



msa *news*

MSA Trust Members Magazine | Issue 59 | October 2020



Let's Keep Talking

*Voice banking through
'My-Own-Voice'*



Welcome to Issue 59

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Once again, we offer a very warm welcome to your latest issue of MSA News.

We hope you will enjoy the range of articles we have for you this time round. We are particularly interested in your experiences of getting (or not getting) emotional support – see page four for more on this.

As it is our last MSA News before Christmas, please consider buying your Christmas cards from us, both to raise funds and awareness. You can order on our website or use the form on the back page.

We are all only too aware that this year has been like no other and that you and your families have had to make huge changes and sacrifices over the last few months.

As you will have seen, the Trust has continued to keep our services and support running and maintained our funding for research projects. Please see the next page for an update on this from our CEO, Karen.

We could not have done all this, or continue to do so, without the support of our fundraisers and our volunteers. We know we say it often, but we are so, so grateful for all your support and commitment. A heartfelt thank you from all of us.

Emma and Andy

msa news



The view from our CEO



Karen Walker, the Trust's CEO, looks at how we have been continuing our work over the last few months.

It is lovely to see the latest MSA News being published, certainly an indicator that our work at the Trust goes on despite everything happening at the moment. I thought I would use my space to share how we have managed since our world changed earlier this year.

Our office is open again, however staff are commuting much less and working from home wherever possible. This is very important to minimise the time our team are in contact with others on their travels. As the colder weather arrives and we all spend more time indoors, we will monitor staff risk carefully and if necessary, revert to working entirely from home again.

I want to mention how hard our team here at MSA Trust have been working and to say a big thank you from me for the way in which they have responded over the last few months. They have been flexible and willing to adapt their working practices and have worked incredibly hard to maintain a seamless service.

I am pleased to say that we have been able to work on addressing some of the needs identified in our MSA Needs Survey from last year. Our Trustees were keen that we should not start new projects during the early stage of the pandemic but did wish us to begin to scope out ideas and, where possible, to seek funding for new projects. The team in Information and Services, along with the MSA Nurse and Social Welfare Specialists, have been busy scoping out new initiatives to make a positive difference as soon as funding can be secured.

As you will see throughout the magazine our fundraising team continue to work hard to ensure the money is available to keep all our services operational. Later in the magazine we share some great news about the Trust's new commitment to fund voice banking, one of our initiatives that we have been able to bring to fruition.

We also have news in this issue on the restart of some of the Phase 3 drug trials, which should have started

early in the summer. A Phase 3 drug trial will test medication in a larger number of people with MSA, to measure how effective the treatment might be in the intended clinical population. The Research Roundup on page nine outlines all the great work that has continued during this pandemic. The new grant awards we are funding

are all rescheduled to begin in January 2021. As ever, we will do our best to keep you up to date on research progress and drug trials, so keep checking back on the website and on social media.

Finally, I hope that you are keeping safe in this challenging time and would love to hear from you if you have any suggestions, either for the magazine or ideas of other ways in which we can help you. [msa news](#)

We have proved we can work in a different way effectively so please continue to use all our services as you would do normally. We remain here to serve you all.



Emotional Support for people living with the impact of MSA

From member conversations with our Nurse Specialists and from our MSA Needs Survey, it is clear that living with MSA is emotionally stressful and, at times, overwhelming.

Feelings of worry, anxiety, hopelessness or low mood are commonly experienced by people affected by MSA. However, very few people are routinely offered professional support for their mental health and wellbeing, with emotional support needs often being overlooked or overshadowed by the practicalities of daily living.

We are currently reviewing what steps we can take to help members access better support for their emotional and mental wellbeing. This might be, for example, by developing befriending or telephone/online emotional support services or by helping members access local services such as NHS psychological support or hospice counselling sessions.

Whether you have a diagnosis of MSA, or are caring for someone who is living with MSA, we are keen to hear your views on what types of support or activities might help you or a member of your family maintain emotional and mental wellbeing. Perhaps you have accessed face to face or online psychological support, have tried music therapy, practice mindfulness, or have found that talking to others who are living with MSA is the most helpful form of support? Whatever your experiences, positive or negative, we would like to hear your views.

Email support@msatrust.org.uk or call us on 0333 323 4591. [msa news](#)

HCP STUDY DAY ON MSA

We usually hold our Study Day for Health and Care Professionals in October each year but due to the Coronavirus pandemic have had to delay to 2021. The planned date will be Thursday 18th March at the same venue in St Neots, Cambridgeshire. Our programme will look at what MSA is, what it's like to live with and the practical ways that Health and Care Professionals can best support people living with the condition. It aims to be an interesting and engaging day with plenty of discussion and opportunities for networking, with an excellent panel of presenters.

