msa news

MSA Trust Members Magazine | Issue 57 | February 2020

We hear you

MSA Needs Survey results

CAN YOU GIVE REGULARLY? - PAGE 19

CHIEF EXECUTIVE OFFICER:
Karen Walker

MSA NEWS EDITORS:
Andy Barrick
Emma Rushton

ALL ENQUIRIES TO OUR ADDRESS:
Multiple System Atrophy Trust
51 St Olav's Court
City Business Centre, Lower Road
London SE16 2XB
Tel: 0333 323 4591
www.msatrust.org.uk

Welcome to Issue 57

A warm welcome to your latest edition of MSA News and the first for 2020.

In this issue we're very pleased to share a sample of the results from our MSA Needs Surveys which many of you completed last year. On pages six and seven you will see what members of the MSA community think about a number of topics such as the physical and emotional aspects of living with MSA, benefits support and end of life care. We have already started work on rejigging some of our services to align them with your needs and to consider how we can persuade other organisations to develop better support for people affected by MSA.

You may have already noticed that our website has had a refresh. Everything that we had on the old site is still there but we hope you can now find the information you need in a quicker and easier way. If you have any feedback on this, or any questions at all please email us at ***support@msatrust.org.uk****.*

As ever, we hope you enjoy this edition and do let us know if there is anything you especially want us to cover in the future. We look forward to continuing to support you throughout this year. With all best wishes, Emma and Andy. msa news

Registered Charity Number 1137652. Scottish Charity Number SC044635. Company Number 7302036
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.

“How can I get involved in MSA research?”

Clinical trials recruit small numbers of participants to test potential new treatments in designated study centres. Not all people will be eligible for clinical trials, but any new treatments discovered may in future be used to treat symptoms of MSA. We’re often asked “How can I get involved in MSA research?”, so below our MSA Nurse Specialist, Emma Saunders, outlines some current and upcoming research studies…

We continue to fund the PROSPECT-M study and encourage people with MSA to sign up for this. The study will follow people over time and its aim is to improve the chances of earlier diagnosis and track disease progression. This may enable future clinical trials at an early stage of MSA. If you would like to find out more about the PROSPECT-M study please contact **alkyoni.athanasioufragkouli@nhs.net** or speak to one of our MSA Nurse Specialists.

Theravance Biopharma are running a study into Orthostatic Hypotension. This is a form of low blood pressure that happens when you stand up from sitting or lying down. It causes light headedness and dizziness. This study, called the SEQUOIA Study is looking at an investigational drug called Ampreloxetine. Researchers want to learn whether this drug can reduce symptoms and assess its safety. The SEQUOIA Study is made up of a three-week screening period where assessments will be performed to determine eligibility and for people to decide whether they want to take part. This is followed by four weeks of taking the study medication in tablet form and attending a study site for assessment. Upon completion of the SEQUOIA Study, people may be eligible to join another related study lasting up to 22 weeks. Currently there are sites open in London, Devon and Birmingham, with more sites due to be opened in future. Please see our website for contact details.

Biohaven Pharmaceuticals have started recruitment to the M-STAR trial of Verdiperstat, thought to suppress an enzyme called myeloperoxidase (MPO). MPO is believed to cause inflammation and damage to neurons in the brains of people with MSA. The main purpose of the study is to see if it helps slow progression of MSA and assess safety. There will be several sites in the UK including London, Newcastle, Oxford and Wales starting to recruit in 2020. The international trial website is **www.msaresearchstudy.com**. Speak to your specialist for more information about how to be involved in this study.

A pilot study of the drug Exenatide is taking place in London in 2020. Exenatide is currently licenced for use in type-2 diabetes. Eligible participants will be randomised into two groups. One group will add Exenatide to their regular medication regime and the other group will continue to take their regular medication alone. The two groups will then be compared to see if there is any effect on the rate of progression of MSA. The study follows on from two previous small trials that indicated that the drug may slow decline in Parkinson’s Disease. Further information is available from **c.girges@ucl.ac.uk**.

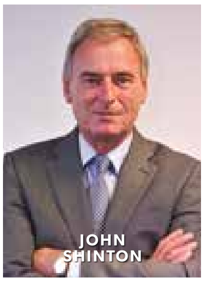
To find out what research is happening in your area, ask your specialist about research opportunities that you may be eligible for. Further details about MSA research are available at **www.msatrust.org.uk/cause-and-cure**. msa *news*

NEWS ROUNDUP

Our Trustee Board

We are delighted to welcome two new Trustees to our Board: Professor David Oliver, a retired Consultant Physician in Palliative Medicine with a special expertise in neurological conditions; and John Shinton, a retired Finance Director and Assistant CEO in the social housing sector. Both of our new Trustees bring a wealth of knowledge and experience to the Board and will be a real asset to us. We said a fond farewell in December to Hugh Matheson, our outgoing Honorary Treasurer and a long-standing member of the Board. Our grateful thanks go to Hugh for his incredible contribution to the development of the MSA Trust over many years and for helping to build the strong organisation it is today. msa *news*


PROFESSOR DAVID OLIVER


JOHN SHINTON

Public Health England MSA Patient Registry

The Trust has been working with Public Health England to set up the first registry of people with MSA in England. The National Congenital Anomaly and Rare Diseases Registration Service (NCARDRS) has recently been formed and MSA is one of the first conditions to have a registry. This will enable analysis of interactions within the NHS system and give the NHS a clearer idea of the needs of people with MSA, hopefully leading to better, more targeted services.

The system is rigorously protected for confidentiality under NHS data policies. We have been asking new members in England for consent to pass their name and details on to NCARDRS through encrypted transfer, however any existing members with MSA in England can also register with them if they haven't already. Please contact the office if you wish to do so and we will organise this. msa *news*

Research Funding

By the time this edition of MSA News reaches you, our Scientific Advisory Panel (SAP) will have met to assess which of the new research project applications they will recommend for funding over the next two to three years. SAP is made up of leading figures in MSA research, neuropathologists, movement disorder specialists and lay advisors. It is led by our Trustee, Dr Christopher Kobylecki, a Consultant Neurologist and Honorary Senior Lecturer at Manchester University. Decisions made by the SAP will be presented at the Trustee Board meeting in March for final approval and in our June edition of MSA News we will share information on the successful applicants and their projects. msa *news*

Thank you for your Christmas Appeal support

Many thanks to supporters who kindly donated towards our Christmas appeal. With your help we raised an incredible £3,460 which will go a long way in helping members who are struggling to cope with the increased financial pressures that life with MSA can bring.

