



# msa news

MSA Trust Members Magazine | issue 50

## Seeds of hope

*the launch of  
Sarah's Wood*

How to outfox  
*winter*

Our front cover is by Jill Barrow - called "Coming Home". Jill had MSA herself and received a Highly Commended award for her beautiful picture in the British Wildlife Photography Awards.



KAREN WALKER

Welcome to issue 50

SARAH'S WOOD LAUNCH EVENT - PAGE 7

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Welcome to our 50th edition of MSA news.

I hope you like the changes to our magazine, bringing more information, updates and news than ever before. We are delighted to celebrate this fantastic milestone of 50 issues in our 20th anniversary year. Enjoy the read and the pictures. It has been a busy summer with so many of you out and about supporting us and raising money in whatever way you can. This is really paying off.

We are about to put a call out for more research projects (updates on page 18) and of course we have in post both our new Nurse Specialist and our Research Fellow. All of us here are looking forward to advancing our understanding of MSA through all our latest developments.

Please don't forget your Milk, Sugar And Tea party pack. Yes, it is already that time again when we get together for a cuppa to support our wonderful Nurse Specialists, including our latest recruit, on World MSA Day – 3rd October 2017. Wherever and whenever you hold your tea party, we want to hear about it and look forward to sharing your pictures.

[msanews](http://msanews.org)

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# NEWS ROUNDUP

## Professionals MSA Study Day

In two weeks' time we will be holding our very first MSA Study Day for Health and Care Professionals. Held in Southampton, 100 attendees will hear from respected consultants, therapists and nurses and join in discussions about how best to support people affected by MSA. Raising awareness of MSA, and educating healthcare professionals, has been something our members have always been keen for us to focus on, so we hope to run more of these study days in the future.

## Service of Light – Save the date!



Since 2014 our feature memorial event, Service of Light (SOL) has been held to remember loved ones lost to MSA. All proceeds raised go towards funding vital research into MSA. Please save the date as SOL will be held next year on **Saturday 19th May** in the North of England (most probably Wakefield). Look out for further details in our February issue of MSA News.

## Two new Trustees join the board



LINDA NICOLAIDES

ROSEANNE BLAZE

We are delighted to announce that after a successful recruitment campaign the Trustees welcome Linda Nicolaides and Roseanne Blaze to our Board in September, following hot on the heels of Professor Niall Quinn who joined us in March. Both have had experience of the massive impact MSA has on a family and both bring particular skills the Board was keen to tap into.

Many of you in the Kent region may already know Linda, who runs the Kent Support Group and she also sits on our Services Committee that meets twice a year. Linda has been part of this committee since its inception in 2012 and we are delighted that she brings her expertise as a carer to the Board.

Roseanne is currently working as a fundraiser with the RNLI in Southampton and brings to the Board her specialist knowledge in developing volunteers and supporting the work that they do at a local level. Roseanne lost her uncle to MSA and since then has wanted to support us in whatever way she can.

## Golden Girl

You may remember the recent article by Julie Payne, one of our members, about how she deals with life with MSA (issue 47). Well huge congratulations are due to Julie as she has just won gold in the Para-Dressage European Equestrian Championships in Gothenburg. Riding her horse Athene Lindebjerg she scored a whopping 77.6% to win. Julie said, "That is one of the best feelings I have ever had!" Well done Julie!



## Dixons Travel Support



We're pleased to announce that staff at Dixons Travel have voted to support us as one of their Charity Partners, alongside CRISIS and CRUK. They chose to support the Trust as a former staff member, Andy Cox, has been diagnosed with MSA and has been fundraising (see page 19). They will be placing collection tins in stores as well as taking part in fundraising events and volunteering. Their staff have already given us support with Tony Brady taking on the Edinburgh Ironman and Jas Chan and Shaun Carter taking part in the Race to the Stones. Thank you to all at Dixons Travel! [msa.news](http://msa.news)



# Communication Matters

*We covered communication in a previous MSA News (Issue 42, page 6). However, it's an issue that crops up again and again with new techniques and products becoming available all the time.*

If you are having difficulties with communication your first port of call should always be a referral to a Speech and Language Therapist. They will be able to provide a proper assessment and advise on what will work best for your needs. We have produced a Guide to MSA specifically for Speech and Language Therapists so if you feel this would be useful to your Therapist we can send it directly to them.

There is a range of equipment available that may be suitable but before you buy it is always worth checking with your Therapist to first make sure it will be of benefit, and second to see if it can be provided through their service. A list of assessment services in the UK can be found on the Communications Matters website here: [www.communicationmatters.org.uk/page/resources/aac-assessment-services](http://www.communicationmatters.org.uk/page/resources/aac-assessment-services)

There may also be opportunities for you to find out more about the types of equipment available and to get your hands on some. For example, Communication Matters run roadshows throughout the UK so you may be able to attend one of these. The next ones are planned for Cardiff on 22nd November and Ashford in Kent on 29th November. See their website (above) for more information.