The cost will be £25.00 which includes a delegate pack, a certificate of attendance, complementary hot lunch and refreshments throughout the day. To express your interest, view the provisional programme and find out more visit our website - www.msatrust.org.uk/2021-study-day.

Please spread the word to your Health and Care Professionals and help us to raise awareness of MSA. [msa news](#)



NEWS ROUNDUP

Our New Colleague at the Trust

We are delighted to welcome Bunmi Akinwale as our new Events and Community Fundraising Officer who joined our Team over the summer. Bunmi says:

"I have been working in the charity sector for two and a half years in a similar role. I take real pleasure in both engaging with and encouraging selfless supporters to fundraise from organised events and community fundraisers. Despite joining in an unprecedented year, the entire staff team has made my introduction here very welcoming. I cannot wait for next year when we can all hopefully get back to some normality, but in the meantime, I look forward to continuing to support as many of you as possible undertaking virtual events for the Trust's great work." [msa news](#)



TV Licences - Should yours be free?

From the 1st August 2020, TV licences ceased to be free for people aged 75 and over unless they receive Pension Credit. Pension Credit is a means tested benefit for people over state pension age that many people miss out on. To check if you are entitled, call the

Pension Credit Helpline on 0800 99 1234. Have your National Insurance Number(s) to hand along with details of income and savings for you and any partner. Receiving Pension Credit can also entitle you to a range of other benefits. Once in receipt of Pension Credit register online for your free TV licence or call 0800 232 1382. [msa news](#)



Connecting Members

Our MSA HealthUnlocked community is thriving with over 170 active users sharing their experiences of living with MSA. We have found that people prefer the user experience and ease of HealthUnlocked over the forum currently on our website. We have therefore decided to close our website forum and will solely use HealthUnlocked in the future. The current website forum will close on 1st December 2020 and will then be read-only for one month. After this it will be taken down. **We encourage everyone to sign up to our MSA HealthUnlocked Forum here –** www.healthunlocked.com/msa-trust. [msa news](#)



Our Radio Stars

We were honoured earlier this year to be one of the charities nominated for a BBC Radio 4 Charity Appeal. Member Paul Wheeler, who has MSA and his wife, Gill made a compelling and engaging appeal asking listeners to support our MSA Nurse Specialists. They spoke about the lack of support before they found our MSA Nurse, Samantha Pavey who they thought in their own words had been "God sent". You can hear the full recording on the Radio 4 website: www.bbc.co.uk/sounds/play/m000lslm.

The appeal was very successful and managed to raise over £32,000. This will go a long way in a year when our MSA Nurse Specialists are needed more than ever. [msa news](#)





Tips to Help you *Stay Mobile*

As most people with MSA will experience mobility problems at some time or another, it can make a lot of sense to plan ahead. Here our MSA Nurse Specialist Katie Rigg, explains what you should be thinking about and where a wheelchair can help...





Most people with MSA will experience significant mobility difficulties. Your Physiotherapist and Occupational Therapist can assess your mobility needs and advise on appropriate aids to keep you mobile, with maximum safety. Keeping mobile safely is very important and doing exercise – little and often – keeps limbs and joints as healthy as possible.

However, an infection episode or fall, may mean there are times your mobility becomes reduced or less safe. In view of this, it makes sense to have a wheelchair available as a safety net for those less good days.

In this initial situation a manual wheelchair is adequate – your Physiotherapist can take the back, seat width and length measurements you need for a fitted chair and refer you to NHS wheelchair services.

The thought of needing to use a wheelchair fills some people with trepidation. Although to balance this, some people with MSA tell us the public often make assumptions about them when they are out and their walking is unsteady. So seeing a wheelchair activates instant recognition that a person has mobility difficulties and can initiate a more helpful (and understanding) response from others.

Most people with MSA will not have the arm strength to self-propel in a manual wheelchair. To self-propel you need a wheelchair with large back wheels and a push-rim attached. Some people can use the push-rim and push with their feet on the floor to get around indoors – however this is rarely sustainable longer term.

To use a manual wheelchair outdoors you will need someone to push you, so it is easier to have a wheelchair with smaller back wheels – these are also usually lighter and easier to get in and out of a car boot. Adjustable handle height is important so the person pushing is in a comfortable and good position. Handlebars that fold down for getting in the car boot are useful too. All wheelchairs should have a lap belt to prevent being tipped out or slipping out if the wheels catch on something unexpectedly.

