MSA NEWS

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MSA Trust – *Marking our* **20th year**

Tuning in…
to **music therapy**

ALL CORRESPONDENCE AND ENQUIRIES TO OUR ADDRESS:
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MEMBERSHIP AT FEBRUARY 2017

Current MSA members	1,317
Carers, relatives & friends	2,268
Healthcare professionals	2,413
Total	**5,998**

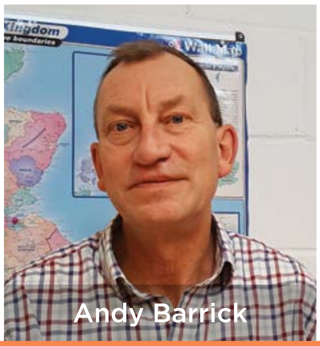
MSA NEWS CONTENTS

Multiple System Atrophy Trust

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

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



A quick hello to you all from me, Karen, and to give my thanks to our Deputy CEO, Andy Barrick, who has kindly agreed to introduce this first edition of MSA News of 2017. It's great to get a perspective from our Information and Support team…

2016 saw us providing help to more people than ever before. We ran our biggest number of Support Groups and our MSA Nurse Specialists dealt with the most enquiries since we began, as well as continuing to regularly attend clinics and run education events for Health and Care professionals. We also maintained our NHS Information Standard accreditation, which means that the information we provide has been independently assessed as being of high quality and accurate. However, we would be the first to say that so much more needs to be done to raise awareness of MSA and the specific needs of people who are affected by it.

We welcome Hannah Hutton to our Fundraising Team, joining Tanya, and we hope that we can continue to build on the marvellous support that you have given us over the last few years. In our 20th year we hope to run several events that you can get involved in, read more on page 12.

We have become increasingly involved in several issues that we know mean a lot to people affected by MSA. For example, we are part of a coalition that is aiming to improve the provision of Continuing Healthcare, which affects many people when needs become more complex. We are members of the Disability Benefits Consortium and of the Neurological Alliance, and have been supporting work looking at counselling needs for people. Whilst this forms a relatively small part of our work, the chance to be part of a wider network means that our voices can be heard more loudly and in many more places than if we just worked on our own.

We are aware that the NHS, and other public services, face continuing budget constraints but we also know that the needs of people with MSA are varied and complex, and we need to ensure people with influence recognise this and respond accordingly. If you have any specific issues you want us to look at, please let me know and we'll do our best to address these.

However, our work both directly supporting our members and progressing our research strategy will always remain at our core. We are hopeful that we will be able to recruit our fourth MSA Nurse Specialist during the course of this year. This will provide extra help to our existing Nurses, Jill, Katie and Samantha, whose workloads have increased as our membership has grown. Any support that you can give us to make this a reality will be very welcome.

Thank you again for your commitment to the work of the Trust. MSA

Andy Barrick, Deputy CEO
020 3621 1347 | andy.barrick@msatrust.org.uk

YOUR STORIES

When the doctor told me I had Multiple System Atrophy (at the relatively young age of 50) I was, in a way, relieved. At least I now had a name for all the problems I was having. I wasn't losing my mind or being a hypochondriac. I asked him to spell it out for me, to be blunt and give it to me straight. And he did.

Since that day in 2013 I have worked hard at living my life to the full and I have made a long list of adventures I am determined to have.

As an equestrian, the first thing I did was get my doctor to complete the forms so I could compete in the Paralympics. I didn't get to Rio but I have represented my country at International level and am now aiming for the European Championships. I have to train really hard to keep fit and to maintain my core strength, both essential for dressage. I work out at the gym 3-4 times per week and swim just as often. At home I use physio-resistance exercise bands. I also ride for about fifteen hours per week - plus competitions. None of this is easy. There have been times waking up in the morning when it has taken over an hour for me to be able to move. I get tired far more quickly than I used to. I've recently been re-graded in my dressage as there are some moves I can no longer sustain. I personally believe that I have been able to keep going as long as I have because I haven't let myself give up. It is also due, in part, to living in Oxfordshire and the excellent services provided here.