Some communication aids can be relatively simple but still be extremely useful. One of our Members, Gerion Piper developed a booklet for her husband to use for basic conversation. We have put a version of this on our website – [www.msatrust.org.uk](http://www.msatrust.org.uk) - which you can download and adapt, or ask us for a copy in the office. Gerion writes:

*"This communication book was very individual to Robert, but it is easily altered to the needs, likes and dislikes of anyone else. We made it into a book for ease of use, whether you need to know the level of pain or ideas for an afternoon out. It came about because Robert loved to chat, so his increasing difficulties with speech really upset him. We made the booklet to include his favourite sayings and questions, places he liked to go, things he liked to do. It was*

*simple to point to whatever he wanted and then we could go from there. Often schools and libraries have simple binding machines which you can use, the pages are then easier to turn than using staples. Otherwise, use a string tie. We really hope it helps."*

If affordability of equipment is a problem you may want to consider investigating the following:

- **Check you are claiming any benefits you are entitled to – [www.turn2us.org.uk](http://www.turn2us.org.uk) has a helpful benefits calculator**
- **Ask to see if NHS services or Social Services can help**
- **Check whether you could get a grant to cover the costs, see the [Turn2us](http://www.turn2us.org.uk) website. The [Sequal Trust](http://www.thesequaltrust.org.uk) also help with grants towards the cost of Communication Aids, [www.thesequaltrust.org.uk](http://www.thesequaltrust.org.uk)**
- **The MSA Trust can sometimes loan Communication Aids called *Lightwriters* which some people find helpful. In certain circumstances we can also help with small grants towards the cost of equipment.**
- **Speak to your MSA Nurse Specialist who may be able to advise further**

Finally, we often hear that explaining MSA to children can be difficult. Another of our members, Claire Williams, took a unique approach to this - she wrote a children's book...



GARETH WILLIAMS, FORMER RUGBY INTERNATIONAL

*"I wrote the book with the intention to allow my children to dream and remember my father as the fit and active man that he has been. My father, Gareth Williams, has been dealt a bad hand, yet watching how strong and determined he has been has shown all of us how much of an amazing man he is.*

*He was diagnosed with Multiple System Atrophy (MSA), in 2013. I made it my mission to help my children understand what MSA is, alongside giving them the opportunity to make new memories with my father.*

*I published the book in time for Father's*

*Day and read it to my father. My family, including my father have all loved the book and have asked for me to provide them with a batch to sell on. All profits from the book selling will go the MSA Trust to*

*help towards the research for finding a cure.*

*I have also published an ebook on Amazon that can be downloaded onto e-readers such as tablets and phones."*



GARETH &amp; GRANDCHILDREN



CLAIRE WILLIAMS &amp; KIDS

To get in touch with Claire and order a book, email her at [clairemariewilliams@outlook.com](mailto:clairemariewilliams@outlook.com) or Facebook message her - Claire Marie Williams. If any readers have had any innovative ways of discussing MSA with children and young people we would be very pleased to hear of these, as we are hoping to develop this aspect of the information we provide and on our website. [msa.news](http://msa.news)



# Our new MSA Nurse Specialist

As Karen mentioned in her welcome, we are very pleased to welcome our new **MSA Nurse Specialist, Emma Saunders**. Emma will be joining Samantha, Katie and Jill to support our members affected by MSA in areas including the Midlands, North Wales, Greater Manchester and South Yorkshire. Emma will start her role proper in the New Year, but in advance of this we asked her to let you know a bit about herself:

## Tell us about your Nursing experience and what attracted you to this role?

I undertook nurse training in Coventry in 2003. After qualifying, I worked locally on a busy surgical ward before moving to London where I was a neurological research nurse. I undertook research in the clinical areas of stroke, dementia, Huntington's, Motor Neurone and Parkinson's Disease. I was then a Rare Disease Clinical Nurse Specialist, and most recently I have been working as a Parkinson's Disease Nurse Specialist in the Midlands.

I was attracted to the job because I already knew of the MSA Trust and the brilliant service they offer to people with MSA, and I hoped my background of working with both rare diseases and neurological patients would make me suitable for the post.

## What are you most looking forward to?

I am really looking forward to joining the team and getting to know everyone at the Trust.

I am also looking forward to learning more about MSA and specialising in the field of MSA, and eventually being able to support people with MSA and their families.

## Any worries?

Yes! I am nervous about learning a new role and working with existing staff who I know to be very knowledgeable and experienced in the area of MSA.

## What is your experience of working with people with MSA or Neurological conditions?

I have previous experience of working with people with rare diseases, as well as the neurological conditions I mention above. As a Parkinson's Disease Nurse Specialist I have cared for people with MSA,



and have worked with patients at every stage of the condition on both an out-patient and inpatient basis. People who have been in contact with, and supported by, the MSA Trust value the Trust and the support offered by the team very highly.

## Hopes for the role and the future:

I hope to learn as much as I can and be able to put old and new knowledge and experience into delivering a service that is relevant and useful for people with MSA and their families.

## A fun fact!

I come from a large (extended) family and on one side alone I have over 100 cousins!

## Favourite film

I feel like I should choose an important, philosophical and considered answer... but in truth my favourite film is Good Will Hunting.

