MSA NEWS

MULTIPLE SYSTEM ATROPHY TRUST | MEMBERSHIP MAGAZINE

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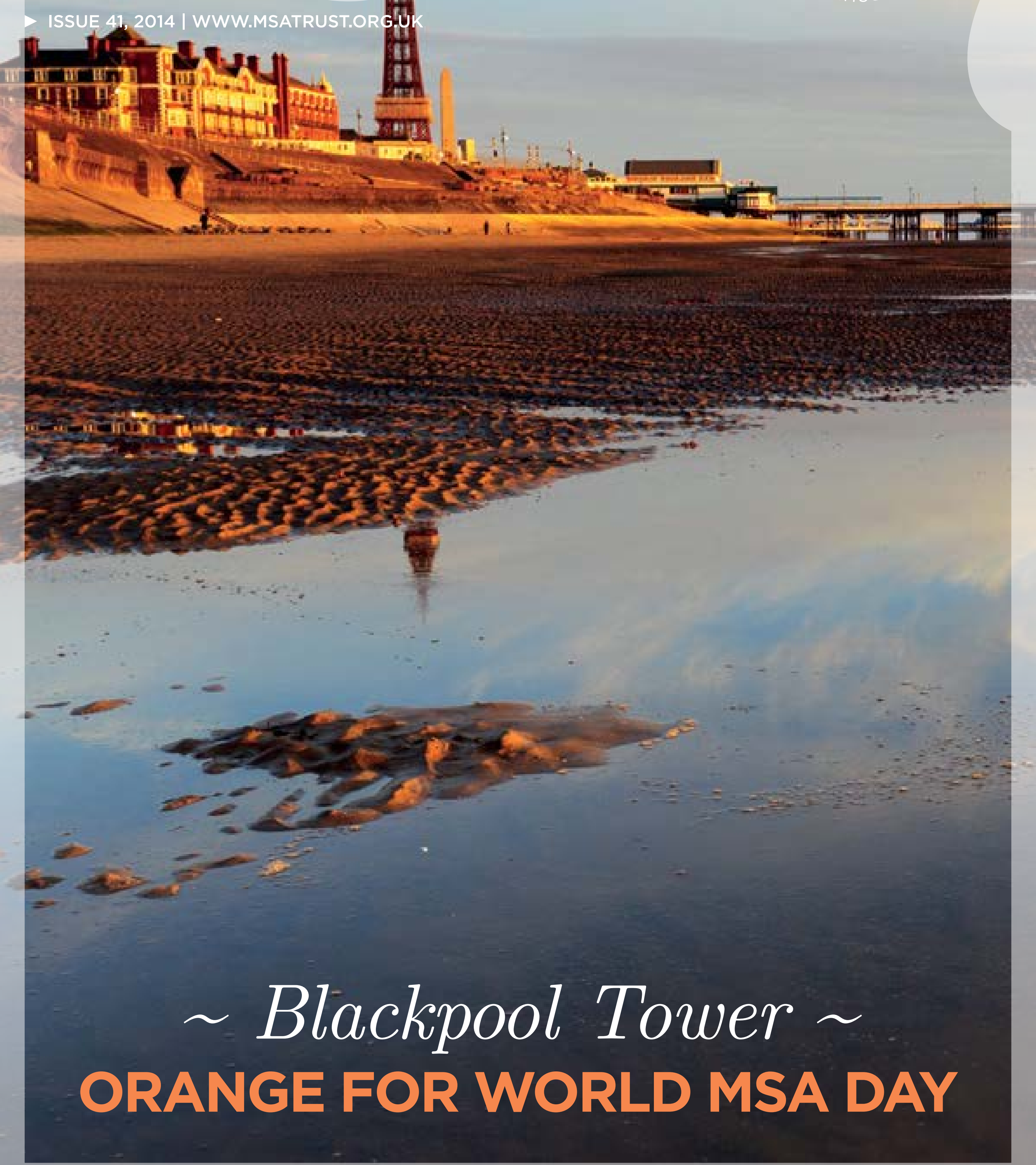

~ *Blackpool Tower* ~

ORANGE FOR WORLD MSA DAY

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MEMBERSHIP AT SEPTEMBER 2014

Current MSA members	1,084
Carers, relatives & friends	1,838
Healthcare professionals	2,243
Total	**5,165**
New MSA Members since June 2014	53

MSA NEWS CONTENTS

Multiple System Atrophy Trust

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

CARERS CORNER 04
Our guide for new carers

NEWS ROUND-UP 05

MSA GUIDE 06
Postural hypotension

VOLUNTEERS 08
Building a community prescence

TRUST SUPPORT SERVICES 09

RESEARCH 11
A day in the life of a researcher

BUILDING AWARENESS 12
World MSA Day 2014

FUNDRAISING ROUND-UP 14

SWALLOWING AND MSA 16

KEEPING WELL 17
Seasonal flu jab

IN MEMORY 18

SUPPORT GROUPS 19
Directory of meetings

CELEBRATING CHRISTMAS 20
Trust Christmas cards

WELCOME TO MSA NEWS

Influencing, lobbying, campaigning are all words used by health charities to describe activities designed to bring about change. These activities, sometimes described as policy work, are not as visible as funding research or providing support and information, but are still important.