Horses always took up my time but with my MSA diagnosis I've had to get on and do other things. I've climbed Snowdon, wing-walked, ridden the UK's longest zip wire, been ice skating and competed in endurance rides in our glorious countryside - riding up to 120km in a weekend.

I try hard not to put things off on one day hoping I will feel better on another. Some things I can no longer do, like closing the ramp on my horse trailer by myself, and I do now have the occasional rest day. I use a mobility scooter and this allows me to keep on track. I also have the unfailing support of family and friends - most notably Ro (my very close friend). I even have a tame photographer, Wendy Aldiss, who has been documenting my progress these past years.

This year I'm planning to climb Ben Nevis and Scafell and hoping to go abseiling. I'm also seeking sponsorship for myself and my horse Pandora. Who knows? With funding we might even make it to the World Equestrian Games™ 2018 in North Carolina. **MSA**

Article by Julie Payne
Photographs by Wendy Aldiss

CARING FOR YOURSELF SO THAT YOU CAN CARE FOR OTHERS

We know from the enquiries we get and from speaking to you, our members, at Support Groups that many carers feel that they aren't fully aware of the range of help that's available.

We are currently reviewing our Carers Guide so we thought it would be helpful to summarise some key things that carers might find useful.

It is now becoming more widely recognised that carers make a vital contribution and as such need, and deserve, particular attention.

If you haven't already done so it is worth asking your local authority social services for a Carers Assessment, as this will help ensure you get any support and other benefits you could be entitled to. In some areas local authorities are able to provide an annual lump sum payment to carers to pay for respite support or regular activities. This means that people can get a break from caring every now and again.

Late in 2016 it was announced that any family with somebody entitled to Carers Allowance will be exempt from the benefit cap and there may also be other benefit support available if you are a carer.

If you register as a carer with your GP this can give you priority booking for appointments as a recognition that your health is important. Our MSA Nurse Specialists also recommend that you and the person you care for get the flu and pneumonia jabs (two weeks apart).

You may also want to look at particular sources of information depending on your own needs and those you are caring for. For example, the Carers Trust has an excellent section on their website around Health and Wellbeing of carers, as well as an online community www.carers.org/article/health-and-wellbeing.

Both Carers UK and NHS Choices have a range of useful information, as well as videos explaining the best way to provide help. NHS choices has a brief video on moving and handling the person you care for and on the same page has a very brief carers self-assessment tool which can point people to help www.nhs.uk/Conditions/social-care-and-support-guide.

Marie Curie also do a range of simple videos explaining how to undertake basic caring tasks www.mariecurie.org.uk/help/being-there/caring.

Our own website Forum as well as our new Health Unlocked community (www.healthunlocked.com/msa-trust) remain places you can go to ask questions and of course the Trust's MSA Nurse Specialists are always available for advice.

Finally, the Surrey Support Group have for a long time had a "break off" carers group and the Cambridgeshire Support Group leaders are looking at the possibility of holding occasional Support Groups where people living with MSA and those caring for them can have separate breakout sessions where their specific interests can be explored in more detail.

We will let you know how these progress. MSA

FOREWARNED IS **FOREARMED**

Our MSA Nurse Specialist Jill Lyons explains the importance of recognising and dealing with Urinary Tract Infections.

Urinary tract infections (UTIs) are common infections that can affect the bladder, the kidneys and the tubes connected to them. Anyone can get them, but they are often a particular feature of life with MSA. The most common urinary symptoms people may experience include:

- An increased need to pass urine urgently
- An increased need to pass urine frequently
- Nocturia - a need to pass urine frequently at night
- Retention - difficulties in emptying the bladder completely.

As people with MSA will already have urinary symptoms it is important to look out for any worsening or additional issues relating to these. **The presence of any type of infection can make all MSA symptoms much worse for people living with MSA, so prompt treatment with antibiotics is key. Because of the nature of MSA it can be possible for people to develop an infection but not demonstrate common symptoms e.g. a high temperature, so it is important that if you notice anything different you check the symptoms outlined overleaf.** UTIs can lead to a sudden deterioration in your condition which can lead to an increased level of care required and also to hospital admission. Hospital admissions are best avoided for people with MSA so recognising a UTI is very important.