## Hobbies and interests

I enjoy spending time with family and friends, going to the theatre and travelling. My favourite thing to do is read and I can usually be found with some sort of crime thriller novel in my hand. [msa news](#)



# Sarah's Wood Launch Event

**On a sunny afternoon in June, members of the MSA Trust gathered at the magnificent Thoresby Estate in Sherwood Forest to share the opening of Sarah's Wood.**



Many of you will know that the MSA Trust was founded 20 years ago by Sarah Matheson who, having been diagnosed with MSA, felt she had nowhere to turn for support. The Trust has grown since then to become the UK and Ireland's only charity solely designated to supporting people with the condition. Sarah's brother, Hugh, is one of our Trustees and he was inspired to create Sarah's Wood as a lasting symbol of hope for everyone affected by MSA.

Each guest at the event planted an oak sapling with the help of a team of Foresters. Many people found it incredibly moving planting the trees in what will become a national symbol of hope and support for those affected by MSA. The saplings will now be looked after by the foresters on the estate awaiting the peak planting time of the cooler winter months, when the saplings will be planted in the Wood itself. At the moment, a single, 20-year old oak tree thrives in the Wood, representing Sarah and the beginning of the MSA Trust. By the end of this year we anticipate many more saplings will be standing together with it.

Guests at the event were treated to afternoon tea and listened to speeches given by our CEO, Karen Walker; the Chair of the Trust, Clare Fowler; and Hugh Matheson. Clare gave an update on the research that is happening into MSA, explaining it in layman's terms which was most appreciated! Hugh gave a moving speech about the motivation behind Sarah's Wood and how he hopes that the Wood will become a serene place where people can visit and gain strength and hope.

Moving forward, everyone who joins the Trust will be able to plant an oak tree in the wood – either in person during specific months of the year, or by way of the foresters at Thoresby Estate who can plant a tree on their behalf. We have plans to set up a bench in the Wood and carve out a walkway so that everyone, including members of the public, can understand more about the condition and feel a part of the MSA community.

If you are interested in planting a tree in Sarah's Wood, please contact the office:

[support@msatrust.org.uk](mailto:support@msatrust.org.uk). We'll be planting

more saplings on the 20th of November, December and January, so do let us know if you'd like to come along and plant your tree. [msa news](#)

A close-up photograph of two hands with red nail polish, cupped together to hold a single, white snowflake. The hands are wearing a dark, textured sweater. The background is a soft-focus, light-colored surface, possibly snow or a light-colored wall. The overall mood is gentle and protective.

# Winter Health

**Whether we like it or not, winter will soon be upon us again. We know that people with MSA are more vulnerable to infections which are more prevalent in colder months, so it pays to be prepared. In this article, we take a brief look at some of the things you can do to minimise problems if they occur.**





The first practical step you can take is to make sure both you, and any carers supporting you, get flu and pneumonia jabs (make sure each one is given two weeks apart). Ask your GP for these. It is also worthwhile your carer registering themselves as a 'carer' with your GP Surgery so that they are offered priority appointments should they become unwell.

**You should also make sure that one of your Christmas preparations is to check that your prescriptions won't run out over the holidays, when many of the pharmacists are closed. Check your local pharmacies opening hours well in advance.**

If you are concerned about heating your home you should check to see whether you might be entitled to any benefits that could help you meet extra costs, both disability benefits but also winter fuel payments. The Trust has a leaflet on basic benefits which we are happy to send, or you can download it from our website - [www.msatrust.org.uk](http://www.msatrust.org.uk).

Finally, if infections or other symptoms do necessitate hospital treatment there are a range of things you can do to make everything a little bit easier.

Some emergency admissions can be arranged through your GP who can organise for the relevant hospital doctor to see you in the Accident and Emergency Department.

It is likely that the medical staff you meet in hospital will not know much, or indeed anything, about MSA. This is especially true if you are admitted for something unrelated to your MSA. The Trust have a Hospital Information Folder which we are happy to send to you, (which contains basic information

about MSA, including a leaflet and Guide). You can personalise this so that staff will know about you, your specific needs and what they need to look out for. Having this handy can make a real difference.

You may also want to prepare a basic "kit" bag, including:

- **Wash gear**
- **Underwear**
- **Nightwear**
- **Continence aids, pads, catheters etc.**
- **List of emergency numbers in case you need to cancel carers or health professional appointments**
- **Copy of last consultant clinic letter with up to date medication list**

Our leaflet 'Going into hospital' (which is available in the Hospital Information Folder or on our website) has more detail on this and also contains a planning sheet.

If you are a carer it may be you that needs to go into hospital, so for your peace of mind it is advisable to put an emergency plan in place.

For example, if an emergency happens, you need to know that replacement care will be sorted out speedily and efficiently.

In order to create an emergency plan, you will need to consider:

- **The name and address, and any other contact details for the person you look after**
- **Who you, and the person you look after, would like to be contacted in an emergency – this might include friends, family or health and care professionals**
- **Details of any medication the**

**person you look after is taking**

- **Details of any on-going treatment they need.**



You may be able to arrange this with friends and family but it can be reassuring to have the involvement of your local council in case informal arrangements fall through. You can do this through a social care assessment for the person you look after, or a carer's assessment for yourself. The social services department of your local authority should be able to help you with planning. Every carer who has an assessment should be asked about emergencies and offered help to plan for them.

