

# M S A

NEWS



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**RESEARCH ADVANCES**  
offer new hope for future MSA  
drug developments

**MSA**  
MAKES NATIONAL  
MEDIA DEBUT!

**TOP TIPS...**  
TO HELP YOU GET A GOOD NIGHT'S SLEEP



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

The Trust is financed entirely by voluntary donations.

Registered Charity Number 1137652.  
Company Number 7302036.

**MEMBERSHIP AT SEPTEMBER 2012**

Current MSA members	949
Carers, relatives & friends	1,309
Healthcare professionals	1,644
<b>Total</b>	<b>3,902</b>
New MSA Members since 1 June 2012	67

# MSA NEWS CONTENTS

## Multiple System Atrophy Trust

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



### UK RARE DISEASE PLAN

*Getting closer to launch day*

03

### NEWS ROUND-UP

04

### DIRECTORY OF MSA CLINICS

*Helping you to find your nearest specialist clinic*

05

### DRUG DEVELOPMENTS IN MSA

*A review of recent advances*

06

### RESEARCH UPDATE

*News from Trust-funded projects*

08

### RECIPES

*Easy to digest meals - Beef casserole*

09

### FUNDRAISING

*Members in action!*

10

### SUPPORT GROUP DIRECTORY

*Dates & venues; Behind the scenes at the Kent group*

12

### CARERS CORNER

*Sleep - it's the quality that matters!*

14

### IN MEMORY

17

### RAISING THE PROFILE OF MSA

*Spreading the word to improve understanding*

18

### MSA SHOP

*Trust Christmas cards*

20

# UK RARE DISEASE PLAN

The Trust is a member of the national alliance for people affected by rare diseases, Rare Disease UK (RDUK), which has recently been in discussions with the Department of Health about progress in developing the final UK rare disease plan.

Around 350 responses were submitted to a public consultation, and the UK's four health departments are now currently working on their summary of responses. These will be publicly available towards the end of the year. It is hoped that the rare disease plan will be launched early next year, although given its broad scope and the need to get agreement from four different health departments, this may be subject to delay. RDUK are primed to campaign for the launch of the plan should this not happen in 2012.

As well as continuing to influence NHS policy decisions, RDUK's plans for 2013 include contributing to the knowledge base around rare diseases. As part of this, it will be conducting a review into how centres of excellence for rare diseases would work in the context of the UK's health systems.

RDUK will also be launching a report on the value of care coordinators to patients and the health service, and need your help.

## REPORT ON CARE COORDINATORS

This report will investigate the benefits care coordinators bring both to patients and to the NHS, and will help RDUK in its work to ensure all patients affected by multi-system rare diseases have a named care coordinator. RDUK has been campaigning for this to be part of the forthcoming national plan for rare diseases.

The exact role that a care coordinator plays in a person's care depends on the nature of the condition. It can also depend on whether the role is provided by the NHS or by patient organisations. Care coordinators generally ensure that a patient can access the

services they need, when they need them. They also play an important role in providing information and support to patients and families about their condition.

RDUK are looking to speak to people about their experiences in this area. This includes patients or their carers who currently benefit from a care coordinator, patients who previously had a care coordinator but the post was discontinued due to lack of funding, people who work as care coordinators and clinicians who can speak about the value of care coordinators.

If you are willing to speak to RDUK about this topic, have any information that might be useful to this work or would like further information, please contact Samantha Reeve, Policy Research Officer at [samantha@raredisease.org.uk](mailto:samantha@raredisease.org.uk) or by calling her on 020 7704 3141.



# NEWS ROUND-UP

## GIFT AID

Gift Aid is an extremely important source of income for the Trust. If you have ever made a donation to us and you are a UK taxpayer, by completing a short Gift Aid form we can claim an additional 25p in every £1 you have donated. You only need to fill out the form once, meaning this is an easy way for your donation to go that little bit further and make even more of a difference. A copy of our Gift Aid form is available on our website or call the Trust's office and we'll pop a copy of the form in the post to you. Last year, we claimed an additional £12,000 in Gift Aid, enabling us to provide further support to all those affected by MSA.

## A CALL TO ALL HEALTH AND SOCIAL CARE PROFESSIONALS

The Trust is conducting its first health and social care professionals' survey to provide a greater understanding of how the Trust could be supporting professionals treating patients with MSA.

The survey should take around ten minutes to complete, and can be accessed through the Healthcare Professionals section of the Trust's website: [www.msatrust.org.uk](http://www.msatrust.org.uk).

It's important to gather responses from health and social care professionals who have not yet encountered MSA, so please encourage work colleagues and contacts to complete the survey too.

Findings will be available on the Trust's website later in the year.

## MSA AWARENESS DAY

This year's World MSA Awareness Day took place on Wednesday, 3 October.

Across the world people affected by MSA lit candles at 8pm for one hour, creating a virtual 24-hour wave of light across the globe as it moved from time zone to time zone.

Many people also walked one mile for MSA, with the aim that everyone affected by multiple system atrophy collectively walked around the earth (ie, 24,901 miles at the equator).