The money is allocated to our welfare grants fund which supports families in many ways such as, providing equipment for voice banking and contributing towards powered wheelchairs and communication aids. Grants have also helped members receive counselling sessions to help them cope with the emotional turmoil of an MSA diagnosis. Thank you again for helping people in such a vital way. 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 so far we have released 57 editions.

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 next year we will be outlining previous articles covering three core topics – Symptoms and Management of MSA, Living with MSA and Caring.

In this edition we have focused on 'Symptoms and Management of MSA':

Subject Matter	Issue	Page	Article Title	Factsheet Available
Looking at options to manage saliva effectively	55	6	**Support with saliva control**	Saliva Control
Possible issues with eye health and self-help tips to support you	54	7	**Looking after your eyes**	Eye Health and MSA
Support with speech and language issues	53	4	**Communication Matters**	Equipment - Communication, Eating and Drinking
Support with catheters	"	12	**Finding a catheter that's right for you**	Continence in MSA
Voice banking for communication purposes	"	18	**Record and press play**	
Causes and management of breathing difficulties	51	6	**Managing breathing difficulties**	
Identifying support with coat-hanger pain (across shoulders)	"	13	**Coping with coat-hanger pain**	
Techniques and products to aid communication	50	4	**Communication Matters**	Equipment - Communication, Eating and Drinking
Help to improve postural hypotension (low blood pressure)	"	13	**Abdominal Binders**	Postural Hypotension
Causes and management of restless legs whilst sleeping	"	8	**Restless Legs Syndrome**	
An explanation of the differences between MSA-P and MSA-C	"	12	**MSA-P or MSA-C**	
Recognising and dealing with Urinary Tract Infections (UTI's)	"	6	**Forewarned is Forearmed**	Continence in MSA
The options available for help with bladder, bowel and incontinence issues	45	4	**Managing Toilet Needs**	Continence in MSA and Bowel Management and MSA
Suggestions to help when softer speech makes communication difficult	42	6	**MSA Guide: Speaking Up, Speaking Louder**	Equipment - Communication, Eating and Drinking
Causes and management of low blood pressure and its effects	41	6	**Postural Hypotension**	Postural Hypotension
How to get help when swallowing becomes a problem	"	16	**Swallowing difficulties in MSA**	
How to manage tiredness and fatigue	40	6	**Fatigue in MSA**	Fatigue in MSA
The different types of pain associated with MSA and how to manage this	37	6	**Pain in MSA**	
Managing bladder problems – Part 1	33	12	**MSA and the "Loo"**	Continence in MSA
Managing bowel problems - Part 2	32	4	**MSA and the "Loo"**	Bowel Management and MSA

MSA NEEDS SURVEYS

We hear you!

Last year we launched two surveys aiming to take an in-depth look at the needs of people living with MSA and those around them.

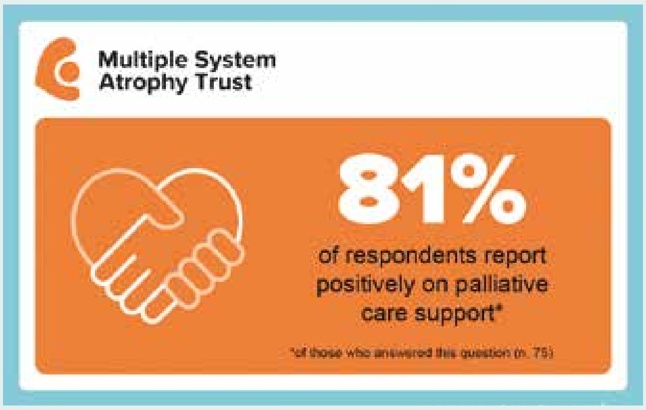
Our research looked at both people living with MSA, and people who previously cared for somebody with MSA, making it the largest ever study of people affected by the condition. It covered the UK and Ireland and could be completed online or as a paper questionnaire. We had 655 respondents in total.

The headline results below indicate the main findings and over the coming months we will be working towards adapting our support to better meet the needs identified. The full technical report will be available on our website.


Multiple System Atrophy Trust

ALL

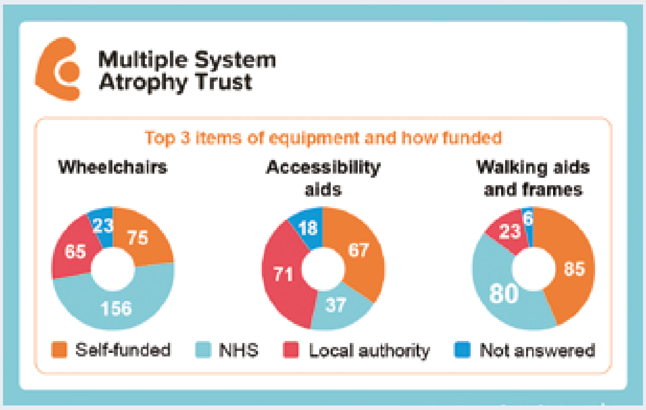
respondents have experienced problems with movement

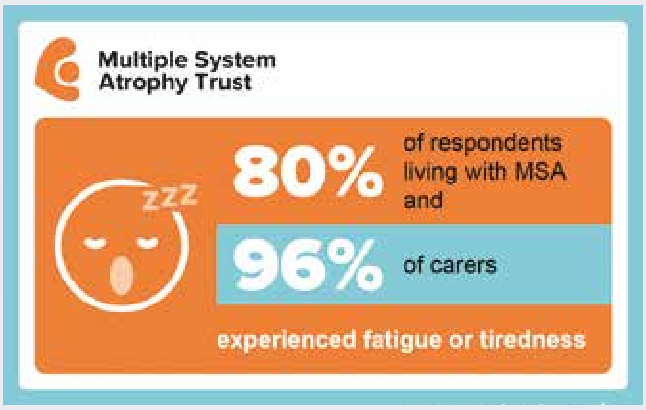

Multiple System Atrophy Trust

81%

of respondents report positively on palliative care support*

*of those who answered this question (n. 75)