Symptoms of UTIs

Infections of the bladder (cystitis) or urethra (the tube that carries urine out of the body) are known as lower UTIs. These can cause:

- a need to urinate more often than usual
- pain or discomfort when peeing
- sudden urges to pee - feeling as though you're unable to empty your bladder fully
- pain low down in your tummy
- urine that's cloudy, nasty-smelling or contains blood
- feeling generally unwell, achy and tired.

Infections of the kidneys or ureters (tubes connecting the kidneys to the bladder) are known as upper UTIs. These can cause the above symptoms and also:

- a high temperature (fever) of 38°C (100.4°F) or above **(However people with MSA often do not have a high temperature so this is not a reliable indicator)**
- pain in your sides or back
- shivering and chills
- feeling and being sick
- confusion
- agitation or restlessness

Upper UTIs can be serious if left untreated, as they can damage the kidneys or spread to the bloodstream.

It's important to contact your GP at an early stage if you think you might have a UTI.

Your GP can rule out other possible causes of your symptoms by testing a sample of your urine and can prescribe antibiotics if you do have an infection.

Causes of UTIs

UTIs occur when the urinary tract becomes infected, usually by bacteria. In most cases, bacteria from the gut enter the urinary tract through the urethra.

This may occur when wiping your bottom for example, but often it's not clear why it happens.

Women may be more likely to get UTIs because their urethra is shorter than a man's and is closer to their back passage.

They can also arise if people have difficulties with their self-catheterising technique.

Preventing UTIs

If you get UTIs frequently, there are some things you can try that may stop them coming back. These measures include:

- avoiding perfumed bubble bath, soap or talcum powder around your genitals – use plain, unperfumed varieties, and have a shower rather than a bath
- staying well hydrated
- wiping your bottom from front to back when you go to the toilet
- emptying your bladder before and after having sex
- wearing underwear made from cotton, rather than synthetic material such as nylon
- avoid wearing tight jeans or trousers.

Treatment for UTIs

UTIs are normally treated with a short course of antibiotics.

Your urinary symptoms will normally start to improve within three to five days of treatment, but make sure you complete the whole course of antibiotics that you've been prescribed, even if you're feeling better. It may take three weeks or more for all your symptoms to improve.

Painkillers such as paracetamol can help with any pain. Drinking plenty of fluids may also help you feel better.

Return to your GP if your symptoms don't improve, get worse or come back after treatment.

Speak to your GP if these measures don't work. They may suggest taking a long-term course of antibiotics or they may give you a prescription for antibiotics you can use as soon as you experience symptoms of a UTI. The GP may well want you to have a bladder scan to see if you are retaining urine which will make you more prone to infections. If you self-catheterise, or have a long term catheter you are more likely to get UTI's. Careful hygiene and hand washing are really important, ask your nurse to check your technique. For further information please contact our MSA Nurse Specialists - www.msatrust.org.uk/support-for-you/contact-us. **MSA**

REGULAR GIVING

Making a monthly donation to the Trust is a great way of contributing to our work without making too big a dent in your budget planning. It enables us to plan ahead in confidence that we have regular and firm income.

Any regular donation can make a big difference! A regular donation of **£20** per month can provide emotional support to someone over the phone from a MSA Nurse Specialist, but even **£5** per month will have an impact on our ability to help our growing membership.

The best way to make a regular donation to us is to set up a monthly standing order with your bank in favour of the MSA Trust. Call 0333 323 4591 for details and a form, or download one from our Regular Giving section of the website. Complete the form and return to us.

We will then send your standing order form direct to your bank and send you an acknowledgement. We will write to you annually to let you know the progress of our work and what we have been able to achieve thanks to your donations.