Further information about planning for emergencies can be given by your MSA Nurse Specialist.

[msa news](http://www.msatrust.org.uk)

For more information on anything you have read in this article please contact your MSA Nurse Specialist whose details can be found on our website [www.msatrust.org.uk](http://www.msatrust.org.uk).



# In Memory

Michael Cook  
Andrew Rowlinson  
Thomas Flanagan  
Derrick Jeanes  
John Coatham  
Mel Daniels  
Thomas Nelson  
Roger Bardsley

John Arch  
Brian Stanley  
Joan Brown  
John Hancock  
Tessa Hamp  
Elizabeth Payne  
Jennifer Lassman  
Cliff Miller

Christine Webster  
Jane Griffiths  
Linda Shinton  
Shirley Crawford  
Margaret Maylor  
Eric Boswell  
Marjorie Hance  
Christine Hubbard

John Clark  
Mohammed Rafiq  
Valerie Doyle  
Desmond Osborne  
Pauline Last  
Frank Crowley  
David Tate  
John Brett

## STILL MAKING A DIFFERENCE IN OUR 20<sup>TH</sup> YEAR



**Multiple System  
Atrophy Trust**

20th ANNIVERSARY

This year the MSA Trust is marking 20 years of supporting people living with MSA.

As you will have read in the article about Sarah's Wood the Trust has now been in existence for **20 years**.

During this anniversary year we have certainly not let the grass grow under our feet. Our increased membership has topped the **6,000** mark and to help us respond to this we have recruited our fourth MSA Nurse Specialist, who will help us to increase our individual support and raise awareness amongst professionals. We are also holding our first MSA Study day for Health and Care Professionals. We've also welcomed Viorica Chelban, our first ever Association of British Neurologists MSA Research Fellow to drive forward our research capacity into the cause and eventual cure of MSA.



To mark this 20 year milestone we have launched our **20th Anniversary Campaign**.

Whilst we've made huge strides in providing support and research over the last 20 years, we are only too aware that there's still so much more to do. If you could help us do more it would mean so much to so many people. If you are able to donate please send a cheque to the office or visit our Just Giving Campaign page: [www.justgiving.com/campaigns/charity/msatrust/anniversary](http://www.justgiving.com/campaigns/charity/msatrust/anniversary).

In addition we are also producing a special 20th Anniversary china mug. This can be purchased from our online shop [www.msatrust.org.uk/shop](http://www.msatrust.org.uk/shop) or by calling the office on 0333 323 4591 to order yours.  
msa news



# Research Focus

## What do secret agents and research into MSA have in common?

*Aoife Kiely, a great friend of the Trust over the years, reports back on her study into neuroinflammation in brain cells as her research comes to an end.*



AOIFE KIELY

The brain is made of tiny units called cells which can only be seen using a microscope and they include neurons, oligodendrocytes, astrocytes and microglia. When the brain is damaged, or experiencing disease, these cells respond with a process called neuroinflammation. Cells have been shown to react with neuroinflammation to diseases such as Alzheimer's disease, Parkinson's disease and Lewy body dementia, and we want to know if this is also the case with MSA.

Like a military operation there is a particular sequence of events that occurs in order for a cell to launch this response. Firstly in the command centre of the cell, called the nucleus, a set of instructions are written for response called messenger RNA, or mRNA.

This mRNA then travels to another part of the cell where it is read and used to make the troops: proteins or chemicals that will act out the cell's response. These troops do several things, they can signal to other cells to alert them of trouble, they can recruit assassin cells which will destroy damaged cells and neutralise invaders or they can act as peacemakers, healing damaged cells and calming the situation.

It is important that we figure out how cells in a brain with MSA are responding to the disease so that we can understand what could be going wrong or what responses may need to be intensified.

**At Queen Square Brain Bank we decided to spy on the command centre of the cell to see what instructions or mRNA were being sent out to the rest of the cell. Our secret agent wasn't James Bond but a state of the art technology called NanoString.**

With NanoString we were able to look for a large number of possible instructions or mRNA that are being made in a situation of neuroinflammation. We also spied on healthy brains to compare our findings.

We discovered that cells in MSA brains are producing instructions that healthy brains are not. We believe these instructions are an important insight into how cells of the MSA brain are trying to respond to and cope with the disease. Importantly this has given us a vital new avenue of research to pursue and we will be publishing our findings very soon.

It is hoped that this research will be finalised in late October and the MSA Trust will share the report with members as soon as possible. [msa news](#)

**MSA Trust**  
20th ANNIVERSARY

**£1,000,000**  
and counting, to fund  
**vital research**  
to find the  
cause and  
cure for MSA.



# Could you support our Support Groups?

*As you know, our Support Groups help people get together and share experiences. Adrian Koe, one of our Group Facilitators, writes about how running a Support Group needn't be too daunting and what he's learnt about making meetings useful, interesting and enjoyable.*

**A**t the beginning of May I attended a Facilitation Skills training course provided by the Trust to learn new techniques to use in the Cambridge Support Group I run with my wife, Liz.