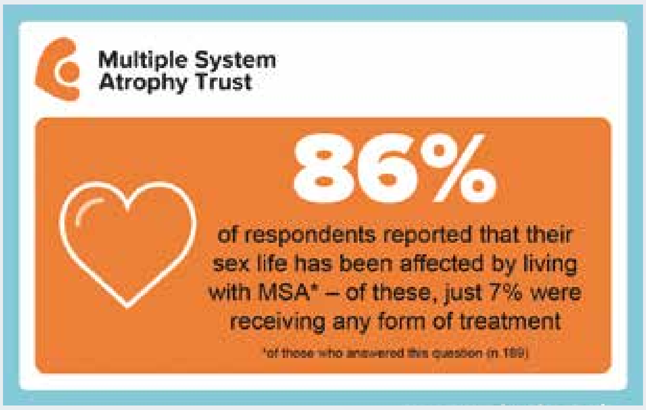




80% of respondents living with MSA and

96% of carers

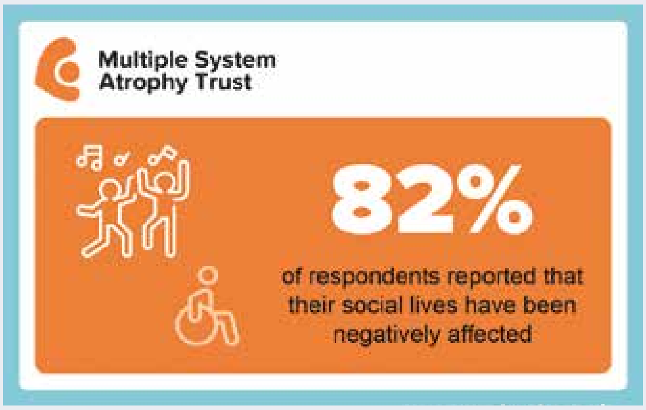
experienced fatigue or tiredness



86%

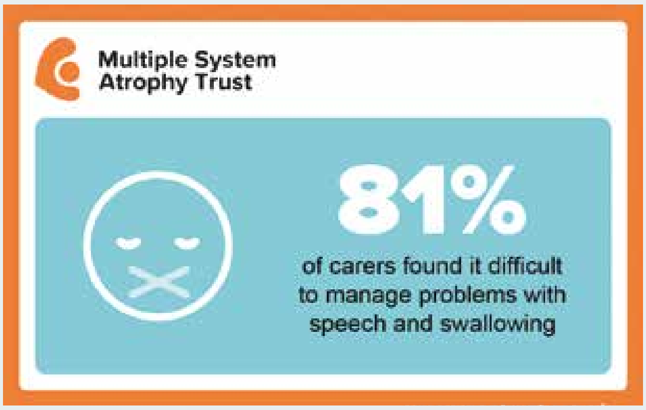
of respondents reported that their sex life has been affected by living with MSA* – of these, just 7% were receiving any form of treatment

*of those who answered this question (n 189)



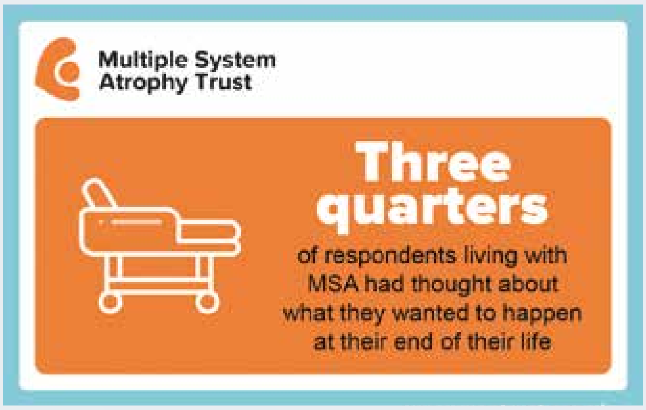
82%

of respondents reported that their social lives have been negatively affected



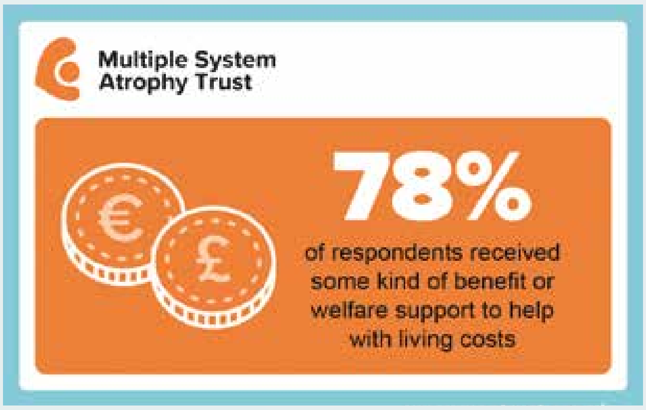
81%

of carers found it difficult to manage problems with speech and swallowing



Three quarters

of respondents living with MSA had thought about what they wanted to happen at their end of their life



78%

of respondents received some kind of benefit or welfare support to help with living costs

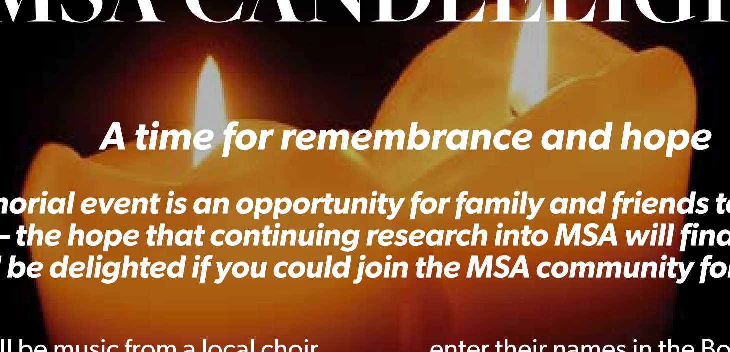
We understand that some of the facts and figures from the surveys may be sensitive but these reflect the honesty that people have demonstrated in their responses and for which we are incredibly grateful.