Taking a wheelchair with you for trips out means you can go further than the short distance you may manage to walk safely. This means you can fully explore and enjoy where you are. Often people will walk pushing the wheelchair (like using a rollator), then sit in it to rest or be pushed the rest of the way. Using the wheelchair enables you to access areas you may otherwise avoid e.g. busy places or unpredictable ground for fear of being knocked off balance. This significantly increases

your horizons!

To qualify for an NHS provided power/electric wheelchair your Physiotherapist, GP or Occupational Therapist will need to assess, measure and refer you for one. Each regional area has different eligibility for indoor or indoor/outdoor electric wheelchairs. Either way, your house doors will need to be wide enough to get your wheelchair through and you may need ramps fitted. The person needing the chair has to undergo a safety assessment for moving and controlling the wheelchair before it will be provided. There are different controls, position of controls and sensitivity that can be adjusted to enable best fit for each person.

Attendant controls can be fitted to an electric wheelchair but NHS wheelchair provision will only provide what is assessed as needed. If the person can't control the electric chair independently then an attendant has to be with them, so it may be deemed that a manual wheelchair that can be pushed by the attendant carer meets the need.

Most power chairs are too heavy and bulky to get in the boot of a car, so ideally you need a wheelchair accessible vehicle so you can drive into the vehicle and then travel in the wheelchair. An article on wheelchair accessible vehicles is in

As time goes on people with MSA will increasingly and consistently need to use a wheelchair. For some people this will always be a manual wheelchair. If your partner/ carer has their own health issues or is of slight stature compared to you, it may be an option to fit a portable battery pack to the chair to assist them. However, most NHS wheelchair services are not supportive of these being fitted to their chairs.

issue 56 of MSA News – you can find this on our website. Some electric wheelchairs are designed to be portable so are lighter and can fold down to get into the boot of a car. However, these usually have minimal postural support so are only suitable for sitting in for short periods of time.

Regardless of whether you use a manual or electric/ power wheelchair, if you are needing to spend significant time in the chair then it is vital that the Physiotherapist and Occupational Therapist assess your needs for any extra components. Such components may be pressure relieving cushions, gutter armrests, elevating leg raise, head rest, lateral supports or a tilt in space seat to allow pressure relief, postural support and blood pressure management. Any or all of these extras may be needed.

Find out more here - www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/walking-aids-wheelchairs-and-mobility-scooters.

Given assessment and delivery timescales, it is best to plan ahead for wheelchair use so please do contact your MSA Nurse Specialists at support@msatrust.org.uk if you have any questions or need some support. msanews



In Memory

Susan Gregory
Christine Banks
Marian Woods
Michael Richer
John Hoad
Janette Banner
Jane Perkins
Alan Bowles
George Moyes
Dominique Doe

Norma Heron
Keith Heyes
Robert Stephenson
Christopher Hawksby
Peter Ford
Janet Hayton
Alison Cunliffe
Christine Cratchley
Norman Gardner
Kenneth Thompson

John Collinge
Mary Ellis
Adrian Harrison
Joanne Wright
Mark Ward
Raymond Hussey
Nicholas Frost
William Sate
John Lawson
John Foot

Michael Mears
Martin Lowe
Bryan Smith
Elaine Loraine
Elaine Stevens
John Ritchie
Natalie Gowing

REMEMBERING LOVED ONES DURING CHALLENGING TIMES

Losing a loved one is always extremely difficult, but perhaps this year has been made even worse due to the challenges and social distancing rules. Our thoughts are with those families who were unable to attend remembrance or funeral services in the manner in which they would have hoped.

Some families have found solace in creating an online tribute for their loved one - where family and friends can leave messages both celebrating their lives and of hope, while supporting the Trust as a charity close to their hearts.

We have partnered with the MuchLoved Charitable Trust who specialise in a Tribute website service. Opening an online Tribute page here can be a meaningful way to remember lives lost to MSA. It's free, quick and easy to set up a page and you can personalise it with pictures, videos, stories and even timelines to mark milestones in your loved one's life. You can light a virtual remembrance candle and add entries to

an online journal to ensure that your loved one's memories live on.

You can add offline donations (such as cheques) to the Tribute page, so that it counts towards the total raised in your loved one's memory. Funds get automatically forwarded to us by MuchLoved and all donations will be gratefully received to ensure we carry on supporting our MSA community as best as possible.

Please get in touch with Tanya at fundraising@msatrust.org.uk if you wish to open such a page. *msa news*

much loved
The online tribute charity



Research Round Up

There continues to be a growing number of research projects looking at MSA. Here we explain some of the headliners and two projects that are currently recruiting patients.

