange bra, hair band or even a fake tan so please share your photos with us. If you're not on Twitter or Facebook, this is a good opportunity to join our online communities. If you'd rather not, that's fine, just email your photos to support@msatrust.org.uk and we'll share them.

If you like us on Facebook or follow us on

Twitter please support our Thunderclap. We'll be building up to this from Tuesday, 1 March and making a big noise for the last day of MSA Awareness Month.

If you haven't heard of a Thunderclap, imagine a lot of people using a megaphone to spread the same message, at the same time, but online. It's similar to crowdfunding but rather than donating money (but please do if you can), supporters donate tweets and social media posts.

However you support us, whether you wear an orange ribbon or orange socks for the whole of March, if you raise funds, share our media posts or just talk to more people about MSA – we will be extremely grateful. **MSA**

JOIN IN

Download your MSA Awareness Month materials on our website www.msatrust.org.uk and join in on the addresses below:

Facebook: [Multiple System Atrophy Trust](#)
Twitter: [@MSATrust](#)
LinkedIn: [Multiple System Atrophy Trust](#)

MEMBERS STORIES

In the last edition of MSA News we gave details of research being run by Astra Zeneca. One of our members has been accepted on to this project and has written about their initial experiences.

“My first contact is with a friendly and approachable research consultant. If age and experience were the deciding factors, it should be me in the important leather chair outlining the research programme, judging the patient’s cognitive ability, physical fitness and present frame of mind. But I was the recipient of questions asking about alcohol consumption (I lied), Margaret Thatcher (mm!) and suicide (weirdly fascinating). The questions continued about past medical history and present symptoms. The physical examination with the usual prodding and pulling determined that I was indeed severely ataxic with ponderous speech patterns and a confirmation letter from a neurological expert guaranteed my progression to the second stage.

ECG next. I was wheeled off to the ‘to do’ room, set up with beds and equipment and two eager nurses (I was patient number one; would they be so enthusiastic by patient num-

ber 15? Actually, I think they would). A protracted session on the new ECG machine supplied especially by AstraZeneca was accompanied by much groaning from the lovely nursing team; a collection of eight phials of blood was accompanied by much groaning by the not so lovely me and numerous blood

“

The drug has seen positive results with Parkinson’s patients so it may benefit MSA/P sufferers more.

”

pressure readings saw the end of the first visit and very nearly of me.

The next outing consisted of an MRI scan and then we were ready for a PET scan. Mind you, can you ever be ready for 90 minutes of lying completely still, listening to Jeremy Vine? Double whammy!

Four sessions in and time to start the drug... or not!! The experiment is double blind so neither the research consultant, nor I, know whether I am on full dose of the myeloperoxidase inhibitor, half a dose or the placebo. Four weeks consecutively

of attending the centre for a weekly supply of the drug and routine tests has been followed by a respite of a month. I’m at present enjoying this break, but still taking the drugs. I haven’t noticed any discernible miracle like effect which suggests I’m ‘drugged’ up to the eyeballs with the placebo or that it does not respond to MSA, but it’s early days! The drug has seen positive results with Parkinson’s patients so it may benefit MSA/P sufferers more.

The whole process has been gruelling, exhausting, even at times boring (waiting for the medication and taxis). However, I believe it is incredibly worthwhile and will hopefully have wider positive future benefits.

The research consultant is professional, considerate and delightful and the nursing staff interested, patient and willing to ensure my wellbeing. I would fully recommend participation. I am the lab rat and I’m sure the processes will be easier for all of you who follow me.” MSA

SUPPORTING & HELPING EACH OTHER

Emma Rushton, our Services Support Officer, details some of the useful tips and hints shared at Support Groups in the last few months...

With the help of our fantastic Support Group Leaders we now have 36 groups across the UK and Ireland, with new ones starting in Hertfordshire and the Scottish Borders this month. We are starting to reach full capacity so if you would be willing to help at one of the Groups (especially those currently run by our Nurses) then please do get in touch.

The most valued aspect of attendance at our Support Groups seems to be the ability to share experiences and spend some social time with others. The opportunity to hear from health and social care professionals attending is also a big draw for people who may not know what's on offer. As usual I have picked out some useful tips people have shared:

One member at the East Yorkshire group explained that some Red Cross branches provide hand and foot massages at home. You can ask a healthcare professional to refer you, or in some cases you can self-refer. For more information please contact your local Red Cross branch at www.redcross.org.uk or by calling 0344 871 1111.

The Shropshire Support Group had a demonstration of the U Step walking frame. This piece of equipment comes with different features suitable for people with neurological conditions. Speak to your physiotherapist about this, or to find out more visit their website www.attainability.co.uk.

At the Limerick meeting they spoke about

problems with restless or irritable legs and feet. One person shared how they rub in Aloe vera gel before going to bed and doing this had really reduced the unpleasant sensation.

Our Dorset Group came up with some great tips including; Clinell wipes being brilliant for quick and simple bed baths, they can be bought cheaply in bulk online, delivered free and can be exempt of VAT. Chewable toothbrushes also proved helpful for some people with MSA. These are available from most large supermarkets but you may also have seen them in motorway service station washrooms.