## NEW HEAD OF FUNDRAISING

We're delighted to report that we have successfully appointed into our newly created Head of Fundraising position, established to help secure much needed funds for our support services and research projects.



Katie Heyward joined us in August, and brings with her extensive experience. She says, "There is no doubt this is an exciting time for the Trust and I'm looking forward to securing essential funds to enable the charity to successfully carry out its work, now and in the future."

Katie can be contacted at the Trust's office on 020 7940 4666 or by emailing her at [katie.heyward@msatrust.org.uk](mailto:katie.heyward@msatrust.org.uk).

# DIRECTORY OF MSA CLINICS

Although it is usually the case in the UK for people with MSA to be seen in general neurology clinics, a specialised MSA clinic can provide more in-depth care including diagnosis, symptom management and on-going support for the person with MSA as well as their families.

This directory has been compiled to help you find an MSA clinic if you would like your GP to refer you. If you have any queries, please contact Lyn Shaw at the Trust on 020 7940 4666 or email [office@msatrust.org.uk](mailto:office@msatrust.org.uk).

## **Dr Thomas Bak**

7 George Square, Edinburgh  
EH8 9JZ  
0131 650 3441

## **Professor David Burn**

Department of Neurology  
Queen Victoria Road  
Royal Victoria Infirmary  
Newcastle Upon Tyne, NE1 4LP  
0191 282 3697

## **Dr Jonathan Frankel and Dr Alice Manson**

Southampton General Hospital  
(and Isle of Wight)  
Tremona Road  
Southampton, SO16 6YD  
023 8077 7222

## **Dr Alex Gerhard**

Salford Royal NHS Foundation  
Trust  
Stott Lane, Salford, M6 8HD  
0161 206 4100

## **Dr Marios Hadjivassiliou**

Royal Hallamshire Hospital  
Glossop Road  
Sheffield, S10 2JF  
0114 271 1900

## **Professor Henry Houlden**

National Hospital for Neurology  
and Neurosurgery  
Queen Square  
London, WC1N 3BG  
020 7837 3611

## **Dr Michelle Hu**

John Radcliffe Hospital  
Headley Way, Oxford, OX3 9DU  
01865 741166

## **Professor Nigel Leigh**

Hurstwood Park Neurological  
Centre  
Lewes Road, Haywards Heath  
West Sussex, RH16 4EX  
01273 696955 (Sharon Elder -  
same secretary as for Dr Saha)

## **Fiona Murphy PNS**

Mount Gould Hospital  
Mount Gould, Plymouth  
Devon, PL4 7QD  
01752 268011

## **Dr Huw Morris**

Royal Gwent Hospital  
Newport, Gwent, NP20 4UB  
01633 234829

## **Dr James Rowe**

Disorders of Movement and  
Cognition Clinic  
Cambridge University  
Department of Clinical  
Neurosciences  
Herchel-Smith Building  
Forvie Site, Robinson Way  
Cambridge, CB2 0SZ  
01223 760696

## **Dr Anirban (Romi) Saha**

Hove Poly Clinic  
Nevill Avenue  
Hove, East Sussex, BN3 7HY  
01273 696955 (Secretary Sharon  
Elder, Royal Sussex County  
Hospital)

## **Professor Kevin Talbot**

Nuffield Department of Clinical  
Neurosciences  
West Wing  
John Radcliffe Hospital  
Oxford, OX3 9DU  
01865 231893

## **Professor Zcyicek**

Derriford Hospital  
Derriford Road, Crownhill  
Plymouth, Devon, PL6 8DH  
01752 202082

# THE PRESENT & FUTURE OF DRUG DEVELOPMENT IN **MSA**

Recent advances have generated new hope for future drug development in MSA. Groups of researchers in Europe and the US have developed rating scales that can be used to track progression of MSA, and there are now a number of new animal models that can be used as a test bed for new therapies. There has been a great deal of activity in the development of treatments for MSA. Dr Wassilios Meissner reviews recent progress.

Although there are lots of therapies that can help patients with MSA, there are currently no treatments that can stop the progression of the disease. The development of these “disease-modifying” therapies is a key priority for research.

In order to evaluate the effectiveness of any new therapy, a comparison with a dummy treatment (placebo) needs to be made. Several placebo-controlled studies assessing the efficacy of growth hormone, Riluzole and Minocycline, have not shown benefit for MSA patients. Despite the



negative results, these studies are very encouraging because they show that as many as 400 MSA patients can be enrolled

in a treatment trial — which is remarkable for a rare disorder — underlining the feasibility of conducting large clinical trials

in the future.

Brain inflammation in response to the disease process seems to be an important part of MSA. In the Minocycline trial, there was a suppression of the activation of cells that are crucial in the development of brain inflammation (microglia). Minocycline or other related compounds that reduce microglial activation, may be effective in earlier disease stages where microglial activation more clearly contributes to disease progression.