Open and recruiting trials

MSA can cause dizziness, light-headedness and fainting due to a drop in blood pressure called neurogenic orthostatic hypotension (nOH). This is due to changes to the autonomic system and can be a difficult symptom to treat. Theravance Biopharma are investigating a new drug for nOH. Ampreloxetine has already been shown to be safe in a phase 2 trial. Now, an international phase 3 trial hopes to show benefit in a larger number of participants with MSA. **Research sites in Birmingham, London, Guildford and Plymouth are currently able to screen and recruit participants in a Covid-secure environment. Help can be given with transportation if needed.**

For further information call 0800 802 1030 or visit www.recognitionhealth.com/sequoia-study for an informal discussion to see if you might be eligible to participate.

A new study of Exenatide in MSA is now open and seeking people with MSA to participate. Exenatide is a drug used to treat diabetes and has shown potential benefit to people with Parkinson's Disease in previous studies. The open label, randomised controlled trial, coordinated by Professors Foltynie, Houlden, Morris and Dr. Chelban will be carried out at The National Hospital for Neurology in London. **People from any location can be considered for the trial if they meet the inclusion criteria.** In the first instance, contact Christine Girges c.girges@ucl.ac.uk for more information and an informal discussion. If suitable, people wishing to be considered can then ask their doctor to refer them for a one-off clinical assessment in the MSA clinic at Queens Square, via email to violet.Lefevre@nhs.net. *msa news*

Completed and early-phase studies

Recruitment to the M-STAR trial is complete, comparing experimental drug Verdiperstat to placebo in 325 people with MSA. Verdiperstat works to suppress an enzyme that may cause damage to neurons, which may slow progression of MSA. Results are expected in Autumn 2021.

Modag have completed a phase 1 trial of new compound, anle138b. The trial evaluated the effects of anle138b in 68 healthy volunteers on safety, tolerability and pharmacokinetics. Pharmacokinetics is the movement of a drug into, through and out of the body. In MSA a build-up of the protein alpha-synuclein in the brain causes neurodegeneration. Anle138b is designed to dissolve toxic structures found in clumps of alpha-synuclein and prevent new ones forming, with the aim of alleviating neurodegenerative symptoms. A larger clinical trial assessing the safety and efficacy of anle138b in people with MSA is planned for 2021.

Alterity Therapeutics is testing a new drug in a phase 1 trial. ATH434 works to inhibit the build-up of proteins associated with neurodegeneration in MSA. They aim to assess the safety, tolerability, and pharmacokinetics of ATH434 in healthy volunteers in this initial study in humans. *msa news*

For more information about the research studies we are funding and details of studies taking place, visit our website here - www.msatrust.org.uk/cause-and-cure.



How you can bank your voice – *from your own home...*

Many people living with MSA notice that their voice has become softer or quieter, particularly as they become tired. Samantha Pavey, MSA Nurse Specialist, looks at whether voice banking might be an option for some and explains how the MSA Trust can support financially through our new partnership with Acapela - 'My-own-voice'.



A quiet voice (hypophonia) is a Parkinson type symptom and over time some people with MSA will notice that their speech becomes slurred, particularly if they have the symptoms of Ataxia. The voice can sound a little bit

'drunk' and wobbly due to poor muscle control of the mouth and tongue or vocal cords (dysarthria). For some of our members, speech can become more difficult and this can cause frustration, both for the person living with MSA and their

loved ones. Unfortunately for some people with MSA, speech can deteriorate further and may become unintelligible. To help with this, we have formed an arrangement with Acapela – a company that supports voice banking. There are



several companies which offer voice banking; you should discuss this with your Speech & Language Therapist who can then contact the MSA Trust regarding the Acapela service.

What is Voice banking?

Voice banking allows someone to record a list of phrases and words with their own voice while their speech is still reasonably good. This recording can then be converted digitally to create a personal voice. The voice will be similar to their own, but not a true copy; it will sound synthetic but it does bear a resemblance to the person's own voice. From this bank of words and phrases the system can create most of the words you need when communicating with others. This will allow you to continue communicating verbally through a device which is invaluable if your speech can't be understood. For example, you can use it to ask for things you need or to express how you are feeling. You might wish to bank some phrases that are personal to you, such as nicknames or things you like to say to a loved one.

The process used to be tiring and time consuming but newer systems require less recording. However, it is still necessary to consider voice banking sooner rather than leaving it until speech is more difficult. Then, when and if needed, it can be downloaded and used as necessary on various communication devices such as a phone, personal computer or tablet. The download of your voice triggers a cost and this is where the Trust can help with payment.

What equipment do I need?

Voice banking services are accessed online so a PC or laptop is required, with access to the internet. Tablets do not usually have the processing power needed for voice banking, so are not recommended for the

recording process. They may, however, be used with the synthetic voice as a communication aid afterwards.