A wonderful way to remember a loved one who has passed away from MSA is to make an annual donation to the Trust to commemorate their birthday. Just tick the annual donation option, instead of monthly, on the standing order form. **MSA**

Call 0333 323 4591 or visit:
www.msatrust.org.uk/get-involved/individual-giving/give-a-regular-gift/

In Memory

Margaret Benney
Betty Brown
Michael White
Margaret Leach
Alistair Watt
Roger Lockett
Robert Moore
David Hearsey
Brian Meleady
Ian Jones
Glen Davey
Tony Whittle
Louis Hanney
Valerie Cousins
Elizabeth Carey
Graham Penfold
Helen Ruddock
Susan George
Alan Faulkner
Brian Smith
Kitty Vaughan
Ken Herring
Freda Inwood
Zulakhan Begum Aslam
John Hillary
Ian Popadenis
William Henry Johns
Elizabeth Handscombe
Valerie Foulkes
Jean Herring
Karen Thomas
Cliff Buchan
Arthur Rawlinson
Thomas Johnson
Janet Waites
Jill Howell
Fred Male
Ann Thorpe
Veronica Steele
Mae Sutherland

RESEARCH UPDATE

Our CEO, Karen, rounds up our current research projects and plans for 2017.

Photo of microglia in the brain's frontal lobe showing inflammation in MSA.

Research Fellow

2017 will be a momentous year for the MSA Trust as we recruit, in partnership with the Association of British Neurologists (ABN), an MSA Research Fellow. 21 applicants for three clinical research places were received by the ABN for shortlisting after an advertising round in October 2016. The interview process will take place in the middle of March and it is hoped that a suitable applicant will be found for the Trust funded post, to begin in September 2017. I hope we will have an update for you in the next MSA News. The Trustees are very excited by the possibility of supporting the development of a clinical specialist in MSA for the UK. We work closely with many neurologists and the Trustees believe the need to ensure clinicians are increasing their knowledge of MSA is vital. This is in order to both continue our understanding into the progress of MSA and to look at possible future treatments.

Current MSA Trust funded projects

At present we continue to fund three projects now in their last year of study. One project has been completed but the report is still to be finalised. Below is a short update on two of those projects to whet your appetite for an exciting year:

Transcriptomic insights into MSA pathogenesis and target pathways for therapeutic intervention

This study was slightly delayed due to the researcher being on maternity leave and is now proceeding at speed. This is an extended project, the researchers managing to match funding from us and increase their sample size to 200. This includes 30 MSA brains and 20 healthy brains. The sequencing that the study is undertaking is to look at the gene expression in different regions of the brain and blood in MSA versus control brains. The team working with the researcher have also managed to partner another study which will help in the analysis of the gene expression.

Understanding the degradation of alpha-synuclein (a-synuclein) protein in MSA

This study has required a short extension to finalise the results and determine if the breakdown of a-synuclein protein can be altered. The study is being undertaken in Bristol and London and brain tissue samples have been taken from six regions of the brain, both affected and unaffected by MSA. Some interesting results have already been found in the first part of the study which looked at the expression and activity of enzymes breaking down the a-synuclein protein. It appears that particular enzymes were noted to have increased expression in areas affected by MSA and to act differently in MSA affected parts of the brain, which suggests a possible molecular switch for these enzymes. The work continues and we are pleased to say an interim presentation will be made at the International Alzheimer's and Parkinson's Disease Conference in Vienna in March.

Key Changes Music Therapy © Alick Cotterill

THE POWER OF MUSIC THERAPY

We are surrounded by music. You might have already experienced music today – perhaps you've heard a song on the radio, watched a performance on TV, or simply had a good sing in the shower! We're all familiar with the profound effect music can have on us. It has the power to access our deepest emotions and memories, re-energise us and soothe the soul.

However, the power of music goes way beyond how we feel – it is scientifically proven to help our brains. Music is processed across many parts of the brain and making music increases brain activity and can help create new neural pathways. This 'neuroplasticity' allows nerve cells in the brain to compensate for injury and disease and to adjust their activities in response to new situations or to changes in their environment. This means that music therapy can play a unique role in helping people living with a neurodegenerative condition because of the ways in which the brain processes music.

The British Association for Music Therapy (BAMT) is the professional body representing music therapy and music therapists in the UK. They define music therapy as 'an established clinical intervention delivered by qualified music therapists to help people whose lives have been affected by injury, illness or disability through supporting their psychological, emotional, cognitive, physical, communicative and social needs.'