If you have any questions about the topics covered here or have any queries about your MSA, please do get in touch with our MSA Nurse Specialists or Social Welfare Specialist. They can all be contacted through our office on 0333 323 4591 or at **support@msatrust.org.uk**. msa *news*

In Memory

Phil Walker
Anita Brindle
Richard Ryan
David Palmer
John Sheehy
Susan Tighe
Jonathon Litchfield
Linda Sheward
Sylvia Hynes
Sandra Murphy
Sean Murtagh
Martin Downie
Roger Turner
Elizabeth Rowlands
Lisa Marshall
Mark Fidler
Christopher Griffin
Teresa Dodwell
Pauline Knight
Ruth Brett
Michael Morris
Bernie Kirby
David Foley
Jeffrey Payne
Jeyaranee Meadows
Geoffrey Ball
Susan Bailey
Philip Cartlidge
Linda Edwards
Gary Meade
Arthur Mayle
Gill Hamer
Joseph Quinn
Jean Flynn
Peter Ellam
Mohinder Sandhu
Stephen Booth
Stephen Young
Sandra Vigor
David Oldershaw
Derek Byrne
Paul Shute
Mark Ashthorpe
Julia Kirkwood
Barbara Boyce
Norman Birkett

MSA CANDLELIGHT



A time for remembrance and hope

The Trust's memorial event is an opportunity for family and friends to come together for a message of hope – the hope that continuing research into MSA will find its cause and cure. This year we would be delighted if you could join the MSA community for this event in Bristol.

On the day there will be music from a local choir, poetry read by families affected by MSA and afternoon tea. Money raised from this event will be allocated to research we are funding into MSA and so we will also be providing an update on our research work. An important part of the day is the dedication to those lives lost to MSA. For this purpose, we will light candles in honour of your loved ones and prior to the day we will enter their names in the Book of Remembrance. A copy of the book will be presented to you at the event.

To fund research into MSA and cover expenses, we are asking for a minimum donation of £12 per attendee. If you cannot attend, for a minimum donation of £12, we will light a candle on your behalf and post you the Book of Remembrance.

Sunday 29th March 2020

Stoke Gifford Trust Ground, North Road, Stoke Gifford, Bristol BS34 8PE

2:30pm - 5.00pm

To buy tickets or to send a dedication you can donate online at ***www.msatrust.org.uk/msacandlelight***, call us on 0333 323 4591 or send a cheque payable to 'MSA Trust'. Please let us know if you can attend or provide your dedication by Friday 13th March.

msa *news*

Something new for you to try in 2020?

High on the New Year resolution list for many is committing to exercise more. Whilst this can seem a challenge when you have MSA, a number of our readers have shared activities they enjoy which may encourage you to try something yourself…

Many people with MSA participate in Pilates and T'ai Chi classes which can help with core trunk strength, joint flexibility, balance, relaxation and improved breathing control. Do speak with the group leader so they are aware of your particular needs.

Chair circuit sessions are increasingly popular – at each chair there is a designated seated exercise. If moving between chairs is tricky stay in the same seat and swap exercise type when everyone else moves round.

Hiring a power assist or tandem trike (partner/friend = power assist!) is a great way to still get out and encourage family and friends to join you. Louise (pictured) gets great enjoyment out of using this trike with her friend at a local park; they both get some exercise whilst catching up for a chat. Many public parks and reservoirs have cycle centres attached that hire out trikes and bikes. If there is nothing near you then how about trying a pedal exerciser, great for arm and leg exercise from the comfort of your chair indoors or in the garden. You may be able get these on loan from your Physiotherapist or can be purchased from stores such as Argos and sports shops.

Other 'home-based' exercise that can be fun, is to set up a 'wii-fit' on your TV monitor and challenge younger members of the family to a game of tennis for example.

Getting out of the house and doing things with others is beneficial for us all, so if the weather is not enticing ask staff at the local leisure centre to help you devise an accessible exercise programme. They may also have times when there is support to access the swimming pool safely. This is a great way to exercise and an opportunity to encourage others to join you, as well as providing some additional support for getting to and from the pool.

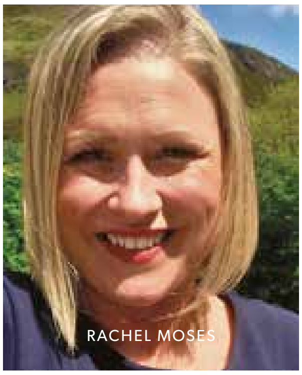
One of our members has found a centre with an 'Alter-G', which has a weight-bearing harness that enables her to use the treadmill despite balance problems. Alter G is available through some private physiotherapy clinics and some Neuro Centres, so do try and research where one might be near you.

If you are wheelchair dependent, as well as home-based chair exercises there may be wheelchair based activities at the local leisure centre.

Research indicates that exercise benefits us not only physically but with our sleep, mood and autonomic functions. Any exercise is better than none, moving around frequently for short periods is better than long intense sessions and getting outdoors to exercise is an added benefit when able. The important thing is to have fun, exercise safely, regularly and encourage others to join in with you! msa *news*

Breathe In... *and* Breathe Out

As MSA progresses it may affect muscles relating to breathing, speech and swallow. Rachael Moses, a Consultant Respiratory Physiotherapist, looks at some issues that can arise in people with MSA and ways to help treat these...



RACHEL MOSES

The extent of involvement of the respiratory muscles vary between individuals living with MSA but it can result in loss of speech, swallow and ability to cough effectively. In some cases, this can lead to changes in breathing patterns, sleep disorders, increased saliva production and recurrent chest infections.

It is very important if you have problems with speech, swallow and breathing you seek advice from your Speech and Language Therapist. Problems with the way the vocal cords are working can not only cause swallowing difficulties but also voice and breathing changes. If there are breathing changes then a specialist Respiratory Physiotherapist will be able to assess specific problems and help with symptoms. Signs to look out for may include:

1. **Increased saliva or drooling**
2. **Inability to take a deep breath or feeling short of breath when doing simple activities**
3. **Poor cough effort or difficultly clearing phlegm**
4. **Recurrent chest infections**
5. **Noisy breathing either during the day or when asleep.**

Some of the symptoms that people with MSA may experience are explained below with ideas of how to treat these.