The Trust is keen to influence change for people with MSA, particularly around care and treatment. We do this largely through the work of our services team who provide educational material and training to health and care professionals to help them with the care they provide to their patients with MSA

We're keen also to go a little deeper into the workings of the NHS to try and influence change at the heart of care provision. As a small charity we have to "cut our cloth", and so look to piggy back wherever we can on the activities of larger charities, or umbrella groups such as the Neurological Alliance. The latter, eg, published a report in September which questioned how easy it is for people to engage with the new health system – Healthwatch in particular. Not easy was the answer. A full summary of their findings, conclusions and recommendations is available on our website: www.msatrust.org.uk, and we'll be monitoring developments.

Supporting the carer is an area the Trust is focussing on, so it was particularly interesting to see the report produced by the Carers Trust which looked at caring from the perspective of the male carer. Their findings highlighted many issues, one for noting by employers as well as health and care professionals, that a quarter of the male carer respondents said they don't describe themselves as carers to others which means their need for support may not be immediately obvious and might result in them missing out on vital help.

On a different tack, the Trust took the opportunity to comment on the review by the National Institute for Health and Care Excellence (NICE) on the Parkinson's disease guidelines. We saw this as an opportunity to stress the need for clinicians to be more aware of the possibility of a re-diagnosis from Parkinson's to MSA, and the implications of this when speaking to patients, along with the need to provide information quickly on MSA, including signposting to the Trust. Our comments will be considered by the NICE review group and we hope will be taken on board.

On a very different note, we welcome our new Head of Services, Andy Barrick, who has taken over from Neil Hunter. Neil was instrumental in developing our information and support services and we will miss him, whilst wishing him the very best in his new role as CEO of a counselling charity local to his home town.

Nickie Roberts
Executive Director - Mission

CARERS CORNER

AN INTRODUCTION FOR NEW CARERS

Caring is in our nature, is part of life and part of being who we are. Carers enrich the lives of loved ones, helping them to get the most out of life.

Adopting the role of a carer, whether full time or for a few hours a week, is life changing. Without the right systems in place and support around you, caring can be very demanding and stressful.

Becoming a full time carer for someone living with MSA is a gradual process. At the beginning you may not even see yourself as a carer. Our members often tell us that they arrived at being a full time carer without having taken time to prepare for the role, causing unnecessary stress and anxiety.

In recognition of the vital role carers play in the lives of people with MSA, in 2013 we consulted with our members and asked what practical mechanisms we could introduce to make life easier.

Feedback identified the need for us to build on the support we offer to carers, and we have been busy since developing more carer-specific projects.

In the last issue of MSA News we announced the launch of our Carer's Guide. This was the first stage of our carer's project support work. We are now moving to the next stage, and are planning two events specifically for new MSA carers.

These events will help us shape similar events we are planning for the future in other places around the country. The sessions will take the form of a half-day introduction to caring for someone with MSA, and will be hosted by one of our MSA Specialist Nurses. We aim to cover the following topics in the session:

- MSA education for new carers
- Advising new carers on planning for the future
- Ways to care for yourself

We have invited an experienced MSA carer to speak and a member of staff from a local Carers Centre will also be there to promote the services they offer. Other local specialists will also be on hand to give information on other forms of support, such as employment rights and practical ways to look after yourself.

The first two events will take place in:

- Manchester Carers Centre: Thursday, 29 October 2014 from 11am to 3pm
- Aylesford Priory (nr Maidstone, Kent) on Thursday, 6 November 2014 from 11am to 3pm

Lunch will be provided on both days. The event is informal and will provide you with an opportunity to speak to other new MSA carers. To attend, please complete a registration form or contact emma.rushton@msatrust.org.uk, or by calling 020 7940 4666.

"Caring for someone with MSA is a very demanding job. Apart from the ever changing day-to-day needs, it requires enormous amounts of patience and understanding. I feel confident that the MSA carer's project will be a great help to those who are currently caring for someone. I am happy to support this project and wish it every success." Judie Marie, former MSA Carer and supporter of the Trust's carers conference. MSA

NEWS ROUND-UP

BBC RADIO 4 APPEAL

Please set your alarms and put a reminder in your calendars to listen to BBC Radio 4 on Sunday, 11 January 2015 at 7.55 am.

We are delighted to report that the BBC Radio 4 Appeal will feature the Trust on 11 January next year. Competition for charities to be included in the BBC Radio 4 Appeal is immense, so it is great news that the Trust's application was successful, particularly as it will be four years before there will be another chance to apply.

More details to follow, but for now please remember to the listen to the BBC Radio 4 Appeal on 11 January which will be repeated on Thursday, 15 January. **MSA**

A BBC RADIO 4 APPEAL

BBC RADIO 4

NHS NON-EMERGENCY MEDICAL HELPLINE

NHS 111 is a free-to-call single non-emergency number operating in England and Scotland. The service is part of each country's NHS and has replaced the telephone triage and advice services provided by NHS Direct, NHS 24 and local GP out-of-hours services. The service is available 24 hours a day, every day of the year and is intended for "urgent but not life-threatening" health issues. It is designed to complement the 999 emergency telephone number for more serious matters, although 111 operators are able to dispatch ambulances where appropriate. NHS Direct Wales continues to operate via 0845 4647, although it is intended the 111 service will be offered during 2015. **MSA**

MSA FEATURES ON KEY NHS WEBSITE

Following two years of lobbying by the Trust, the UK's biggest health website, NHS Choices (www.nhs.uk), has agreed to include information about MSA. NHS Choices provides a comprehensive health information service to help put patients in control of their healthcare and includes more than 20,000 regularly updated articles.