*During the course, it became apparent that many groups struggle to run with limited volunteers, and some have no volunteers at all.*

This is sometimes because people assume somebody else will do the organising but it can also be because people think it will be too difficult. In reality, a couple of hours every 3-4 months is all we need to support many families affected by MSA. Helping set up the room ready for the meeting, greeting people as they come in and making people feel comfortable or making refreshments can all make a real difference.

The actual organisation and facilitation of meetings need not be too difficult either, as some of the ideas on the day illustrated how meetings could flow smoothly.

We heard from our nurses (our wonderful nurses) and it was quite apparent that there are as many types of meetings as there are numbers of Support Groups around the country. I thought I would outline some of the activities we tried at our Support Group that you might be able to try, or help your Support Group volunteers to co-ordinate:



- A research doctor attempting to find markers in patient's DNA similar to some results he had with Parkinson's
- A therapist talking about their role and how they help
- A member of the Carers Trust
- A more social meeting, for example a friend of ours gave a talk on the history of nursery rhymes
- A Hospice staff member to talk about the Hospice Movement and the need to tell people all about the benefits of hospice care and support
- We also try to have local health professionals from various disciplines so that they can in turn both learn from us and provide general information to attendees
- One of our members works in our local hospital, Addenbrookes and she was able to arrange for the Trust to have an information table in a particularly busy corridor.

The Trust provides comprehensive support and guidance for volunteers thinking of running or being involved in Support Groups, so you would not be alone.

Any time that you can give would be gratefully received so get in touch with the Trust now at

[volunteer@msatrust.org.uk](mailto:volunteer@msatrust.org.uk). *msa news*



# Abdominal Binders

*Our MSA Nurse Specialist, Jill Lyons explains about a new piece of equipment which might help improve your symptoms of postural hypotension (drop in blood pressure)...*

**M**SA affects the autonomic system. One of the symptoms of this is postural hypotension, where blood pressure drops when moving from lying to standing, (or from lying to sitting and sitting to standing!) We have a factsheet that outlines ways to help manage this drop in blood pressure. It can cause a range of things including; dizziness, blurred vision, blackouts and coat-hanger pain (pain across shoulders and neck), as well as fatigue and weakness. Managing postural hypotension is very important in making you feel better and therefore your quality of life. The factsheet can be found here - [www.msatrust.org.uk/wp-content/uploads/2015/11/FS102-Postural-Hypotension-V1.6.pdf](http://www.msatrust.org.uk/wp-content/uploads/2015/11/FS102-Postural-Hypotension-V1.6.pdf).

There have been some recent studies into the use of abdominal binders in helping to manage postural hypotension. Abdominal binders are worn underneath clothing and are made of strong, stretchy but supportive material. They are fastened by a wide strip of fastener so they can be tensioned correctly. The binders come in different sizes so it is important to be measured correctly.

The binder should be tight enough to exert gentle pressure. It should be put on before rising from bed in the morning and taken off when lying down, to avoid blood pressure getting too high when lying down. The advantages are that a binder's effects are immediate, its benefits can be easily assessed and it can be used on an 'as-needed' basis. They are also easy to fit and can be washed in a regular washing machine.

When abdominal compression alone is not enough, the addition of compression of the legs can result in further benefits. This can be achieved by using compression stockings that ideally extend to the waist or, at the least, to the thigh.

*Abdominal binders are made by a number of different companies and it may be possible to make individual adaptations if you have a feeding tube or supra pubic catheter.*

If you think that an abdominal binder might be useful for you, discuss this with your consultant or MSA Nurse Specialist. If appropriate, they can then arrange for

you to be measured and for your blood pressure to be monitored.

As this is a more recent tool in the kit for managing postural hypotension, we would be very interested to hear any comments from people using abdominal binders. Please email [nurses@msatrust.org.uk](mailto:nurses@msatrust.org.uk) or post your thoughts on the thread on our website forum or HealthUnlocked community –

[www.healthunlocked.com/msa-trust](http://www.healthunlocked.com/msa-trust). *msa news*

ADVERT



## Abdominal Binder

- Cotton Faced Foam Fabric For Comfort
- Machine Washable • Air Permeable • Latex Free





## GETTING ACTIVE FOR MSAT!



**Natasha Blanchett** cycled 1,000 miles from Land's End to John O'Groats for her best friend's mother who has MSA and raised close to £6,000! Earlier this year, Natasha along with friends organised two successful quiz nights, which helped her reach this fantastic total. Well done Natasha!



**Julie Payne** (see Golden Girl - page 3) successfully abseiled down the Orbit Tower at the Olympic Park and raised more than £500 - Well done!

**Kimberley Honey** and some of her Structured Finance Corporate Team at RBS got together for a great Tough Mudder Challenge as part of their **Corporate Fundraising**. They got wet and muddy (as you can see!) but also managed to raise more than £1,000!



## OUR EVENTS

Nine supporters ran an epic 10km through the streets of London in the **British 10K** raising more than £2,000! A huge thank you to all of our fantastic runners.