Hypersalivation: This is when you have too much saliva which can cause drooling resulting in sore skin, frustration and social isolation. It is important that the actual cause of hypersalivation is determined as this will help the treatment. There are a number of medications that can be helpful to dry up and reduce the volume of saliva produced e.g. atropine eye drops (which are used under the tongue!), Glycopyrrolate, Hysocine patches or even Botox injections to the glands that produce the saliva. Your Speech Therapist can help you with practical techniques but if the problem persists then they can refer on to your GP or Consultant; or you can contact the MSA Trust Nurses to talk through medication options.

Thick Mucus: This is a common complaint for people with MSA when they have a poor cough effort and can no longer clear mucus and secretions easily. The mucus can build up and be problematic as it can block the smaller airways and increase the effort of breathing. If left untreated it can cause recurrent chest infections. Medications called mucolytics (for example Carbocisteine) may help to reduce the amount, thickness and stickiness of mucus. Nebulisers may also be effective as they can loosen secretions and moisten the mouth and airways making clearing of secretions easier. If someone has a problem with cough strength, then a number of devices may be helpful e.g. a Lung Volume Recruitment (LVR) Bag or cough assist machine to help increase lung inflation to give power to the cough to make mucus clearance easier. A suction machine may also be helpful if it is difficult to fully clear the secretions from the back of the mouth or upper airway. A Respiratory Physiotherapist or Specialist Respiratory Nurse may be able to access these devices as well as give advice on specific exercises, positioning or breathing techniques that may help.

Stridor: People with MSA can develop intermittent noisy breathing which could be a result of overactive vocal cord muscles that can close the airway to the point it becomes difficult to breathe in and/or out. This is known as stridor and may occur in the day or night. Stridor during sleep can be one of the first respiratory symptoms and it can be very common in people with MSA. You may notice the breathing is faster or noisier during sleep. It can be difficult to treat stridor but a Specialist Respiratory Doctor, Speech and Language Therapist or Physiotherapist can provide advice to help manage this.

Sleep Apnoea: Sometimes people develop a condition called obstructive sleep apnoea which causes frequent episodes where the breathing will temporarily stop during sleep. This is problematic as poor sleep quality will result in more daytime fatigue, increased stress and risk of infections (due to lower immunity). It is important if anyone has these symptoms that they are referred for an assessment by a Respiratory Physician specialising in sleep. They will determine if a continuous positive airway pressure (CPAP) machine with a mask that aids breathing would be beneficial at night.

Respiratory problems can cause anxiety and distress as well as further fatigue so it is important people are seen by a respiratory specialist. Often physiotherapy can also be very beneficial to improve quality of life for people living with MSA. There are specialist teams that exist across the country but sometimes it may be difficult to get a referral into a team who knows how to manage the complex problems that come with MSA. Often regional long-term ventilation services will have a specialist multidisciplinary team if your GP is struggling to find a respiratory team that can help.

msa *news*

Speak to your MSA Nurse Specialist for further information or support. Their contact details can be found on our website – **www.msatrust.org.uk**.

Making the most of the wide net of support

There is a wealth of expertise and support available from the third sector (non-statutory, not for profit organisations such as the MSA Trust itself) but finding out more about these organisations can be challenging. The information here is designed to give an insight into what types of support are available and how to access this.

Employment linked Benevolent Organisations and Funds

Are you, or were you ever a nurse, care worker, teacher, banker, engineer or accountant? Do you, or did you ever, work in the grocery trade, motor trade, retail, hospitality or in agriculture? Were you ever in the armed services? Almost every trade, industry, service or profession has a benevolent fund and the scope of their work can be surprising.

Grants, practical help, legal advice, counselling and friendship may all be features of the support offered. We can seek these organisations out for you and check your eligibility, or you can search online using **www.turn2us.org.uk** (covers all of the UK and the Republic of Ireland) or by looking at the list at **www.carers.org/sites/default/files/media/grants_and_other_sources_of_funding_1.pdf**.

Some organisations will operate a means-test when considering grant applications but the other types of support they offer are usually free of charge. Support may extend to family members.

National Voluntary Organisations

Some grant making organisations specialise in supporting people living with illness or disability. For example, Independence at Home - **www.independenceathome.org.uk** and Parkinson's UK **www.parkinsons.org.uk** offer grant help that people living with MSA may apply for.

Paul from Lincolnshire was able to access support from a variety of third sector organisations towards the level access shower he needed.

For advice on benefits and rights including assistance with the completion of official forms, Citizens Advice can help **www.citizensadvice.org.uk** or in Scotland **www.citizensadvice.org.uk/scotland**. In Northern Ireland 'Advice NI' offers similar support see **www.adviceni.net** or call **028 9064 5919**. In the Republic of Ireland you can contact Citizens Information on **0761 07 4000** or see **www.citizensinformation.ie/en**.

Age UK provides a range of support (except in the Republic of Ireland). They have a very good selection of factsheets and can offer advice on benefits and services. In some areas they run social events or provide help with managing at home or with transport (charges may be made). See **www.ageuk.org.uk** or call their advice line on **0800 678 1602**.

Independent Age has a range of factsheets on a wide variety of topics (including benefits, care support, powers of attorney and driving) and has a helpline (**0800 319 6789**) and website **www.independentage.org**. They operate in the UK but not in the Republic of Ireland.

Age Action in the Republic of Ireland offers information, computer training and a free small repairs service. See **www.ageaction.ie** or call **01 475 6989**.

For advice on equipment (especially that is not provided by a statutory agency such as the NHS or Social Services) the Disabled Living Foundation **www.dlf.org.uk** has a wealth of information and operates a helpline – call **0300 999 0004**.

Specific Interest Organisations

If you enjoy a specific hobby but find living with MSA is making it difficult to continue there may well be an organisation able to help. For example, the British Disabled Angling Association **www.bdaa.co.uk** provide information on accessible areas to fish and on specialist equipment. The Gardening for Disabled Trust **www.gardeningfordisabledtrust.org.uk** can provide small grants and advice on adapted tools. For those interested in computers and technology **www.abilitynet.org.uk** can offer information and advice. If you enjoy UK based travel 'Tourism for All' offers online information about travel and holidays in the UK **www.tourismforall.co.uk**.

We are happy to seek out special interest organisations on your behalf.