Nickie Roberts, the Trust's Executive Director, said: "Increasing numbers of people are going online to find out about health issues. NHS Choices is a respected and trusted website that contains bona fide information, and we felt it was important that MSA was listed.

"NHS Choices staff were dealing with a severe backlog and we waited far longer than expected for the inclusion of MSA, but we're pleased that we got there in the end. Not only will this help people with MSA, but also health professionals. The Trust is committed to raising awareness amongst doctors and nurses about MSA as we believe this will contribute to improving the care people with MSA receive." **MSA**

TRUST 2014 RESEARCH GRANT ROUND

The Trust has made a commitment to spend a minimum of £150,000 pa on research grants and has recently closed the 2014 grant round. All applications will be considered by the Trust's Scientific Advisory Panel, and details of successful applications will be reported in a future issue of MSA News and on the Trust's website. A copy of the Trust's current Research Strategy can also be found on www.msatrust.org.uk. **MSA**

MSA GUIDE: POSTURAL HYPOTENSION

One of the symptoms of MSA can be postural hypotension (also known as orthostatic hypotension). Blood pressure that is too low is known as hypotension. Hypotension can be a medical concern if it causes signs or symptoms such as dizziness, fainting or, in extreme cases, shock. Our Specialist Nurse, Samantha Pavey, looks at ways to manage this MSA symptom:

MSA blood pressure can sometimes drop significantly when a person changes position, eg, standing up from sitting. Gravity reduces the rate of blood return from the body's veins below the heart back to the heart, thus reducing volume and cardiac output. When pressure in the arteries and blood flow decrease beyond a certain point, the perfusion of the brain becomes critically decreased (ie, the blood supply is not sufficient) causing light-headedness, dizziness, weakness or fainting.

Blood pressure varies from person to person and is highly dependent on hormonal and autonomic nervous system response. When people are healthy, the veins below their heart quickly constrict and the heart rate increases to minimize and compensate for the effect of gravity. This happens automatically, without us being aware, by the autonomic nervous system. The system usually requires a few seconds to fully adjust and if the compensations are too slow or inadequate, as in MSA, an individual can experience reduced blood flow to the brain, resulting in dizziness and potential blackout. This can put people at an increased risk of falls.

Low blood pressure can be defined as readings lower than 90 mm Hg systolic (the top figure, when the heart is contracting) or 60 mm Hg diastolic (the lower figure, when the heart is resting) but in MSA we are interested in the drop in blood pressure when changing position. We generally look for a drop of more than 30 mm Hg when standing up from a sitting or lying position.

If you experience postural hypotension it can be helpful to keep a record of your blood pressure to take to your appointment with your specialist. Try not to get too anxious about it, once a week is usually adequate, at the same time of day. You need to record it first while you are sitting and then again after you have been standing for three minutes. The Trust has a factsheet called Living with Postural Hypotension which explains how to record your blood pressure at home. You can request a copy from the Trust's office.

CHOOSING A BLOOD PRESSURE MONITOR

There are many different kinds of blood pressure monitor, but it is easiest to use a monitor that is fully automatic. Upper-arm monitors usually provide the most accurate and consistent results rather than ones that monitor by using your wrist or finger. Make sure that the monitor you choose has been 'clinically validated' for accuracy. This means that it has gone through a series of tests to make sure it gives results that you and your doctor can trust.

Blood Pressure UK can give

you a list of clinically validated monitors www.bloodpressureuk.org.

TREATMENT OF LOW BLOOD PRESSURE

In many cases a change of lifestyle may be all that is needed.

- Increasing the amount of fluids you drink each day can significantly improve blood pressure levels. Try to aim for a minimum of 1.5 litres a day, ideally 2 litres. Try to increase your fluids in hot weather and remain in the shade.
- Adding salt to meals at the table can also help, as can sleeping with the head of the bed raised and wearing elastic stockings (contact your district nursing service for assistance).

You are most at risk of losing your balance when you have been lying down or sitting for some time, and then change your position to standing.

- Before attempting to stand, have a glass of water nearby and drink this before doing five minutes of foot exercises; rotate your ankle round and round and pump your foot up and down to increase your blood pressure. Then raise yourself up from an armchair slowly (riser recliner chairs are ideal for this) and stand with support for a few minutes before walking to allow your blood pressure to stabilise.
- If you are in bed, sit on the edge of the bed for five minutes before attempting to stand and carry out the same foot movements.

If your blood pressure doesn't improve with these measures your specialist may recommend medication to increase the blood pressure, particularly if you have symptoms that are problematic (eg, blacking out). Commonly used medications include Fludrocortisone, Midodrine and Ephedrine. Doses are very individual and should only be adjusted by your specialist.

And remember, the Trust's MSA Specialist Nurses will be happy to answer any question or concerns you have about blood pressure and its treatment. **MSA**

The Trust has a fact sheet with more information on Postural Hypotension in MSA. It can be downloaded from the website or by contacting us on: 020 7940 4666 or office@msatrust.org.uk.

OUR VOLUNTEER PROGRAMME

BUILDING A COMMUNITY PRESENCE

Since the appointment of Emma Myers as Volunteer Coordinator, work has started on the Trust's plans to build its local prescence and a model for volunteer support in each area of the UK. **Emma reports.**

The feedback from members about our plans has been extremely positive, and I've been thrilled to receive a number of enquiries from members who are interested in getting involved.