According to BAMT, everyone has the ability to respond to music, and music therapy uses this connection to bring about positive changes in emotional wellbeing and communication, through the engagement of live musical interaction between therapist and client. By developing a relationship with a music therapist, people who live with a neuro-degenerative disease can also be helped to adjust emotionally and psychologically to living with and managing their condition, to express emotions and support their communication and relationships with others. Playing and listening to music – following the tempo and rhythm, musical sequences, responding to musical and verbal cues – can improve attention, memory and problem-solving skills. Vocal improvisation and singing can sometimes help with speech, improve pronunciation and breath control.

Anna Ludwig is a qualified music therapist, having studied at the Guildhall School of Music and Drama in London. She has worked with people with wide ranging needs, including people with MSA. Anna is also a certified Neurologic Music Therapist and a British Lung Foundation 'Singing for Lung Health' leader. Here she describes her time with a person with MSA called Les:

"I was introduced to Les by one of the nurses working at Kilbryde Hospice, near Glasgow. As he had such a strong love of music we thought he might benefit from music therapy sessions as a means of stimulation and creativity and for an outlet to express his emotions. During our weekly sessions together we listened to music, improvised on instruments and also wrote songs. Les dictated words or phrases both verbally and by using his letter board and then he would choose the type of sounds he wished to accompany it. This led to my discovery of the Mellotron – an electronic, keyboard-like instrument which was used by prog-rock groups in the '60s and '70s, which Les was particularly fond of. By the wonders of modern technology, I downloaded an app of a Mellotron that Les was able to access easily on an iPad.

Les wrote songs for his wife and granddaughter which were both moving and loving and showed his sense of humour. We often spent an hour improvising together – Les would use 'virtual' instruments on the iPad such as a guitar and with very small finger movements Les could change the chords. I accompanied him on my harp and I often found it a challenge to keep up with him! Les also enjoyed playing my small Celtic harp with support. Although challenging both physically and mentally, the combination of technology and a good old-fashioned acoustic instrument worked really well for Les. I also invited a student to join us and Les particularly enjoyed it when she played her violin and he even had a go at playing it himself!

For Les, music therapy was an opportunity to express himself through improvisation and choice of music and the sessions were filled with joy and laughter. He was able to be creative and to explore instruments he had never even seen or played before. His extensive knowledge of music was a joy to hear about and he relished finding bands that I had never heard of."

There are almost 800 music therapists currently registered in the UK and like other arts therapists, qualified music therapists must be registered with the Health and Care Professionals Council and abide by their Standards of Conduct, Performance and Ethics. Music therapists are highly trained and hold a Master's degree in music therapy. They work across hospitals, schools, care homes, hospices and in people's homes. **MSA**


Anna Ludwig

BAMT BRITISH ASSOCIATION FOR MUSIC THERAPY

To find out more about music therapy services in your area or to learn more about music therapy, please visit www.bamt.org or call them on 020 7837 6100.

20TH ANNIVERSARY

This year the MSA Trust will reach 20 years of age. Here's what we have planned…

In May 1997 Sarah Matheson and a group of close friends met to discuss the possibility of setting up a Support Group for people who had been diagnosed with MSA, Sarah had received her diagnosis in 1993. The rest, as they say is history and this year we are eager to mark this milestone. Events will be taking place from mid-March (MSA Awareness Month) 2017 to March 2018 to mark the year. Below we outline two initiatives we hope you will join in with.


Sarah Matheson

20 in 20 for 20

During the period of April to September 2017 we are pleased to announce our 20 events in 20 weeks. These will include: sponsored skydives, cycling challenges, trekking, running or walking events completed by you, our members and supporters. If you would like to get involved in any of these events, or have any ideas of your own to add, please visit the events page on our website (www.msatrust.org.uk/get-involved/events) and keep an eye on our social media pages for updates. 2016 was an amazing year with our supporters raising a huge amount of money through sponsored events – we hope to keep this momentum going for our 20th year. Our aim is to raise £20,000 towards the cost of a forth MSA Nurse Specialist. We know how much you value our Nurse Specialist service, and hopefully by recruiting our forth we can reach and support even more people with MSA.