It is important to have a suitable microphone. This needs to be a headset model with a USB connection, allowing the person to keep a consistent distance from the mouth to the microphone.

Whilst making the recording, the environment should be quiet and have no background noise. Some of the services need a microphone test to be carried out first to make sure the recording environment is suitable. It is important that the same recording environment is used every time.

Your Speech and Language Therapist will talk you through the process and support you to carry out voice banking if they feel it will work for you. Unfortunately, voice banking isn't suitable for everyone with a speech problem.

Points to consider:

- If you wish to consider voice banking, it should be done before your voice changes too much
- You can discuss the voice banking process with your Speech and Language Therapist
- It can be done from home with support, you don't need to travel to a hospital appointment
- The finished voice will sound similar to your own voice but won't be an exact replica.

We understand that voice is an essential part of self-identity and many of our members feel they are losing a part of themselves when speech starts to deteriorate. Voice banking helps to preserve identity, allowing people to express themselves and elevate feelings of isolation.

If you feel you would benefit, contact your Speech and Language Therapist or speak to your MSA Nurse Specialist. *msa news*

VOICE BANKING

The BIG Give - the Gift of Communication

Although recording (banking) your voice through Acapela is free, they charge a fee when you 'activate' the synthetic voice. We have agreed to support up to 150 people with this service through payment of this charge, as we appreciate that not all of our members can afford this cost. This Christmas we hope to raise up to £10,000 to make this vital service accessible to those that need it.

For this purpose, we have partnered with Big Give, a matched funding platform that specialises in bringing charitable organisations together to multiply their impact.

Due to the generosity of our major donors, we have already secured pledges that can be match funded with online donations received during the Big Give's Christmas Challenge. The benefit of matched funding is that for every single Pound donated, our pledgers will match it, effectively doubling the donations from our supporters.

The campaign will run from 1st - 8th December so please support us and give a voice to the MSA community this Christmas - www.msatrust.org.uk/get-involved/support-us-this-christmas.
msa news





Powers of Attorney

We know from our Needs Survey that many people affected by MSA worry about what may happen if they are no longer able to voice or make decisions. In this situation having someone you trust to make decision on our behalf can be vital.

Jane Stein, our Social Welfare Specialist, explains the benefits of setting up Powers of Attorney.





You can help ensure decisions about your money, property and (in some areas) your health and welfare are made by those you trust the most by putting in place what is known as a 'Power of Attorney'. This is a legal document that allows an individual to give authority to someone else (usually a family member or trusted friend, but it can also be a paid professional such as a solicitor) to make certain decisions on their behalf. People frequently believe that their partner, or next of kin, will have an automatic right to make decisions for them if they are unable to do so - this is not the case.

People can only set up and grant Powers of Attorney whilst they retain 'capacity'. Capacity refers to a person's ability to understand, retain and weigh up information so they can reach an informed decision. Crucially, for people living with MSA - who may have communication difficulties - to 'have capacity' you must also be able to communicate your decision although this does not need to be verbally. Capacity should always be considered in respect of individual decisions as someone may be able to make and communicate a simple decision (for example, what they would like for lunch) but not a more complex decision (such as whether to spend a lot of money on a holiday or whether to set up a Power of Attorney). Having capacity is not about making a 'wise' decision - we all know plenty of us make informed yet 'unwise' decisions! If there is any doubt about an individual's ability to make a decision about setting up a Power of Attorney, both legal and medical advice should be sought. Some types of Power of Attorney which relate to property and finance can, if you wish, be used even if you have capacity. You might choose to do this if, for example, you have difficulties managing your financial affairs because your speech is affected or you find online banking a struggle.

It is important that your attorneys are competent and that you trust them to make the decisions that are right for you. Their powers can be considerable so spending time discussing your wishes is helpful in ensuring they are clear about how they can best act on your behalf in the future. For example, depending upon the terms of the Power of Attorney document (and any restrictions you place on their powers), they may sell your home to meet your care costs or spend your money on services to meet your needs. If they hold a Power of Attorney in respect of your health and welfare they may have to decide where you should live and they will be involved in discussions with doctors about which medical interventions are right for you. It is vital that the attorneys you appoint understand their role and are willing to take it on. **Attorneys must always act in your best interests, must keep separate accounts and must not take advantage of their position.** You are free to cancel or amend any Power of Attorney document, or appoint a different attorney, whilst you retain the

capacity to make and communicate this decision. Powers of Attorney cease when a person dies because at this point responsibility passes to the executors of their Will.