**Prudential Ride London-Surrey** this time saw eight supporters cycling either 100 or 46 miles, including some experienced riders from our long term friends - the cycling charity, Club Peloton. A big thank you to all of our cyclists.



**Paul Cox** climbed Mount Kilimanjaro while raising close to £1,300 for us. Paul's uncle, Andy has MSA and you can read more about him on page 19.

If you have been successful in getting a ballot place to run in the 2018 London Marathon then please fundraise for the MSA Trust - **Get in touch with us!**



## MUSICAL SUPPORT FOR THE MSA TRUST!



We were delighted that **The Royal College of Music Student's Union (RCMSU)** chose us as their **Charity of the Year** for the 2016/17 academic year. Their RAG week included a sponsored bake-off, a pub quiz and a jazz jam session. 8 students also completed a Grade 1 challenge where they learnt a new instrument. RCMSU organised free concerts performed by the RCM Student Film Orchestra and collected from the audience in lieu of ticket costs. In total RCMSU raised close to £4,000. Music to our ears!

## IN THE COMMUNITY

Earlier this year the **Sutton Golf Club in Ireland** hosted an MSA fundraising lunch and raised the magnificent sum of €7,216. A member of the Club, **Anne Culhane** whose son Michael has MSA, was delighted that everyone enjoyed the occasion while supporting such a worthy cause.



We'd like to thank **Pauline Chatham** and her Ladies' Fellowship Group who raised £250 by holding a Last Night of the Proms Concert.

The **South Yorkshire Country Women's Guild** organised a Valentine's Dance at the local village hall in Firbeck and raised £2,000. **Eileen Shaw** (right) helped with the event and kindly accepted the cheque on behalf of the Trust.



Thank you to **Cath Levesley** and her friends and family who collect all their 5p coins for us – The 5p ladies have raised £430 so far! We have coin collection boxes we can send you if you want to collect your loose change.



# Supporting & Helping Each Other

*Once again our Support Groups have been fountains of knowledge - with many more tips than I'm able to fit into this article. So if you can, try to go along to your local group and share some of the amazing stories, experiences, tips and information from people affected by MSA. Here's a snippet of what's been going on...*

Our MSA Nurse Specialist Katie Rigg reported back on a discussion at the Strabane Support Group about using Viscotears (available from most pharmacies), to help with itchy or irritable eyes. Make sure that you massage the whole eyelid to ensure that the fluid spreads over the entire eye.

At a full to the rafters Dublin Support Group, a conversation was held about communication aids and the need to become competent using one of these as early as possible so you can find the best fit for you. Some members had found it useful to use a voice banking service and recommended [www.modeltalker.org](http://www.modeltalker.org) which anyone can sign up to, free of charge and can start straight away banking thousands of sentences (see article earlier in this edition of MSA News about communication support).

At the Hexham Support Group people were reminded that if you have any building work on your home, or equipment installed, especially for the personal use of someone with a disability, this should be VAT-exempt. You can download the necessary forms and read further information - [www.gov.uk/government/publications/vat-relief-on-building-work-if-you-have-a-disability](http://www.gov.uk/government/publications/vat-relief-on-building-work-if-you-have-a-disability).

Members at the Inverurie group recommended that if people have bowel issues eating a full-fat probiotic yoghurt in the morning, then not eating or drinking anything for 30-60 minutes after could

help relieve symptoms. They also felt there are some potential benefits to having a gluten-free diet including improvement in gut comfort and feeling less fatigued. We are not able to recommend this but it's worth discussing with your dietitian and GP to see if it might help.

Also at the Inverurie Support Group, some members shared that they own a 'Raizer' aid which helps carers lift people off of the floor after a fall. This can be operated by one person and people found it very easy to use. Speak to your Occupational Therapist about this equipment or for more information visit their website - [www.raizer.com](http://www.raizer.com).

Following our article in the last issue of MSA News about Restless Legs Syndrome, a member emailed to inform us that they find it helpful to wear bed socks throughout the night, which has stopped their restless legs symptoms. We're always very grateful for people taking the time to email in their comments and thoughts which we can then pass on to you all – so thank you!

*msa news*

If you have any questions about anything included in this article please contact your MSA Nurse Specialists at [support@msatrust.org.uk](mailto:support@msatrust.org.uk).