'Sarah's Wood'

Our second main event this year will be the launch of 'Sarah's Wood'. This idea is supported and sponsored by Hugh Matheson, our founder Sarah Matheson's brother, who wanted a way to symbolise the hope and support the MSA community can create for each other. The Wood will be located in Thoresby Park in Nottinghamshire, in the heart of Sherwood Forest. There will be a launch event for 'Sarah's Wood' on 13 June 2017. On this date we will be inviting our members and supporters for afternoon tea and to plant the first acorns for the Wood. Don't worry if you can't make the date as there will be future acorn planting days held during the best planting months for Oak trees (the winter). Details for this event will be on our website soon, or please call the office for more information.

Some of our Support Groups or local volunteers will be holding 20th anniversary events such as MSA Tea Parties near you during this year. Please keep an eye out for these as they are a great way to raise awareness of MSA and funds for the work of the Trust. We will be reporting on more events planned for 2017/18 in future editions of MSA News. **MSA**

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KEEPING GOOD COMPANY

Do you work or know someone who works for a large company, or even a small one? Perhaps you would like to know about corporate fundraising?

We are always keen to work with organisations who want to make a difference by raising money for MSA research or our services.

Our fundraising team are available to chat about your ideas any time. It might be just putting our logo and link to our website onto your information, or you might want to have our collection boxes beside your tills, encouraging people to give their small change. Perhaps you want to undertake a challenge, like the Acre Foundation staff, who climbed Mount Toubkal in Morocco. Other events that might appeal – the bake-offs at Maurice Turnor Gardner became quite competitive and the staff there raised thousands for us. Through the 5p plastic bag charge, Klondyke Garden Centres raised a whopping £4,000 last year. And Coloplast, who have supported our magazine production throughout 2016, are continuing their fantastic support again this year.

Whatever takes your fancy, the MSA Trust is here to help and support with resources and guidance on the boring but important bits such as gift aid, insurance requirements or risk assessments. Just visit www.msatrust.org.uk/get-involved/corporate-giving to find out more.

Danni Buxton climbed Mount Toubkal after the Trust was selected by the Acre Foundation to be part of their corporate social responsibility programme. Thanks Danni:

"My dad passed away from MSA in January 2015, so I was really touched that my business, Acre, allowed me to focus my fundraising on the MSA Trust. Acre are a recruitment business who have a charitable arm called Acre Foundation. The Foundation grows year on year, as does the scope of our imagination when it comes to raising money, and getting our networks, friends and family to support our worthy causes.

Our fundraising this year included a Sustainable Wine Tasting Event, a Quiz night and a number of internal events, but it all culminated in 11 intrepid explorers climbing Mount Toubkal, the highest mountain in North Africa, over three days.

Mount Toubkal is an epic setting and a challenge that reflects the personal story behind the charities we supported. We encountered freezing temperatures, fresh deep snow above 3500m, hailstorms, thunder showers and character building mountain refuge logistics! We were rising at 4am to climb, thus climbing in the pitch black, and scrabbling up scree on our hands and knees. It was definitely the hardest thing I've ever done and I am certainly in no rush to do it again, but the euphoria felt when we hit the summit is something I will never forget as is the satisfaction we all gained supporting the great work of the Trust." **MSA**

FUNDRAISING

RAISE A CUP FOR MSA

Our Tea Parties from last year have so far raised over £7,000. Some took place during office coffee breaks, others as Afternoon Tea. But they **all** contributed to support our MSA Nurse Specialists.

Belinda Popadenis had her Tea Party at her beauty salon and raised almost £1,000

RUN, RUNS AND MORE RUNNING!

Nearly £1,500 was raised at the popular **Great North Run** by our wonderful runners.

Vicky Shaw at the start of the Great North Run

A fantastic effort by our supporters who took up the **Thames Path Challenge**, running 100km along the river!

Lisa Edwards at the Thames Path Challenge

A big thank you to the MSA Community in Scotland raising close to £6,000 by completing the **Great Scottish Run**.

Fancy running in the snow? James Bradley did for Runvember!

November saw fundraisers doing a **Runvember** challenge collecting almost £2,000!

Elaine Holmes did a fantastic job raising over £2,000 after running in the **Dublin Marathon**.

Elaine with her Dublin Marathon medal

Cathy Anderson works with someone diagnosed with MSA in Worcestershire. She was so inspired by their perseverance that she decided to run in the **Oxford Half Marathon** to raise funds. She was able to raise an incredible £10,000 for us. Well done Cathy!