It can take time to set up and register a Power of Attorney so it is wise to make this a priority. If you lose capacity and don't have a Power of Attorney in place your next of kin may have to get involved in a lengthy and costly legal process to obtain the authority to make decisions for you. This can be very stressful for them and may occur just at a point when urgent decisions need to be made. For a short video about the importance of Powers of Attorney see www.youtube.com/watch?v=P7rvZV9QJrc from Age UK.

Powers of Attorney are just one of a range of documents that you may use to help ensure your wishes are respected. Other documents, some which relate to interventions that you would, or would not, wish to have in respect of health issues (for example, an Advance Decision to Refuse Treatment) may also be appropriate to consider, often in addition to a Power of Attorney. When completing a Power of Attorney or other documentation, consider what you already have in place so that contradictory information isn't an issue.

The types of Powers of Attorney available vary across the UK and the Republic of Ireland. It is important to fully understand the type of Power of Attorney you are setting up and a solicitor can advise on this. It is usually possible to set up a Power of Attorney online but many people prefer the reassurance that using a solicitor gives.

msa news

England and Wales:

www.gov.uk/power-of-attorney

Scotland:

www.mygov.scot/power-of-attorney

Northern Ireland:

www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney. In Northern Ireland there is no Power of Attorney for health and welfare.

Republic of Ireland:

www.courts.ie/general-information-enduring-powers-attorney

Our Social Welfare Specialist, Jane Stein, can advise on sources of information in respect of any questions or queries you have on this topic. Email her at support@msatrust.org.uk for assistance.



Brave the Shave for MSAT!

Two of our members chose to do a head shave fundraiser, after many months of not being able to visit salons during lockdown! **Mary Claire Teahan** did one recently in memory of her father Patrick, while **Lynda Jenkins** who has MSA, bravely shaved her head back in May. Collectively close to £10,000 was raised from their friends and family sponsoring these head shaves – well done everyone!



LYNDA JENKINS



MARY CLAIRE TEAHAN

Thrill-seekers!

Nicky Shaw completed a '12 Hour Virtual Time Trial' challenge through the 'Zwift' app, setting a new app record for the furthest virtual distance cycled in 12 hours. She managed to ride for 11 hours 32 minutes non-stop and covered 423km. Nicky hopes to do the challenge again next year and this time enter the Guinness World Records. She managed to raise £2,155 in memory of her mother, Eileen Shaw. Well done for your great effort Nicky!



Callum Jacob completed a tough and body sapping challenge, running a 100km distance from North London to Brighton's seafront in just a single day in memory of his dad. Callum managed to raise a fantastic £2,515 for the Trust.

Bethany Johnson did not let the pandemic deter her from an exciting 15,000ft tandem skydive in memory of her Nan, Jean Flynn. After months of delays she completed her skydive in August, as soon as the airfields opened up again. Bethany managed to raise an amazing £1,085 - Thank you so much for your commitment!



The next Virgin Money London Marathon has been scheduled for the 3rd October 2021. We are now accepting charity place applications. If you, or someone you know is a running enthusiast and confident in raising the minimum sponsorship of £1,950 for the Trust, please email the Fundraising Team at fundraising@msatrust.org.uk.





The legacy of Gareth lives on...

The Williams family have fundraised for the Trust for several years in honour of Welsh Rugby player, Gareth Williams who sadly passed away in 2018 after a long and courageous battle with MSA.

Gareth was a revered member of Bridgend Ravens Club and played in four successive Welsh Cup finals for the Bridgend Athletic Rugby Football Club. He also played international rugby for Wales and the British and Irish Lions.

Gareth's youngest daughters, Angharad and Nia, began running in 2013, completing a staggering number of races including six marathons collectively.

Gareth's eldest daughter, Claire, wrote an amazing children's book, 'The Secret' portraying MSA and the effects it has on people's families from a child's perspective.

The last few years saw Gareth's son, Mark, put all his efforts into raising vital funds for the Trust, organising a variety of fundraisers from virtual runs to a charity rugby

match and bucket collections at the local rugby fields.

Gareth's wife, Claire, has also recently started running herself, taking part in the Porthcawl 10km last Summer along with the family.

We are ever so grateful to the Williams family and Gareth's friends and colleagues from his rugby community, who have managed to raise an incredible £30,976. They hope to continue fundraising and keep Gareth's memory alive as he was clearly such an inspiration to so many. *msa news*



Virtual MSA Candlelight

We are pleased to have hosted our memorial event, MSA Candlelight, last month after it was postponed in March due to the Coronavirus pandemic.

It was an afternoon of remembrance and hope, hosted online over Zoom, with poetry read by families who have lost loved ones and songs pre-recorded by Singout Bristol Choir. We kept up the tradition of lighting candles at the end of the event, to remember all of the lives lost to MSA.