Our volunteer programme will see teams of local volunteers supporting the Trust through fundraising, developing awareness of the Trust and MSA and building local knowledge of services available to support people affected by MSA. Each team will be overseen by a regional lead volunteer who will coordinate the volunteering activities in their area.

Here's some brief information of what each volunteer role involves:

- Regional Lead Volunteers will help to support and manage a group of volunteers. The role involves instigating regular contact, reviews and network meetings to share best practice and experiences.
- Local Fundraising Volunteers will help the Trust by delivering fundraising activities in their local area. The role involves organising and promoting fundraising events, researching new fundraising opportunities and supporting any other fundraising opportunities taking place in the local community on behalf of the Trust.
- Local Awareness Volunteers will help the Trust by raising vital awareness of MSA and of the work of the Trust within their local community. The role involves attending local events that we can use to raise awareness, seeking opportunities for media coverage and case studies and gaining valuable contacts for the Trust.
- Local Knowledge Volunteers will help the Trust by raising awareness of local services available to support people with MSA. Their role involves collating information for use on the Trust's searchable database, the MSA Local Hub.

Detailed descriptions for each of these roles are available on our website if you'd like further information and, of course, please feel free to contact me at emma.myers@msatrust.org.uk.

The fantastic news is that we have now started recruiting volunteers, initially in the West Midlands and North West England, and details of the current vacancies in these areas can be found on our website. We will be recruiting in other areas too in the very near future, so please keep an eye on our website for further information or contact me if you are interested in offering your support. MSA

TRUST SUPPORT SERVICES

Emma Rushton recently joined the Trust as Support Services Officer in our growing services team. She explains her role:

My work here at the Trust will be to contribute to the services team support services provided to people with MSA, their carers, friends and family. This will involve being on the end of the team's telephone in London, responding to emails, and also working on the big picture of trying to raise awareness of MSA amongst health and care professionals - something that is key to helping people with MSA and their carers gain the best support possible.

From 9 am - 5 pm, Monday-Friday, I will be at the end of the telephone and happy to speak with you and help with any questions and queries you may have, especially concerning our information material and support groups. I also work very closely with our MSA Specialist Nurses who are part of the services team, and who handle all queries around managing MSA symptoms.

Another key part of my role is to liaise with our network of volunteer Support Group Leaders, helping the Leaders in their roles and working closely with potential new leaders on the ongoing growth of our support groups. I will also be on hand supporting at events such as the Friends and Family day in Cardiff that is fast approaching – and please let me know if you'd like more details on events like this.

We're currently looking at how to ensure our administration around support groups is as cost-effective and efficient as possible, and are hoping to eventually email all support group invitations. With this in mind, it would be a great help if you could let me have an up-to-date email address so that I can send you invitations to your closest support group, and also keep you in the loop with Trust information and events - just email me at office@msatrust.org.uk with your name and postcode.

I look forward to speaking and, hopefully, meeting some of you in the future!

Please feel free to call me on 020 7940 466 or email me at office@msatrust.org.uk. **MSA**

POPPYS

Earlier this year we went to a nearby Klondyke garden centre and bought a packet of poppy seeds being sold in support of the Trust. They came up a treat, and I took this photo of one which I think closely matches the "MSA Orange".
John Hewitt
South Yorkshire Support Group Leader

DAY IN THE LIFE OF A RESEARCHER

As well as holding a position as a Consultant Neurologist at the Salford Royal NHS Foundation Trust, Dr Chris Kobylecki is a part-time researcher in clinical and cognitive neuroscience at the University of Manchester.


Dr Chris Kobylecki

His work focuses on the cognitive impairment (memory, thinking and reasoning impairment) of MSA patients, and he and his team received a grant from the Trust in 2012 to fund new research into the condition.

Currently Dr Kobylecki devotes one day a week to research and has been working on a project focusing on comparisons of cognitive impairment in patients with MSA and Parkinson's Disease. His research aims to reveal important information which could help with future treatments for patients with MSA. Research has highlighted that cognitive impairment is a problem for MSA patients as well as patients with other conditions such as Parkinson's disease. Dr Kobylecki says, "Various studies in scientific literature exist which highlight differences between cognitive impairment in MSA and Parkinson's patients compared to control patients, but the differences are not yet fully understood."

A typical research day for Dr Kobylecki involves a number of important jobs, including meeting with patients to discuss their condition as well as asking if they would be willing to take part in his current studies. He then discuss with them issues related to the studies regarding the techniques used. His research of MSA patients involves taking MR scans and another imaging technique known as FDG PET scans, which show the levels of activity in different brain areas. These scans are taken to help highlight which regions of the brain are changing in MSA patients and possibly contributing to symptoms of cognitive impairment.