Local Support

Most areas will have a variety of clubs, societies and services that may be of interest. Your local Social Services may keep a list of some of these or you can access information via a local library. Befriending schemes exist in many areas as do services such as the home library where books or CD's are bought to your home on a regular basis by a trained volunteer. You can usually refer yourself to these services.

Hospices are usually third sector organisations. They can offer support in a variety of ways, often over a long period of time. Some offer day hospice support, others may arrange support groups or run occasional courses. You can often refer yourself or your GP can make a referral.

Support for Carers

Most areas will have a carers centre, often run by a voluntary organisation. Your local Social Services will be able to provide details. These centres usually provide meetings for carers giving carers an opportunity to get together and to share thoughts. Professionals sometimes attend these meetings to offer advice on specific care issues.

The Carers Trust **www.carers.org** has a detailed website with information on finding your local services for carers. Call **0300 772 9600** if you don't have access to their website. Carers UK's website is **www.carersuk.org** or call **0808 808 7777**. Both organisations cover the UK but not the Republic of Ireland. Both websites contain a lot of helpful information for carers and the Carers Trust can make small grants to carers.

In the Republic of Ireland 'Family Carers Ireland' offers support. See **www.familycarers.ie** and their care line number is **01800 240 724**. msa *news*

And finally… but certainly not least, the MSA Trust is here to help in any way we can, wherever in the UK or the Republic of Ireland you live, so please don't hesitate to get in touch. Our MSA Nurse Specialists and Social Welfare Specialists contact details are available on our website – **www.msatrust.org.uk**.

A ROUND UP OF YOUR LATEST FUNDRAISING STORIES

COLD SEA, WARM HEARTS

Christmas Day saw ***David Southgate*** *take the plunge into the North Sea in support of his father who has MSA.* ***Jon Price*** *and family (pictured) took on the Angle New Year's Day Swim in support of Jon's mother, Margaret who has MSA and raised £1,432.*

EVENTS ACROSS EUROPE

Kali Perrow *(pictured) and* ***Jo Elliott*** *both completed the beautiful Amsterdam Marathon and raised £1,780 and £2,180 respectively.*

The Cardiff 10k saw a team of seven, led by ***Owain Leonard*** *raising £2,120.* ***Alun Hathaway*** *also took part and pulled an amazing £575 together in honour of running the event.*

IN THE COMMUNITY

The ***Barlborough Ladies' Fellowship Club*** *raised an incredible £1,000 at a coffee morning after supporter,* ***Patricia Owen's*** *family was affected by MSA. Local volunteer, Stella Herbert attended the cheque presentation on behalf of the Trust and gave a short talk on MSA.*

Kelly Hutchinson *and sister* ***Amanda*** *organised the Hopeful Hearts Charity Ball in Sunderland, raising close to £3,000. The event was in loving memory of their mother, Michelle who sadly passed away last year.*

The family of David Foley *raised £2,250 through St Joes Rugby Club. David regularly attended the Cardiff support group and sadly recently passed away. Our MSA Nurse Specialist, Jill Lyons attended the cheque presentation.*

A record 14 runners took part in last year's Great North Run in Newcastle and managed to raise more than £12,000. It's not too early to sign up for this Half Marathon in 2020, email ***fundraising@msatrust.org.uk*** *to register.*

No bridge too far....

Over the last year, Gill and Paul Wheeler have become wonderful additions to the Trust's community, both fundraising and attending our Support Groups.

Following Paul's diagnosis two years ago, their mutual employer at the Ministry of Defence Police were enormously supportive. They granted Paul medical retirement and upon the couple learning more about the Trust, approved Gill's suggestion that a new trainee class raise money for us, resulting in a very welcome £1,000.

> ***"We decided to start fundraising for the MSA Trust when we were introduced to the team and found out about the great work you do both by funding research and the fantastic support you give to sufferers and their families."***

Paul and Gill's family have also been getting involved with fundraising. Paul's son, Lewis, recently got married and put out a donation bucket at the wedding, collecting over £200.

> ***"We are so grateful to the MSA Trust for their help. Our GP is lovely, but has no clue about MSA. The Support Group meetings are a great way to meet other sufferers and their families to talk about coping strategies, and all the Trust staff that we have met have been so helpful and informative, both at the meetings but also with follow up telephone calls to offer support and further explain things."***

Gill managed to wrangle three of her friends into having an adventure through central London on the 25km Thames Bridges Trek.

> ***"It was such a well organised event. A pleasure to do - even if my feet were killing me at the end. My team was made up of myself and three of our friends who readily jumped in to help fundraising for this fabulous charity."***

Karen, our CEO, was delighted to meet up with Gill and her friends at the finish line in Southwark Park to congratulate them on a fantastic effort.

Gill and her compatriots raised nearly £2,300 in their efforts, finding support through their friends, as well as having employers match their fundraising for an immediate boost. We could not be more impressed or grateful for all the team's hard work – thank you! msa *news*

If you're inspired by Gill and her teammates you can always take part in an event in the same series. There are walking events in some of the most beautiful parts of the UK at various distances, anywhere between 25km and 100km.
Get in touch with our Fundraising Team at **fundraising@msatrust.org.uk**.

NICOLE ADAM PRESENTS A REGULAR ROUNDUP OF YOUR TOP SUPPORT GROUP TIPS

Supporting & Helping Each Other

We know our Support Groups are a useful resource for people with MSA, but they are also valuable for ***everyone*** *affected by MSA including friends and family. Not only can you glean useful information from our Nurses but people also discover useful tips from other members of our community dealing with similar issues.*

At our Kent Support Group, members shared activities they had accessed locally. One member recommended a local choir with connections to neurological services. Others attended seated exercise groups for people with neurological conditions, which they greatly enjoyed (see MSA News 56 for examples). If you have a Parkinson's Nurse, check what services are available in your area or see for yourself at **www.parkinsons.org.uk/information-and-support/exercise-progressing-symptoms**.

Following on from our article on choking on page 18, one of our Inverurie Support Group members shared a simple tip to help avoid difficulties when drinking. When drinking from a cup they were advised to drink a full cup until the half-way point, then refill, this way they avoided tipping the head up at an angle when draining the cup. At this meeting the importance of getting items tailored to suit your individual needs was highlighted, with a member looking into having a Scottish voice put into their communication device.