During one of our Irish Support Groups in Dublin our MSA Nurse Specialist stressed the importance of regular exercise - but only for about 10 to 15 minutes at a time. She suggested building this into daily routines for example, putting the shopping away or doing chair exercises in television advert breaks. Speak to your Physiotherapist about which exercises are best for you

Now turn over to page 19 to see when your next local Support Group will be during March. For meetings from April onwards please look on our website www.msatrust.org.uk. **MSA**

Emma Rushton - Support Services Officer

0333 323 4591 or

emma.rushton@msatrust.org.uk

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.

DATE	VENUE	DATE & TIME
Hertfordshire	Hospice of St Francis, Spring Garden Lane off Shooters Way, Berkhamsted HP4 3GW	Tue, 23 Feb - 2.00pm
County Tyrone	Ranfurly House Arts Centre, 26 Market Square, Dungannon, County Tyrone BT70 1AB	Tue, 23 Feb - 2.00pm
Belfast	Massarene Golf Club, 51 Lough Road, Antrim BT41 4DQ	Wed, 24 Feb - 11.00am
Lincolnshire	Franklin Hall, Halton Road, Spilsby PE23 5LA	Wed, 24 Feb - 10.30am
Sligo	St John's Community Hospital, Ballytivnan, Sligo	Thur, 25 Feb - 10.30am
Dublin	The Red Cow Moran Hotel, Naas Road, Dublin - 22	Fri, 26 Feb - 1.00pm
County Durham	Chester Le Street Hospital Day Room, Front Street, Chester Le Street DH3 3AT	Mon, 29 Feb - 1.30pm
Cheshire	Allostock Village Hall, Chapel Lane, Allostock WA16 9LN	Wed, 2 Mar - 11.30am
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 2 Mar - 1.30pm
Greater Manchester	St Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Thur, 3 Mar - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 4 Mar - 2.00pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 7 Mar - 1.30pm
Cornwall	Cornwall Mobility, North Buildings, Royal Cornwall Hospital, Truro TR1 3LQ	Mon, 7 Mar - 1.30pm
Fife	Burnside Hall, Balmullo KY16 OAW	Wed, 9 Mar - 1.30pm
West Midlands	Moxley Peoples Centre, 3 Queen Street, Moxley WS10 8TA	Thur, 10 Mar - 11am
Aberdeenshire	Community Room, Tesco Store, Harlew Road, Inverurie AB51 4SR	Fri, 11 Mar - 1.30pm
Oxfordshire	The Girl Guide Hall, Southern Road, Thame OX9 2EE	Mon, 14 Mar - 1.00pm
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 16 Mar - 1.30pm
Cardiff	Ty George Thomas Hospice, Whitchurch Hospital Grounds, Cardiff CF14 7BF	Wed, 16 Mar - 11.00am
Cambridgeshire	Barton Bowls Pavilion, High Street, Barton CB23 7BG	Thur, 17 Mar - 2.00pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing BN11 5DR	Tue, 22 Mar - 2.00pm
Leicestershire	Village Hall, Main Street, Swannington, Coalville LE67 8QL	Tue, 22 Mar - 11.00am
Gloucestershire	Whitminster Village Hall, School Lane, Gloucester GL2 7NT	Wed, 23 Mar - 1.30pm
Kent	Room B028, University of Greenwich, Central Avenue, Chatham Maritime, ME4 4TB	Thur, 31 Mar - 2.00pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 31 Mar - 2.00pm

Due to so many Support Groups being held throughout March you will need to check the website, or contact us on the details above, to find out about dates from April onwards.

SERVICE OF LIGHT

MARCH 2016

Our annual Service of Light memorial services offer an opportunity to join together and share memories of loved ones. Please complete and return the form to book your place.

12 March 2016 - St Paul's Church, Covent Garden, London - 4pm

19 March 2016 - St Ann's Church, St Ann's Street, Manchester - 3pm

YOUR ATTENDANCE

I/We will be attending the service

London - St Paul's Church - 12 March 2016 - 4pm Manchester - St Anne's Church - 19 March 2016 - 3pm

Number attending:.....

Please find enclosed my voluntary ticket donation of £..... to attend the Service of Light for MSA (suggested donation of £10 per ticket)

YOUR CANDLE DEDICATION

In memory of:.....

I enclose my voluntary donation of £..... to dedicate a light of remembrance

I am interested in leaving you a gift in my Will (we will be in touch)

YOUR DETAILS

Full name*:.....

Address*:.....

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

Email:.....

Please make cheques payable to 'MSA Trust', and return this form with your donation to: Service of Light, Multiple System Atrophy Trust, 51 St Olav's Court, Lower Road, London SE16 2XB. For further information, please contact Melissa Tindle on 0333 323 4591 or email fundraising@msatrust.org.uk. THANK YOU

MAKE YOUR GIFT WORTH 25% MORE WITH GIFT AID

If you are a UK tax payer you can make your donations worth an extra 25p for every £1 at no extra cost to you, by ticking the box below and providing all information marked * on this form.

I am a UK tax-payer and I wish the Multiple System Atrophy Trust to claim Gift Aid on this and all donations that I make, or have made in the four years prior to this declaration. To qualify for Gift Aid, what you pay in Income and Capital Gains tax must at least equal the amount the Trust and all other charities and Community Amateur Sports Clubs (CASCs) you donate to will claim on your donations in the given tax year. Council tax and VAT do not count.

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