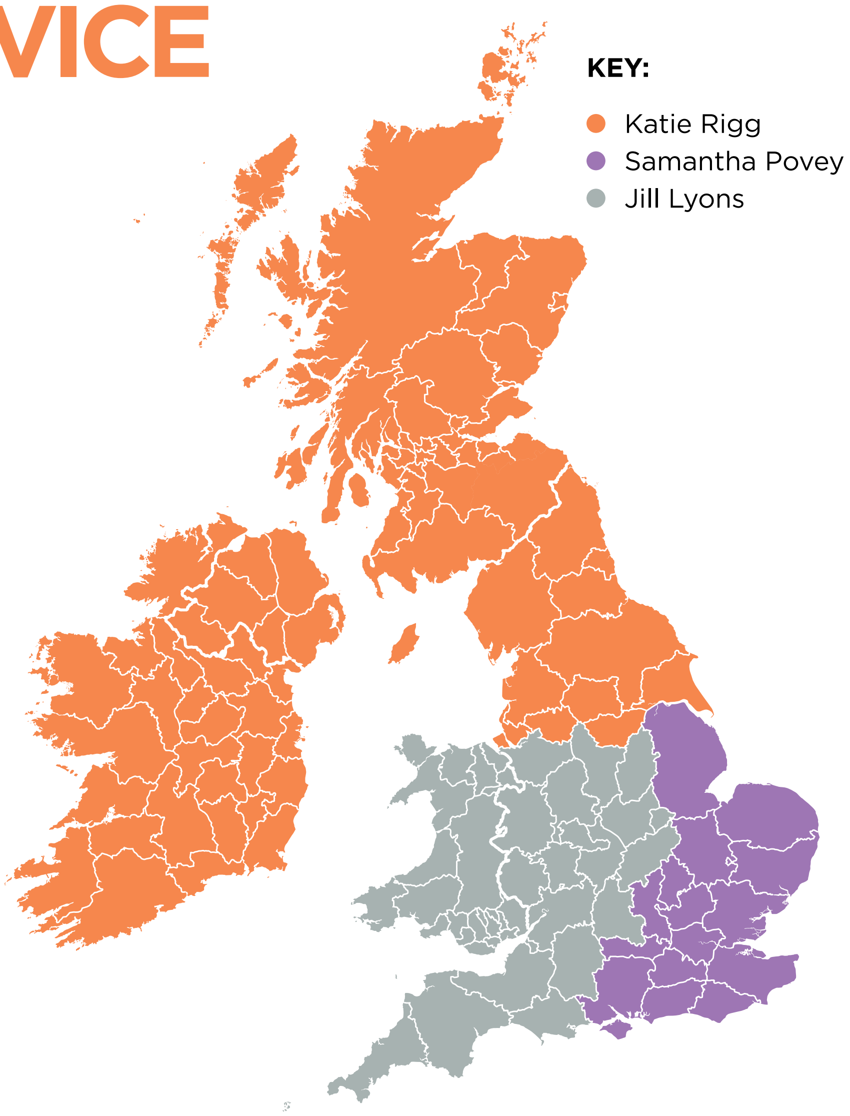
Dr Kobylecki is involved in the day-to-day supervision of patients undergoing brain scans, and it is critical that these are done in a standard manner and that patients feel at ease.

Following the scans, he and his team analyse results as well as the data they have collected on patients such as information on memory and thinking. "Analysis of the data and drawing conclusions can often be the part which takes longest!" Dr Kobylecki says. The team will then ultimately talk to patients about what the scans have revealed, and the conclusions they have come to.

Dr Kobylecki and his team play a vital role in the work to reveal important information about MSA which will hopefully provide new treatments for the future. Without work like this to better understand symptoms such as cognitive impairment, new treatments may not be found. **MSA**

THE TRUST'S SPECIALIST NURSE SERVICE

Our Specialist Nurses provide a telephone and email support service and offer advice and information about MSA from living with the illness to symptom management. They can also help to explain what further support you may need and where to find it.



TELEPHONE AND EMAIL SUPPORT

This operates 9 am - 5 pm, Monday-Friday or, if you prefer, you can email them. There is an answerphone if they're out of the office, so please feel free to leave a message. Calls are returned within 24 hours or by the next working day if you call over the weekend. Most are responded to within a few hours of your call.

Contact the Nurses by either telephone or email:

- **Katie Rigg:**
  01434 381 932
- **Samantha Pavey:**
  0203 371 0003
- **Jill Lyons:**
  01934 316 119
- **Email:**
  nurses@msatrust.org.uk.

SUPPORT GROUPS

The Specialist Nurses attend some MSA support group meetings located throughout the UK. They often give short talks or presentations and are happy to answer questions. They can also answer any concerns on a one-to-one basis at the group meetings. For more information about MSA support groups, please contact Emma Rushton at the Trust's office (020 7940 4666) or visit the website at: www.msa-trust.org.uk/living-with-msa/support-groups.

OTHER SPECIALIST NURSE SERVICES

- The Nurses attend specialist MSA clinics around the country.
- They provide education sessions to multi-disciplinary team members who are supporting someone living with MSA.
- They produce information leaflets for the Trust.
- They can liaise with Parkinson's Nurse Specialists and other health and care professionals.

WORLD **MSA** AWARENESS DAY

FRIDAY, 3 OCTOBER 2014

The lights go orange, our first video, increasing funds for vital research – the MSA Trust celebrates World MSA Awareness Day 2014. Head of Communications, Franca Tranza, reports on the many activities that marked this year's event.

BLACKPOOL TOWER TURNS ORANGE

Thanks to Nuala Herbert, the lights at Blackpool Tower were turned orange on Friday, 3 October in memory of Nuala's husband, John, who was Operations Manager at the Tower from 1988 to 1993.

Earlier this year, I received a call from Nuala, which I remember vividly.