Funds raised from the event are restricted for MSA research. Our chair of the Scientific Advisory Panel (SAP), Dr Christopher Kobylecki presented information about current MSA drug trials and details were presented in the event programme about the four Trust funded research projects that had been approved by SAP earlier this year. £3,230 was raised this year, ring fenced entirely for MSA research, as our generous sponsors Biohaven Pharmaceuticals and the National Lottery Community Fund paid for the event costs. *msa news*





Supporting & Helping Each Other

We still cannot meet in person but that hasn't stopped our members sharing helpful advice at our Digital Support Groups.

We know it has been difficult for everyone not to be able to get out and about to activities they enjoy. Though it is not the same, some people have come up with wonderful ways of staying in touch through technology. One of our South Coast members recommended the Youtube videos created by Nicola Wydenback. In non-covid times Nicola leads the Camberwell Skylarks, a community choir aimed at those living with Parkinson's Disease and she has kindly shared her videos online for all to join along. You can find the videos here - www.youtube.com/channel/UCOJ2IlwyUCT5H6iEvYpQhAA/videos.

Here at the Trust we are big fans of planning ahead where possible, as this can sometimes head off problems or stop them from occurring. We were reminded at our Three Counties Support Group how important it is to look ahead if you use anything mechanical or electrical to assist you in your daily life. Routine maintenance of many devices such as electric scooters, wheelchairs or beds is often advised but is not always included after purchase. If your equipment is provided through the NHS it is sometimes possible to schedule an annual maintenance if you ask. If not, it is worth enquiring with the manufacturer if they have any authorised technicians that may be able to provide this service.

We had several very helpful tips from one of our members in our East Midlands meeting to make things easier in the bathroom. To assist in washing and drying they have had a full body dryer installed. They use it with a rotating shower chair and so far have found it very effective. Find out more at -

www.apresbodydryer.co.uk.

Another useful bathroom tip - if you use an eye-gaze or message board to assist with communication, have one laminated for use in the bathroom. That way you will not have to worry about it getting soggy or wet.

A useful tool demonstrated by one of our members was an absorbent neckerchief sold by Complete Care. This handy cloth is a simple way of catching any dribbling or spills during meals and can easily be changed throughout the day. Even better, it looked very stylish when demonstrated by our member on screen. You can browse their range here -

www.completecareshop.co.uk/eating-aids.

Finally, in our Greater Manchester Digital Support Group we discussed different aids recommended by Health and Care Professionals such as Occupational Therapists or Physiotherapists. It was emphasised that it is important to give new equipment a good try, but also acknowledge when they don't work for you and when to look at other options. This is especially true of tools used to aid balance, for example if they are causing you further discomfort like backache. Professionals would rather try and help solve a problem before it gets worse or causes associated problems. [msa news](#)

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



DATES FOR YOUR DIARY

Staying Connected

Our in-person Support Groups have sadly been suspended for the rest of this year due to Covid-19. We look forward to resuming them in 2021 but, in the meantime, we will continue with our Digital Support Groups hosted by our MSA Nurse Specialists and Support Group Leaders. They are still an informal way to meet others affected by MSA and share advice and experiences.

Our MSA Nurse Specialists will continue to attend the Digital Support Groups for their regions. Invitations for these groups are sent out in advance by e-mail and you must RSVP to get the joining details. **Please contact us if you have not been receiving invites but would like to.**

In addition to our Support Groups, we are launching a monthly virtual 'drop-in' from 11am-12pm on the last Thursday of the month (apart from December). These are open to all our members and are a chance to chat about non-medical issues with others who understand the challenges of MSA. Please contact us at support@msatrust.org.uk if you would like to attend.

11am - 29th October 2020

11am - 26th November 2020

11 am - 17th December 2020

11 am - 28th January 2021

This isn't the only way to stay connected at this time...

Milk Sugar And Tea Parties

Our Support Groups are not the only new and virtual way we are asking members to connect this year.

We are also encouraging you to host a virtual Tea Party to support our four MSA Nurse Specialists who members have told us are a "lifeline" for the MSA community. Usually the Tea Parties are held to mark World MSA Day but as this has been an unprecedented year, we ask that you host one whenever it's convenient for you.

In exchange for a donation, invite friends and family to join you for an online catch-up over tea, cakes and biscuits. Contact the Fundraising Team at fundraising@msatrust.org.uk for your Tea Party pack that has been slightly adapted for this new world - exciting ideas to help keep guests entertained online and a Zoom guide!

And calling all great bakers....

Take part in our new MSAT bake-off competition! Bake and design the prettiest cakes (or any baked goodies), take photos and upload them to our online Bake-Off page in exchange for a donation to the Trust. If your cakes have our orange MSA theme, even better! Not only do you raise vital funds, you have a chance to win our Tea Party gift hamper kindly donated by our generous sponsors. The best efforts will get honourable mentions in the next MSA News!