CHALLENGES NEAR AND FAR

Graeme MacVicar and his crew took part in the **Tour of Mull Rally** in memory of his aunt who passed away from MSA. They raised lots of awareness of MSA wearing their orange T-shirts and sporting our logo on their cars!

Tour of Mull Rally

Stacey Lawrence's, friends and family successfully embarked upon the famous **Yorkshire Three Peaks Challenge** trekking and ascending a total of 5,200 ft. This challenge alone raised more than £3,000!

Tough Mudder

Grace Hughes's mother, Helen passed away from MSA and in her honour Grace and her friends took on a **Tough Mudder challenge**. They raised close to £1,500 for the Trust.

Three Peaks Challenge

A GREAT EVENING OUT..

A fantastic black tie event was held in Formby, Liverpool with lots of celebrities helping to raise awareness and the roof! All this was co-ordinated by Joe Cannon in memory of his Mum, Sharon. They raised a staggering £33,000.

The wonderful music students from the Royal College of Music entertained family and friends to kick-start their year of supporting the MSA Trust. We enjoyed a lovely evening and their first fundraising event raised over £600.

Royal College of Music Student Union President, Alex Fryer with MSA Trust staff

A big thank you to our supporter, Roger Turner and his wife for their successful fundraising event that raised £1,700 for us in April, last year.

SUPPORTING
& HELPING EACH OTHER

Here, Emma Rushton takes a look at some of the tips and information shared at Support Groups...

A member of the Cambridgeshire Support Group informed the meeting about a new product they had found called Napkleen. These are clothing protectors that prevent splashes and stains and can also be re-used. They can be purchased online from www.napkleen.com.

SafeHands Holidays provide holidays for disabled people and their family and friends. They have two hotels in Blackpool and North Wales which a member of the South Yorkshire Support Group has been to. If required the hotels can provide dedicated carers to those travelling alone or if a carer would like some respite. All rooms are fully accessible and transport services can also be provided, including pick up and drop off at home. For more information please look on their website - www.safehandsholidays.co.uk.

Our Irish Support Groups spoke about checking with Healthcare professionals before buying any new equipment or gadgets. They can then confirm that the equipment fits the person's needs correctly and also check if the equipment could be provided by health services.

At the Lancashire Support Group there was a discussion about holidays. One member suggested asking your travel agent or airline about getting an extra luggage allowance. Often if you are flying long haul they will allow you to take an additional piece of luggage for medical supplies such as catheters and spare medication, free of charge.

One of our MSA Nurse Specialists discovered a website called www.wheelmate.com which may be helpful for people with MSA using a wheelchair. Finding clean, accessible toilets and parking spaces when on the move can be a real challenge for wheelchair users, so Wheelmate shows locations all over the world where these facilities can be found.

Our Support Groups couldn't run without the time given by our wonderful volunteers. We need some help at the Support Groups which our MSA Nurse Specialists currently run. If you have a spare few hours through the year, why not come and help our Nurses to set up for a Support Group meeting, help provide the refreshments or come to chat to people affected by MSA and make them feel welcome. If there were a couple of people that wanted to share a volunteer role we would be more than happy to discuss this too.

We would love to hear from you about volunteering or any tips you have to share. Please do get in touch with me on my contact details below. MSA

Emma Rushton – Information & Services Manager
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, listen to presentations from healthcare professionals that can support you and meet our MSA Nurse Specialists.