Nuala was a woman with a mission. She was adamant that the Blackpool Tower, where John worked for several years, would play a part in marking World MSA Awareness Day by turning the lights orange. From that first call I realised that Nuala was not going to take 'no' for an answer.

I have no doubt that a big group of Nuala's friends and family were at the bottom of the Tower sporting the Trust's colours with orange T-shirts when the lights were turned on. Nuala said she wants other Towers around the world to go orange next October – the Eiffel Tower, CN Tower – I wouldn't be surprised if she makes it happen!

> Nuala said:
> "I'm always keen to do whatever I can to raise awareness about the disease and for the MSA Trust. We received such fantastic support from the charity, and having a specialist nurse to turn to helped ease our frustration and isolation. I'm also so grateful to the management of Blackpool Tower for helping me keep John's memory alive."

THE TRUST'S FIRST VIDEO

To help raise awareness about MSA we have produced our first video featuring Andrew Hulkes from Essex who was diagnosed with MSA in 2012 and David Probert from Surrey, full-time carer of his wife, Migs, who was diagnosed in 2011. Our Specialist Nurse, Katie Rigg, and the Chair of our Trustee Board, Professor Clare Fowler, also took part.

You can find the video on our website, www.msatrust.org.uk, and we'll also be promoting it through our social platforms: Facebook, Twitter and LinkedIn. We would be really interested to know what members think of the video - please let us know by emailing franca.tranza@msatrust.org.uk.

PROJECT 12.5

On Monday, 1 September we launched a special appeal

for World MSA Awareness Day asking people to donate £10 towards the Trust's vital research to find the cause and, one day, a cure for MSA.

The Trust's new three-year Research Strategy has a committed spend of a minimum of £150,000 each year. The aim of this special appeal is to help the Trust fund one month's funding - £12,500.

Anyone wishing to donate specifically to fund scientific research can do so through our dedicated Research Appeal page: www.msatrust.org.uk/get-involved/research-appeal.

SOCIAL MEDIA

Everything we do is supported by communications on our social media platforms, Twitter, Facebook and now LinkedIn. On 1 September we began a countdown to 3 October asking followers to donate towards Project 12.5.

COMMUNITY FUNDRAISING

We're working with the supermarket Asda to mark World MSA Awareness Day. Asda branches in Melksham and Wortley have agreed to fundraise for us at their stores on Friday, 3 October. Perhaps the start of an Asda World MSA awareness campaign! We're grateful for their support.

AROUND THE WORLD

World MSA Awareness Day helps us remember there is a global MSA family working together to raise awareness about the devastating impacts of this disease. And this year is no different - all over the world people affected by MSA are doing what they can to spread the word.

In Belgium, Rita Schouppe, who is part of the World MSA Day Volunteer Team, has had ambitious plans - she's been asking supporters to pledge to walk or cycle a mile or kilometre for MSA. The goal is to walk or cycle all 24,901 miles (40,075 kilometres) around the Earth at the equator's line!

Rita is also behind the 24-hour wave of light – she asked supporters to light a candle in their home at 8pm in their local time zone for one hour.

In North America, Miracles for MSA is asking supporters to showcase their photos of candles with family and friends' gatherings to mark World MSA Day on their Facebook page. Last year hundreds of photos were posted as the virtual wave of light started in Australia and travelled around the world. MSA

Why not send your photos to: franca.tranza@msatrust.org.uk.

FUNDRAISING ROUND-UP

This summer saw an array of fundraising events in support of the Trust, and local fundraisers were as busy as ever. Here are a few highlights:

Technically just before the start of British Summertime, in May, Howard Bailey from Hampshire began his 1,000 mile cycle from Land's End to John O'Groats in memory of Colin Griffin, a family friend. With the help of Colin's wife, Pam, Howard raised an incredible **£14,110**.

Having promised his father-in-law before he passed away that he would do a walk to try to raise money and awareness for the Trust, Chris Hill from West Yorkshire organised the first 'Alan Heppenstall Memorial Walk'. On a very bleak 'summer's' day the walkers, including Alan's 12 year old grandson, set off on their 32 mile journey. Between all the walkers they have donated over **£8,000**.

Michelle Linegar from Surrey and Gareth Perkins from Somerset are now officially World Record breakers, having taken part in a record attempt for the most tandem skydives at a single venue in 24 hours.

The Trust was chosen as the nominated charity for a special concert performed during Brighton Fringe Festival. British Music and the Great War was organised by Sophie Bartlette from Brighton, and raised **£317** for the Trust.

July saw a team of eight MSA runners take on the British 10k in London. The team raised almost **£2,000**. If you fancy putting on your trainers and taking part in this fun event next year, please get in touch with our fundraising team for more information.

In August the second Ride-London-Surrey 100 took place, and our five MSA cyclists smashed their team target raising over **£8,000**.

As ever, there are far too many fundraisers to mention each by name, but we are extremely grateful to each and every one of you.

A GIFT IN YOUR WILL

Gifts from Wills are a very important part of the Trust's income every year. We need to ensure that this income continues over the coming years so we can continue to provide vital care, as well as confidently plan the expansion of our services to best support the MSA community across the UK and Ireland.

With 35% of the general population saying they would consider including a gift to charity after providing for their family and friends, and only 7% doing so, there is huge potential to increase our income in this area so that we can help more people affected by MSA.

After you have provided for your own family and friends, please consider providing for people in need of future support from the Multiple System Atrophy Trust.