Hospital admissions were discussed at the West Sussex Group with members highlighting the importance of our Hospital Information Folder and factsheets, especially during emergency admissions. Some members discussed requiring general surgery for issues not directly related to MSA but being refused a general anaesthetic. Please know that our MSA Nurse Specialists are always happy to discuss issues surrounding MSA complications so do get in touch with them.

Our East Yorkshire Group discussed a piece of equipment called the 'Sara Stedy'. The device helps a solo caregiver support someone to go from a sitting to standing position. Some people with MSA found it allowed them to alter position and relieve pressure more easily. More details on the item can be found here **www.arjo.com/int/products/safe-patient-handling/standing-and-raising-aid/sara-stedy**. We always recommend contacting your Occupational Therapist to assess your suitability for any equipment.

Our Cumbria Support Group discussed the physical difficulties faced by carers who spend much of their time pushing a wheelchair or bending over to interact with someone. To help alleviate this, if possible, make sure to adjust the handles on the wheelchair to an appropriate height to relieve strain on the back and neck. Side controls are also beneficial for smaller people pushing a chair so that they can operate from the side and see where they are going. Using a perch stool to interact with someone with MSA when they are seated can alleviate stooping and posture problems for a carer.

Finally, several of our groups discussed holidays and the benefits of fully accessible cottages. A few different groups discussed holidays and it was emphasised how important it is to talk to an actual person to get full confirmation that the facility will meet all your needs. We provide a factsheet on 'Travelling and MSA' so do get in touch if this is of interest you. msa *news*

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

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

We aim to send out Support Group invitations four weeks in advance. If you are not currently receiving them or would like to receive them in a different format, please contact the Trust's office on 0333 323 4591 or email support@msatrust.org.uk.

Group	Venue	Date & Time
Bristol	The West of England MS Therapy Centre, Bradbury House clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 27 Feb - 1pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing BN11 5DR	Thur, 27 Feb - 2pm
Cumbria	Burton Memorial Hall, Main Street, Burton in Kendal, Carnforth LA6 1NA	Fri, 28 Feb - 1.30pm
Dorset	The Grove Hotel, 2 Grove Road, East Cliff, Bournemouth BH1 3AU	Mon, 02 Mar - 11am
Cornwall	Echo Centre, Barras Place, Liskeard PL14 6AY	Mon, 09 Mar - 11am
Leicestershire	Village Hall, Main Street, Swannington, Coalville LE67 8QL	Tue, 10 Mar - 11am
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 23 Mar - 2pm
Kent	Room B028 Blake Building, Medway Campus, University of Greenwich, Central Avenue, Chatham Maritime ME4 4TB	Tue, 24 Mar - 2pm
Essex	Great Tey Village Hall, Great Tey CO6 1JQ	Mon, 06 April - 2pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 08 Apr - 2pm
Aberdeenshire	The Community Room, Tesco Extra, Harlaw Road, Inverurie AB51 4SR	Thur, 09 Apr - 1.30pm
Falkirk	Airth Community Hall, Airth High Street, Airth, Nr Falkirk FK2 8JL	Fri, 10 April - 1.30pm
Cardiff	City Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff CF14 7BF	Wed, 15 Apr - 11am
Southport	St. James's Church Hall, 26 Lulworth Road, Birkdale, Southport PR2 2BQ	Thur, 23 April - 2pm
East Yorkshire	Etton Village Hall, Main Street, Etton Beverley HU17 7PG	Wed, 29 April - 1pm
Lancashire	Community Room, Tesco Extra, Clifton Retail Park, Clifton Road, Blackpool FY4 4UJ	Fri, 01 May - 1.30pm
Tyne and Wear	St. John's Church Community Hall, West Lane, Killingworth NE12 6BL	Tues, 05 May - 11am
West Yorkshire	Marie Curie Hospice, Maudsley Street, Bradford BD3 9LE	Fri, 08 May - 1.30pm
West Midlands	Bournville Gardens, 49 Bristol Road South, Birmingham B31 2FR	Mon, 11 May - 1pm
Sligo	Therapy Room, St John's Community Hospital, 8 Ballytivanan Road, Sligo	Mon, 11 May – 1.30pm
Dublin	Education Centre, St. Francis Hospice, Blanchardstown, Dublin	Wed, 13 May - 1.30pm
South West Eire	Gilbert Centre, Mallow Community Campus, Fair Street, Malow, County Cork	Fri, 15 May - 1.30pm
Oxfordshire	Standlake Village Hall, Rack End, Standlake OX29 7SB	Mon, 18 May - 1pm
Belfast	Tesco Community Room, Knocknagony, Knocknagony Road, Belfast BT4 2PW	Tues, 19 May - 1.30pm
Staffordshire	Katharine House Hospice , Weston Road, Stafford ST16 3SB	Wed, 20 May - 10am
Three Counties	Boy's Brigade Community Centre, Canterbury Leys, Newtown, Tewkesbury GL20 8BP	Tues, 26 May - 1.30pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing BN11 5DR	Thur, 28 May - 2pm
Greater Manchester	St. Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Mon, 08 June - 1.30pm
Cumbria	Burton Memorial Hall, Main Street, Burton in Kendal, Carnforth LA6 1NA	Fri, 12 June - 1.30pm
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 17 June - 1.30pm
Glasgow	The Glasgow Academy, 25 Colebrooke Street, Glasgow G12 8HE	Mon, 29 June - 1pm
County Durham	Eastlee Community Centre, Stockton Road, Seaham SR7 8DX	Tues, 30 June - 1.30pm

Please note we will continue to add dates for other regions as they are confirmed. These groups are subject to change so please check the Support Group calendar on our website or ring the office for up-to-date information.

How to deal with *choking episodes*

Whenever anyone chokes it can be very frightening for both the person and for those looking on.

People with MSA can be more prone to choking with food going down the wrong way due to poor co-ordination of swallow and a weaker cough reflex to clear obstructions. Rachael Hillier, Volunteer Community First Responder, explains what you can do to help someone that is choking.

It is crucial if someone with MSA is having any choking episodes, however slight, that they have an assessment by the Speech and Language Therapist and understand the significance of the advice they provide.

Choking happens when someone's airway suddenly gets blocked, either fully or partly, so they can't breathe. It is very rare for anyone with MSA to choke to death, but in the event of choking it is important to know the first aid management of a choking episode.