Please contact the Trusts 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
Cheshire	Allostock Village Hall, Chapel Lane, Allostock, Knutsford WA16 9LN	Thur, 16 Feb - 1.00pm
Lancashire	Grimsargh Village Hall, Preston Road, Grimsargh PR2 5JS	Fri, 17 Feb - 1.30pm
Greater Manchester	St Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Wed, 22 Feb - 1.30pm
Kent	Room B028, University of Greenwich, Chatham Maritime ME4 4TB	Thur, 23 Feb - 11.00am
Surrey Carer's lunch	Please contact the Trust office for more details	Thur, 23 Feb - 12.30pm
Northumberland	TORCH Centre, Corbridge Road, Hexham NE46 1QS	Mon, 27 Feb - 11.00am
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Tue, 28 Feb - 2.00pm
Dublin	St Francis Hospice, Station Road, Raheny, Dublin 5	Wed, 1 Mar - 1.30pm
County Cork	Gilbert Centre, Fair St, Mallow, County Cork	Fri, 3 Mar - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 3 Mar - 2.00pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 6 Mar - 1.30pm
County Tyrone	Ranfurly House Arts Centre, 26 Market Square, Dungannon BT70 1AB	Tue, 7 Mar - 11.00am
County Down	Downpatrick Hospital , Primary Care Conference Room 1, 1st floor, 2 Struell Wells Road, Downpatrick BT30 6RL	Wed 8 Mar - 11.00am
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamstead HP4 3GW	Mon, 13 Mar - 11.00am
Cambridgeshire	Barton Bowls Pavilion, High Street, Barton, Cambridge CB23 7BG	Thur, 16 Mar - 2.00pm
Bristol	The West of England MS Therapy Centre, Bradbury House clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 16 Mar - 1.30pm
Oxfordshire	The Girl Guide Hall, Southern Road, Thame OX9 2EE	Mon, 20 Mar - 2.00pm
Leicestershire	Village Hall, Main Street, Swannington, Coalville LE67 8QL	Tue, 21 Mar - 11.00am
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 22 Mar - 1.30pm
Cornwall	Echo Centre, Barras Place, Liskeard, Cornwall, PL14 6AY	Mon, 27 Mar – 1.30pm
County Durham	Chester Le Street Hospital, Day Room, Front Street, Chester Le Street DH3 3AT	Mon, 27 Mar – 1.30pm
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 29 Mar - 1.30pm
Lincolnshire	Franklin Hall, Halton Road, Spilsby PE23 5LA	Thur, 30 Mar - 2.00pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 30 Mar - 2.00pm
Essex	Great Tey Village Hall, Great Tey, CO6 1JQ	Mon, 3 Apr – 2.00pm
Dorset	Trinity Methodist Church Hall, Southbourne Road, Bournemouth BH6 5AQ	Mon, 3 Apr – 11.00am
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 12 Apr - 2.00pm

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MAKING A DIFFERENCE

Anna Kent writes about her role supporting people affected by MSA...

My role is that of a community-based specialist nurse providing help for people with rarer neurodegenerative conditions, including MSA. I am based in Milton Keynes. I provide a single point of contact from diagnosis and through the individual's journey, providing ongoing assessment, monitoring, review and overall continuity of care.

It's especially important to me that people and their families are given the right information and support to make informed choices in relation to their care and treatment.

However, another key element of my role is to ensure that other professionals have access to information and education to enable them to provide the best care they possibly can. I therfore provide education and training for health and social care professionals.

In this respect I am fortunate to be able to work closely with a range of colleagues within health, social care and charities. I've seen clear benefits to patients as services work together to provide ongoing support and also benefits to organisations as they improve, reflect and learn. I feel proud my own organisation prioritises service development and puts quality care at the centre of what we do.

For example, I am a member of the Milton Keynes Joint palliative care group, where I have been actively involved in the development of a teaching programme and also creating a local document on advance care planning www.willen-hospice.org.uk.

Being diagnosed with a rare condition that few people have heard of can feel very isolating at times. During 2015 after discussions we felt it could be really useful to see if I could arrange an informal Support Group for people affected by MSA, to meet up with people in a similar position as themselves. I was aware that there were Support Groups run by the MSA Trust, however the nearest one was quite a distance from Milton Keynes. We found a great venue - Strudwicks Coffee Bar where the manager readily agreed that we could meet there free of charge. At the first group I was delighted to see the number of people who came along to meet up. I was really moved when one of the group looked around and said with a smile "so there are this many people in Milton Keynes that know about MSA, I thought I was the only one...".

We have continued to meet every two months since then and some of my colleagues and MSA Trust Nurses have also attended which has been really helpful in attendees feeling more informed about a range of services.

My days are busy, with no two days being the same, but it's unbelievably rewarding knowing that I can help make positive differences to people's lives. MSA

If any Health or Care Professionals reading this want to talk to Anna about setting up a local neurological condition group, please contact her at anna.kent1@nhs.net.

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