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

*Please contact the Trust's office on 0333 323 4591 or email [support@msatrust.org.uk](mailto:support@msatrust.org.uk) for more details. These groups are subject to change, so please check the Trust's website or ring the office for up-to-date information.*

GROUP	VENUE	DATE & TIME
<b>Bristol</b>	The West of England MS Therapy Centre, Bradbury House clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 28 Sept - 1.00pm
<b>Surrey</b>	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 28 Sept - 2.00pm
<b>Worcestershire</b>	St Richards Hospice, Wildwood Drive, Worcester WR5 2QT	Thur, 28 Sept - 11am
<b>Kent</b>	Room B028, University of Greenwich, Chatham Maritime ME4 4TB	Thur, 28 Sept - 2.00pm
<b>Cardiff</b>	Ty George Thomas Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff CF14 7BF	Wed, 4 Oct - 11am
<b>Greater Manchester</b>	St Andrew's Church, Hope Centre, Tattersall Avenue, Bolton BL1 5TE	Wed, 4 Oct - 1.30pm
<b>North London</b>	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 9 Oct - 2.00pm
<b>Scottish Borders</b>	Old Gala House, Scott Crescent, Galashiels TD1 3JS	Mon, 9 Oct - 1.30pm
<b>Cornwall</b>	Echo Centre, Barras Place. Liskeard PL14 6AY	Mon, 9 Oct - 1.00pm
<b>Glasgow</b>	Kilbryde Hospice, Therapy Room 5, McGuinness Way, (grounds of Hairmyres Hospital) East Kilbride, Glasgow G75 8GJ	Tues, 10 Oct - 1.30pm
<b>Aberdeenshire</b>	Community Room, Tesco's Store, Harlewell Road, Inverurie AB51 4SR	Wed, 11 Oct - 1.30pm
<b>Dundee</b>	Day Hospice, Roxburghe House, Jedburgh Road, Dundee DD2 1SP	Thur, 12 Oct - 3.30pm
<b>Cambridgeshire</b>	Barton Bowls Pavilion, High Street, Barton CB23 7BG	Thur, 19 Oct - 2.00pm
<b>Essex</b>	Great Tey Village Hall, Great Tey C06 1JQ	Mon, 23 Oct - 2.00pm
<b>Norfolk/Suffolk</b>	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 25 Oct - 2.00pm
<b>Devon</b>	Baptist Church, High Street, Cullompton EX15 1AA	Wed, 25 Oct - 2.00pm
<b>County Durham</b>	Chester Le Street Hospital, Day Room, Front Street, Chester le Street DH3 3AT	Mon, 30 Oct - 1.30pm
<b>County Tyrone/Strabane</b>	Please contact the Trust for further details	Tues, 7 Nov - 12.00pm
<b>County Limerick</b>	Nurses Home, University Hospital Limerick, St Nessan's Rd, Dooradoyle, County Limerick	Wed, 8th Nov - 2.30pm
<b>Dublin</b>	St Francis Hospice, Station Road, Raheny, Dublin 5	Thur, 9 Nov - 11am
<b>County Sligo</b>	St John's Hospital, Ballytivnan, Sligo	Fri, 10 Nov - 1.30pm
<b>Surrey Carers lunch</b>	Please contact the Trust office for further details	Thur, 16 Nov - 12.30pm
<b>East Yorkshire</b>	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 22 Nov - 1.30pm
<b>Lincolnshire</b>	Franklin Hall, Halton Road, Spilsby PE23 5LA	Thur, 23 Nov - 2.00pm
<b>Hertfordshire</b>	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted HP4 3GW	Mon, 27 Nov - 11am
<b>Northumberland/Tyne &amp; Wear</b>	TORCH Centre, Corbridge Road, Hexham NE46 1QS	Mon, 27 Nov - 11.00am
<b>West Sussex</b>	Worthing Quaker meeting house, 34 Mill Road, Worthing BN11 5DR	Tues, 28 Nov - 2.00pm
<b>Shropshire</b>	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 4 Dec - 1.30pm
<b>Oxfordshire</b>	The Girl Guide Hall, Southern Road, Thame, Oxfordshire OX9 2EE	Mon, 11 Dec - 1.30pm
<b>Surrey</b>	Shalford Village Hall, Kings Road, Shalford GU4 8JE	Thur, 14 Dec - 1.00pm
<b>South Yorkshire</b>	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 20 Dec - 1.30pm

*We are finalising dates for 2018, all of which will be available on our website as usual.*



# Your chance to get involved

In previous editions of MSA News we have highlighted the **Prospect Study**, which aims to create a research bank for MSA study. It aims to become one of the biggest studies on risk factors and natural history in MSA.

To date the researchers have recruited 116 people to the study but still need more. The numbers are currently split into 34 people on a more detailed longitudinal study and 82 on a cross-sectional analysis. It may be possible to become part of the more detailed study if you live within reach of one of the seven centres which are involved in this. These are in London, Oxford, Cambridge, Manchester, Brighton, Newport (Wales) and Newcastle.

However, even if you don't live near these you can still participate in the overall study.

Participants can still be involved by offering to complete questionnaires and get blood samples taken locally to be sent to our Research Fellow Viorica Chelban. She can arrange for the appropriate packs to be sent out to you to enable you to take part.

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**If you wish to be involved with the Prospect Study please contact our Research Fellow: Dr Viorica Chelban at UCL Institute of Neurology, Telephone 020 3448 4068 or email: [v.chelban@ucl.ac.uk](mailto:v.chelban@ucl.ac.uk)**

These samples will be unique in the world and represent an important resource for research into MSA. The researchers have already

started several research projects using the MSA biobank including DNA methylation, RNA sequencing and genotyping in MSA. They will make the biobank an open source for other teams interested in doing research in MSA, in order to advance understanding into the disease.