Visit www.givepenny.com/appeal-for/MSATBake-off or email fundraising@msatrust.org.uk to take part. *msa news*





Roundup of Useful Articles

Our MSA News magazine has been going for 21 years (with a few name changes along the way!) and this issue is our 59th edition.

The majority of magazines (from 2002 onwards) are available to download and read on our website – www.msatrust.org.uk. Inside these magazines there is a wealth of information available to members. Some topics covered are not currently in our factsheets but people still find them helpful.

Over the last year we have been highlighting previous articles covering the topics – Symptoms and Management of MSA and Living with MSA. You will find these article archives in issues 57 and 58. In this issue we focus on our final topic - ‘Caring’.

Subject Matter	Issue	Page	Article Title	Factsheet Available
Support available through the third (not-for-profit) sector	57	12	Making the Most of the Wide Net of Support	I Wish I'd Known that a Year Ago – Regional variations
What to do if someone is choking	“	18	How to Deal with Choking Episodes	Saliva Control and MSA
What support and services you can expect from a GP	56	12	Making the Most of your General Practitioner (GP)	
What is social care and how it is funded	“	19	Arranging Social Care Support at Home	
Information about Continuing Healthcare (CHC)	55	10	When Needs Become Complex	Continuing Healthcare
A resource to support children aged 4-11 who have a loved one living with MSA	54	3	My Special Activity Book	My Special Activity Book
An overview of the benefit – Carers Allowance	“	4	Carers Allowance	Basic Benefits and Entitlements
Carer's breaks and respite care	52	18	Just a short break from the normal routine	Travelling and MSA
Advice for carers wellbeing	48	5	Caring for yourself so that you can care for others	Equipment – Posture and Mobility
When you cannot be there to provide care, how you may still be able to offer useful support	40	12	Caring at a Distance	
Planning ahead for emergencies should they happen	38	12	Emergencies	I Wish I'd Known that a Year Ago – Regional variations
Advice for carers from Carers UK on safer lifting techniques	36	6	Caring for your Back	
Tips on getting a good night's sleep	35	14	Sleeping Well	
Advice on a healthy diet	“	6	Eating Well	
Information for carers who are also working	30	2	Working and caring	I Wish I'd Known that a Year Ago – Regional variations

Support the Trust this *Christmas*



Hand-knitted scarves

£6

Approximately 50cm in length
Available in Grey, Yellow, Green, Light and Dark Blue
Maximum of 4 per order

Knitted by a 90-year-old Mother and Grandmother who wants to help the Trust following her sons MSA diagnosis

£3

Gift Wrap

4 Sheets (2 of each design), 8 tags (4 of each design)

Flat size: 50 x 69 cm

Maximum of 2 per order



Advent Calendars

£4

19x19 cm with postal envelope

Individually wrapped

Maximum of 2 per order



Support the Trust this *Christmas*

£4

Christmas Cards

Each pack has 10 cards with envelopes. Messages read:

A & B: Season's Greetings

C: Happy Christmas

D: Merry Christmas and
Happy New Year

A & B



C



D



To order, visit:

**www.msatrust.org.uk/christmas, call us
on 0333 323 4591 or return the slip below
with a cheque payable to 'MSA Trust'.**

Please include payment to cover postage costs according to the number of items ordered:

Number of items	1 - 2	3 - 6	7 - 10
Add postage	£1	£3	£5

**Our cards from last year are currently available at
sale prices, and can be purchased online:
www.msatrust.org.uk/product/christmas-cards**

Please get in touch with the Fundraising Team if ordering more than 10 items or when ordering from outside the UK.

Email fundraising@msatrust.org.uk or call **0333 323 4591**. Please note we send our merchandise using Royal Mail 2nd Class post but during the busy season it can take up to 5 working days for items to arrive.

Name:.....

Address:.....

Telephone:..... Email:.....

Christmas Cards: A - Winter Robins (Qty.....) B - Snowman in the field (Qty.....)

C - Following The Star (Qty.....) D - We wish you a Merry Christmas (Qty).....

Advent Calendars: Nativity (Qty.....) Red Bus (Qty.....)

Gift Wrap: Snowman (Qty.....) Santa & Reindeer (Qty.....)

Scarves: Light Blue (Qty.....) Dark Blue (Qty.....) Grey (Qty.....) Yellow (Qty.....) Green (Qty.....)

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Please let us know how you want us to keep in touch for fundraising news and events. Fill out your contact preferences below:

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Please return slip to **MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB** with payment by 10th December 2020.