Mild choking - encourage them to cough

To help with mild choking (for anybody over one year old):

- *Encourage them to keep coughing to try to clear the blockage*
- *Ask them to try to spit out the object if it is in their mouth.*

Severe choking - use back blows and abdominal thrusts

Where choking is severe, the person won't be able to speak, cry, cough or breathe. Without help, they will eventually become unconscious and will require emergency action.

To carry out a **back blow** on anybody over one year old:

- *Stand behind them and slightly to one side. Support their chest with one hand. Lean them forward so the object blocking their airway will come out of their mouth, rather than moving further down*
- *Give up to five sharp blows between their shoulder blades with the heel of your hand. The heel is between the palm of your hand and your wrist*
- *Check if the blockage has cleared*
- *If after five back blows the person is still struggling, ask for someone to call 999 and proceed to abdominal thrusts, outlined below.*

Do not give abdominal thrusts to babies under one year old or pregnant women.

To carry out an **abdominal thrust**:

- *Stand behind the person who is choking*
- *Place your arms around their waist and bend them forward*
- *Clench one fist and place it on their belly button*
- *Put the other hand on top of your fist and pull sharply inwards and upwards*
- *Repeat this movement up to five times.*

If the person's airway is still blocked after trying back blows and abdominal thrusts, get help immediately:

- *Continue with the cycles of five back blows and five abdominal thrusts until help arrives*
- *If they lose consciousness and aren't breathing, you should begin cardiopulmonary resuscitation (CPR) with chest compressions.*

Complications

If after clearing the obstruction and the person has recovered from the immediate episode they continue to have a persistent cough that does not settle or they have the feeling of something still being stuck in their airway/ throat, they should be seen by a doctor at the GP Surgery, Walk-in-centre or A&E.

If you gave abdominal thrusts alert the paramedics that this has been done, even if the person has 'recovered' by the time they arrive, as abdominal thrusts can cause injuries. msa *news*

New Ways to Give and Help

As you will see from our front cover and our article on page six, we have been listening to our members. As a consequence, we will be developing ideas for further support based on what you have told us.

However, our ability to respond to your needs depends on our ability to resource our services. Key to this is the crucial importance of your regular contributions. They enable us to plan ahead, confident in the fact that supporters have committed to making confirmed donations going forwards. As the needs of the MSA community are established, we continue our long-term planning and your support for targeted services is needed more than ever. If you can, please consider giving regularly.

There are several ways to set this up while keeping administrative costs to a minimum. We are still accepting standing orders for regular donations, whereby a mandate is sent to your bank and an amount gets transferred at a frequency of your choice. Perhaps an easier and more convenient way to set up a regular donation is through our website using your card details. Through this method you have access to your statement of giving and can decide how long you wish to support us. There is more choice as you can give monthly, quarterly or annually. As the process is administered online, this way of supporting us is even more cost and resource efficient. msa *news*

To set up your regular donation online or to download our Standing Order form visit **www.msatrust.org.uk/regular-giving** or email Tanya at **fundraising@msatrust.org.uk**.

Ride 100 or 46 miles for us

RideLondon is the Trust's flagship cycling event and is back this year on Sunday 16th August 2020.

Celebrating the legacy for cycling created by the London 2012 Olympic and Paralympic Games, the Prudential RideLondon-Surrey 100 (miles) starts from Queen Elizabeth Olympic Park, then follows closed roads through the capital and into Surrey's stunning countryside. With challenging climbs including the famous Box Hill and a route made famous by the world's best cyclists, it's a great way to spend the day on your bike. The Prudential RideLondon-Surrey 100 finishes on The Mall in central London, having snaked past all the city's most famous sights.

The Prudential RideLondon-Surrey 46 begins at the Olympic Park and following the same route as the RideLondon-Surrey 100 for the first 27 miles before taking a new two-mile route, which then links up with Ride 100 to finish in The Mall.

We have places available for all fitness and experience levels. With a very reachable fundraising target of £450 for 100 miles and £250 for 46, there's no better goal to take on this year.

Contact the fundraising team at fundraising@msatrust.org.uk for your place. msa *news*

MSA Awareness Week

22nd - 29th March 2020

As you probably know only too well MSA is a rare and often poorly understood condition. For MSA Awareness Week it would be great if you could all join in with activities that can raise its profile – both where you live and work and with Health and Care Professionals. Our aim is to ensure no one has to face MSA alone. Here are some ideas on how you can help:

Contact Your Local MP

With a new Government recently sworn in it's a great chance to get rare diseases, and MSA especially, front and centre of MP's minds.
Why not contact them via email, letter or even Twitter and raise the following points:

1. ***Social care and provision of equipment is important for people affected by MSA, what will you do to improve support?***
2. ***Carers breaks and respite care are very difficult to access, what will you do to improve support?***
3. ***Can you make sure any increase in NHS funding also benefits people with neurological conditions?***

Bucket or Box Collections

These collections provide a great opportunity to sell MSA Trust ribbons, talk about the condition with the general public, plus get some fundraising done.

- ✓ ***Find a space at your local club, station, shopping mall, or place of worship***
- ✓ ***Distribute our orange MSA ribbons and have a collection for the MSA Trust.***

Email **fundraising@msatrust.org.uk** for our help with permits, buckets and fundraising gear. And of course, you can always order some MSA Trust merchandise to sell to your friends and family and raise awareness of the cause, no bucket required! To order, visit **www.msatrust.org.uk/shop**.

Training for Health & Care Professionals

We are pleased to be working alongside NHS England in conducting a webinar training session aimed at Health and Care Professionals (HCP's). The session will cover a range of topics included in the NHS Progressive Neurological Toolkit and will be run by our information and services staff, MSA Nurse Specialists and professionals with a good knowledge of MSA and the difficulties people face.

We hope the webinar will encourage HCP's to find out more about MSA and provide even better support to people affected by MSA.
The webinar will be held on the 26th March and HCP's can sign up using a link from our website - **www.msatrust.org.uk/hcp-nhs-webinar**. Please do let your HCP's know about this webinar and help us to spread the word and increase awareness of MSA.

Stop Press – Our next MSA Study Day will be held on the 1st October in St Neot's, Cambridgeshire. Please make a note in your diaries.