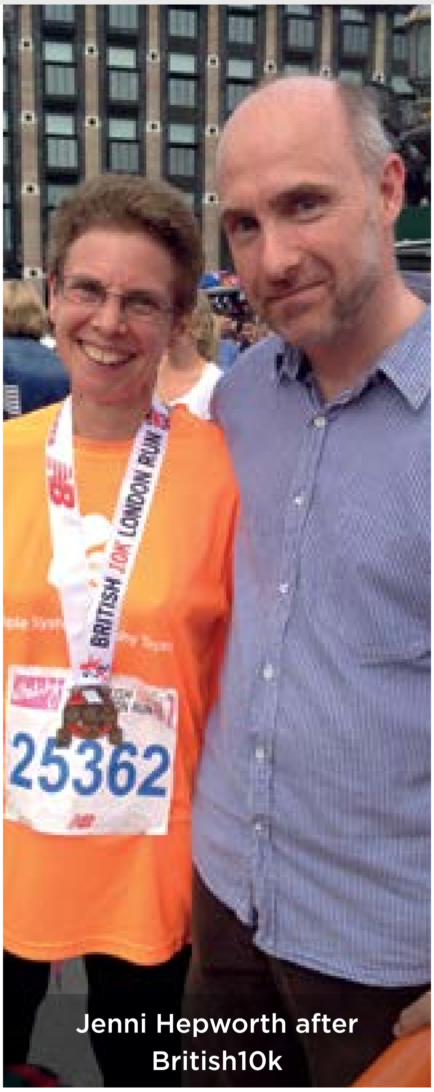
We understand that leaving a gift in your Will is an extremely private matter. However, should you wish to discuss your wishes with us, please contact Katie Heyward, Head of Fundraising, on 020 7940 4134 or email katie.heyward@msatrust.org.uk.

Thank you. MSA

Team shot - Alan Heppenstall Walk

Michael Stevenson & Alex Brown after RideLondon-Surrey

Michelle Linegar at world record tandem skydive attempt



Jenni Hepworth after British10k

Howard Bailey - Land's End to JOG - finish!

SAVE THE DATE

SERVICE OF LIGHT EVENTS 2015

Due to the overwhelming demand for tickets to our inaugral Service of Light in London this year, we are pleased to announce that we will be holding two separate Service of Light events in March 2015.

YOU MAY LIKE TO NOTE NEXT YEAR'S SERVICE OF LIGHT EVENTS IN YOUR DIARY:

- Saturday, 7 March 2015, St Ann's Church, Manchester City centre
- Saturday 21 March 2015, St Paul's Church, Covent Garden, London
- Both events will be held during the afternoon, and full details of each Service will be covered in the next issue of MSA News.

SWALLOWING DIFFICULTIES **IN MSA**

If coughing during meals is a problem, it could be a sign that your swallowing is faulty. Coughing is a normal reaction to help prevent food going into your lungs and causing infection. A Speech and Language Therapist can assess the strength of your swallow and, together with a Dietician, will advise on the best type of food for you.

If you are feeling generally unwell, or perhaps because you have something called oro-pharyngeal dysphagia, ie, difficulty with swallowing often more noticeable with fluids, it may be that your diet should be changed to a "soft diet" .

Your Speech and Language Therapist will assess you and advise on the type of diet that is required; they may also refer to a Dietician for advice. The type of diet they might suggest may include thick puree, thin puree, pre-mashed or fork mashable foods. Initially, advice may be to avoid certain foods that might cause coughing, and later advice may be to change to soft foods or pureed foods. There are also alternative ways of feeding, such as a "Peg" or feeding tube.

People with MSA can find their weight is affected if they have difficulties with swallowing, perhaps being unable to eat sufficient food to maintain weight, or unable to drink adequate fluid to maintain hydration. There are firms who supply foods suitable for an adapted diet, and these include:

www.wiltshirefarmfoods.com
www.icarecuisine.co.uk
www.kealthfoods.com

If you are experiencing difficulties with your swallowing, ask your GP to refer you to a Speech & Language Therapist. You can also contact the Trust's Nurse Specialists if you require further information, or have questions or concerns about swallowing.

KEEPING WELL

SEASONAL FLU VACCINATION

Doctors are encouraging patients in clinical risk groups to book into their GP surgery for a free annual seasonal flu vaccination.

Flu is a highly infectious disease with symptoms that come on very quickly. Colds are much less serious and usually start gradually with a stuffy or runny nose and a sore throat. A bad bout of flu can be much worse than a heavy cold.

The most common symptoms of flu are fever, chills, headache, aches and pains in the joints and muscles and extreme tiredness. Patients in clinical risk groups are up to ten times more likely to experience complications from catching flu than others.

Dr Mark Sanford-Wood, a Devon GP and spokesperson for the doctor's body, the British Medical Association, said:

> "It's really important that patients who are in the clinical risk groups take up the offer of the free flu vaccination. It's quick, easy, and safe. The effects of flu can be much more serious than people think, and vaccination is the best form of protection against the risk."

FOR MORE DETAILS, PLEASE VISIT:

- NHS Choices - www.nhs.uk/Conditions/vaccinations/Pages/flu-influenza-vaccine.aspx
- 10 myths about the flu and the flu vaccine - www.nhs.uk/Livewell/winterhealth/Pages/Flu-myths.aspx
- Keep warm, keep well www.nhs.uk/Livewell/winterhealth/Pages/KeepWarm-KeepWell.aspx

WHO IS AT INCREASED RISK FROM THE EFFECTS OF FLU?