As a sign of our commitment the Trust recently gave a further grant to the study to enable more detailed brain scans to be added to the evidence. These will give any final results in Viorica's research more significance.

In addition, we are pleased to announce another call for new MSA research projects. Full details will be given through our website in the autumn and we hope to be able to announce the grants awarded in our next edition of MSA News. The Trustees have allocated £150,000 of the Trusts Research budget and Professor Burn, Chair of our Scientific Advisory Panel, will once again lead the assessment panel.

We welcome research grant applications on any aspect of basic, translational or clinical neuroscience, aimed at better understanding the cause and/or improving treatment of MSA.

There was excitement earlier in the year from a report on a possible treatment for symptom management in MSA, in the form of a diabetic drug. This has not

entered clinical trials yet, but it indicates there is a potential to discover drugs currently being used for other conditions that might alleviate symptoms in MSA, and we hope some of our research might be based in this field.

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**The Trustees also decided, after a number of very generous legacies were made to us in the 2016-17 year that they wished to support some of the projects being submitted to the MSA Coalition in the USA.**

Having already established a close working relationship, Professor Clare Fowler (Chair of the Board) and Karen Walker (CEO) were asked to be part of the selection panel to recommend the projects that should be taken forward to selection. We will be allocating research funds of £50,000 to these projects and we look forward to hearing from Pam Bower, secretary to the Board of Directors at the MSA Coalition, in the next edition of MSA News, where she will be able to report on the studies chosen. [msa news](#)



ANDY COX, SIXTH FROM LEFT

## Fundraising walk, meeting the Royals, and much more!

In April, Andy Cox walked the Ridgeway with family and friends raising an amazing £3,184.50 for us. Andy was diagnosed with MSA in 2015 and has always been a keen walker. However, because of his MSA he has said that it was probably the last time he could do such a long trek.

Andy's friends and family joined him and there were nine walkers that went from start to finish - Andy's 11 year old son Oli, his brother Richard, David, Steve, Vivi, Kim, Rokiah and Sabine. Andy's wife, Theresa, and his nine year old son Joseph also joined him for parts of the walk, as did many other friends.

Andy said he has had great support from his former colleagues at Dixons Travel where he retired from last year, especially from his boss Gavin Wood. Dixons Travel have also voted to fundraise for us this year and colleagues, Jas and Shaun took on the 50km 'Race to the Stones' in July raising a further £420.

Andy has also raised much-needed awareness of MSA. Last year he wrote a blog for us after he and his wife went on the London Eye for the launch of 'Heads Together'. Whilst in the pod they spoke about MSA with the Duke and Duchess of Cambridge and Prince Harry.

We'd like to say a huge thank you to Andy and all his family and friends for their fantastic fund and awareness raising. We are also grateful to Dixons Travel who are supporting him through corporate fundraising. If you know or work for such an organisation and think they might support the Trust, please get in touch with our Fundraising Team at

[fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk). [msa news](#)

### The Lindy Hop for MSA Trust



Back in May this year, two of our fantastic supporters, Tracy Harding and Stephanie Moore, organised 'Hopathon 2017' in Cambridge. They are part of a Lindy Hop dancing group - The Cambridge Lindy Hoppers - and said "From the day we discovered that both our mums had MSA, we wanted to raise money and awareness for the MSA Trust. We jumped at the chance to organise Hopathon 2017 - a sponsored 12 hour dance marathon, with 19 people from The Cambridge Lindy Hoppers. We also raised extra money on the day through an evening dance with a live band, a raffle and craft/bake stalls which our family and friends helped us with. People told us they had a great time, and we raised a total of £5468.70 for the MSA Trust." Brilliant effort and amount raised - Well done! [msa news](#)

# Support the Trust this *Christmas*

**Buy our cards this Christmas and help raise awareness of MSA.**



**Snowman**



**Robin Postbox**



**Sledging on the Hill**



**Road to Bethlehem**

Our four festive designs have a greeting inside reading:

***"Season's Greetings and Best Wishes for the New Year" or "Wishing you a Merry Christmas and a Happy New Year"***

Each Christmas card design comes in a pack of 10 and costs £4.00 plus postage and packing. Please see our cost table for prices if buying multiple packs. Please return the slip below or order online at [www.msatrust.org.uk/our-shop](http://www.msatrust.org.uk/our-shop).

Pack(s)	1	2	3	4	5	6	7	8	9	10
<b>COST incl. P&amp;P</b>	<b>£5.00</b>	<b>£9.30</b>	<b>£13.30</b>	<b>£17.30</b>	<b>£22.65</b>	<b>£26.65</b>	<b>£30.65</b>	<b>£34.65</b>	<b>£38.65</b>	<b>£42.65</b>

If you live outside of the UK, please contact the Fundraising team for P&P costs: [fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk).



## **Multiple System Atrophy Trust Christmas Card Order Form**

Name:.....

Address:.....

.....

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

Snowman (Qty):..... Robin Postbox (Qty):..... Sledging on the Hill (Qty):.....

Road to Bethlehem (Qty):..... Total payment enclosed £.....

Please return slip to **MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB** with payment by 11 Dec 2017.