Even if you feel healthy, you should have the free flu vaccination if you have:

- A heart problem
- A chest complaint or breathing difficulties, including bronchitis or emphysema
- Kidney disease
- Lowered immunity due to disease or treatment (such as steroid medication or cancer treatment)
- Liver disease
- Had a stroke or a transient ischaemic attack (TIA)
- Diabetes
- A neurological condition

WHO ELSE SHOULD HAVE A FLU VACCINATION?

You should have the flu vaccination if you have any condition listed left, or are:

- Pregnant
- Aged 65 years or over
- Living in a residential or nursing home
- The main carer of an older or disabled person
- A household contact of an immuno-compromised person
- A health or social care worker

WELCOME TO OUR NEW CORORATE PARTNER

Mask-arade was founded in 2008 by three directors, Ray Duffy, Chris O'Nyan and Dean Walton, who shot to fame after appearing on BBC TV's Dragons' Den with their original idea for a celebrity and personalised mask company.

Ray Duffy has become passionate about raising awareness about MSA since his father-in-law was diagnosed with the disease. As part of his commitment to raising awareness and funds for the Trust, for the next year every personalised mask that Mask-arade produces will feature the Trust's logo and a unique text-to-donate code.

For more information about Mask-arade and their products, which include celebrity masks, pet masks, masks for special events such as hen nights and much more, please visit their website www.mask-arade.com.

In Memory

Delia Regan
Dawne Baker
David Cottrell
Maureen Dutton
Chris Purkis
Robin Edgley
Peter Freeman
Richard Griggs
Steve Hammond
Derek Angus
Pat Hoolahan
John Mawer
Yvonne Willott
Gordon Poole
Derek Bilsdon
Lorraine Smith
Doris Stow
Jim Taylor
Grace Voyce
Adrienne Wilmot
Christine Harvey-May
Geoff Aitken
Susan Gibson
Betty Betts
Ken Etchells
Harry Pougher
Janet Ingamells
Edward Thomas Sales
Cliff Fuke

MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people who understand life with MSA. Please contact the Trust's office on 020 7940 4666 or email office@msatrust.org.uk for more details.

GROUP	VENUE	DATE & TIME
Cornwall	Echo Centre, Barras Pl, Liskeard, Cornwall PL14 6AY	Mon, 6 Oct - 1.00pm
Greater Manchester	St. Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton, BL1 5TE	Tue, 9 Oct - 1.30pm
West Sussex	Field Place - Pavilion Room, The Boulevard, Worthing BN13 1NP	Tue, 30 Sept - 2.00pm
Dorset	Trinity Methodist Church Hall, Southbourne Road, Bournemouth BH6 5AQ	Mon, 13 Oct - 11.00am
East Midlands	Holme Pierrepont Hall, Holme Pierrepont NH12 2LD	Wed, 15 Oct - 2.00pm
Kent	Room B028, University of Greenwich, Chatham Maritime ME4 4TB	TBC
Northern Ireland - Enniskillen	Arc Healthy Living Centre, 116-122 Sally Wood, Irvinestown, Fermanagh BT94 1HQ	Tue, 21 Oct - 12.00pm
Northern Ireland - Belfast	Grosvenor House, Main Room, 3rd Floor, 5 Glengall Street, Belfast, BT12 5AD	Wed, 22 Oct - 2.00pm
Republic of Ireland - Dublin	City West Hotel, Dublin	Thur, 23 Oct - 2.30pm
Wales - Family & Friends Day	Future Inn Hotel, Cardiff (see website or contact us for more details)	Thur, 23 Oct - 10.00am
Republic of Ireland - Cork	Knocknaheeny Youth Centre, Holyhill Road, Cork	Fri, 24 Oct - 1.30pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6 1JQ	Mon, 27 Oct - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 29 Oct - 2.00pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 7 Nov - 2.00pm
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 12 Nov - 1.30pm
Gloucestershire	Whitminster Village Hall, School Lane Gloucester GL2 7NT	Wed, 13 Nov - 1.30pm
Belfast - Lord Mayor	Lord Mayor's Parlour, City Hall, Donegall Square, Belfast, BT1 5GS	Fri, 14 Nov - 11.00am
Northumberland	TBC	Wed, 26 Nov - TBC
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 1 Dec - 1.30pm
Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 10 Dec - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 11 Dec - 2.00pm

If you are interested in becoming a Support Group Leader, please contact Emma Rushton at the Trust for more details on 020 7940 466 or by email at office@msatrust.org.uk.

CELEBRATE WITH THE TRUST THIS CHRISTMAS

We are delighted to launch this year's Christmas cards to raise both funds and awareness of MSA.

Our three designs are 137mm x 137mm and each have a greeting inside reading: ***With every good wish for Christmas and the 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.

Thank you for your support!

Pk(s)	1	2	3	4	5	6	7	8	9	10
COST incl. P&P	£4.87	£8.87	£12.87	£16.87	£22.50	£26.50	£30.50	£34.50	£38.50	£42.50

MULTIPLE SYSTEM ATROPHY TRUST CHRISTMAS CARD ORDER FORM

Name:..

Address:..

Postcode:.. Telephone:...

Three Kings (Qty):.. Playing in Snow (Qty):...

Christmas Village (Qty):.. Total payment enclosed £..