The growth hormone trial showed a clear but not significant difference in progression of symptoms between the treatment group and placebo group. It may be that the study was underpowered – that is a larger number of patients would have shown a significant difference between active and dummy treatment. With this in mind, a new larger trial may be successful. At the moment there is no funding for a growth hormone study, but it may be that a collaboration between drug companies, charities and private donors could be effective in developing this approach.

Rasagiline, a licensed treatment for Parkinson's disease, and Fluoxetine, an antidepressant, both reduce neuronal loss in animal models of MSA, Rasagiline and Fluoxetine have recently been assessed in two large clinical trials. The Rasagiline study, which involved a number of UK patients, has unfortunately not shown a benefit for MSA patients.

Transplantation of bone

marrow (mesenchymal) stem cells, an established and effective treatment for many haematological disorders, has been tested in a small clinical pilot study in MSA patients. Symptom severity remained unchanged in patients who were treated with stem cells, while those receiving placebo showed worsening over time. However, the groups of patients who received stem cells and placebo were not well matched, which makes it difficult to be certain about the treatment effect. The positive results of a better-designed study were published in April 2012. Similar to the first study, the effect of bone marrow stem cells were only tested in a small number of patients. A large, international multicentre trial will probably be needed before we can clearly know whether stem cells are an effective treatment for MSA.

Abnormal deposits of a brain protein called alpha-synuclein are a hallmark feature of MSA. In animal models, Rifampicin, a drug that has been used for decades as a treatment for tuberculosis, inhibits the formation of alpha-synuclein and slows disease progression. A clinical trial in the US has enrolled 100 MSA patients into a Rifampicin trial. These patients are now being followed for one year.

There are a number of other experimental therapies in development which will probably take several years to reach clinical trials. These include vaccine treatments in which synuclein deposits are cleared

by the body's own immune system following vaccination. Another promising line of research is growth factor treatment in which chemicals are administered which help to support and promote healthy nerve cells.

It is very encouraging that so many researchers are now working on potential new treatments for MSA. Recent progress has allowed substantial improvement in the development of new ideas for drugs, the clinical environment and methods in clinical trials paving the way to a growing number of treatment trials to come. This progress has generated new hope that we will find treatments that will slow down or stop disease progression in MSA. **MSA**

Reproduced with the permission of Dr Wassilios Meissner, Department of Neurology at the French Reference Centre for MSA, University Hospital Bordeaux and Institute of Neurodegenerative Diseases, University Bordeaux, France.

The Trust has published a research strategy which provides details of its research priorities. Copies are available on our website, [www.msatrust.org.uk](http://www.msatrust.org.uk), or by calling the office on 020 7940 4666.

# TRUST FUNDED RESEARCH

Dr Christopher Kobylecki at the University of Manchester is undertaking a study comparing the cognitive problems in patients with MSA and Parkinson's disease to those of volunteers without either conditions, as well as performing imaging studies to identify which areas of the brain might be responsible for these problems. He hopes the team's research will lead to a better understanding of cognitive symptoms in people with MSA and related conditions, and that this will improve management and treatment.

Back in London, Dr Janice Holton at the Queen Square Brain Bank is applying state-of-the-art morphological and genetic techniques to the Bank's collection of well documented MSA cases. Her team is testing whether or not neuro-inflammation is an early feature of the disease, and will be looking to see if it is possible to influence the neuro-inflammatory response as a treatment for MSA.

**The Trust will be announcing a new grant round early in the New Year. MSA**

## MAKING A REGULAR DONATION

If you would like to make a regular donation to support our work, please complete the form below and send to the Trust's office. If you are a UK taxpayer we can increase the value of your donation by 25% by reclaiming the tax as Gift Aid. Regardless of size, all donations help us to maintain and improve our services and fund research.

Name:.....

Address:.....

..... Postcode:.....

Signed:..... Date:.....

I would like to make a regular donation. Please send me a form.

I would like to make a donation of £..... and enclose a cheque.

I am a UK taxpayer and wish all gifts of money that I have made in the past six years and all future gifts of money that I make from the date of this declaration, until I notify you otherwise, to be treated as Gift Aid donations.

Please fill in this form and return it to us enclosing a cheque made payable to Multiple System Atrophy Trust, and send to: MSA Trust, Southbank House, Black Prince Road, London SE1 7SJ.



# Easy to digest MEALS

.....  
The second in our series of recipes comes to us from Judith Moir from Aberdeen  
.....

## EASY BEEF CASSEROLE:

*Serves 2*

**CAN EASILY BE DOUBLED TO MAKE A DELICIOUS FAMILY MEAL.**

200g beef - stewing steak or beef shin	2 large carrots
1 onion, chopped	1 clove garlic, crushed
1 tbsp cornflour	Chicken stock cube or similar

Preheat oven to 150°C (275°F, Gas Mark 2).

Place the beef in an ovenproof dish and add peeled, whole carrots and the onion and garlic. Top with water until just covered.

Cover the top of the dish tightly with foil or the lid of the casserole dish, and place in a low oven for four hours. After a few hours your house will be filled with an appetising aroma!

Strain the water (which your oven has now transformed into stock) into a pan. If there is too much liquid, boil to reduce it. Mix cornflour with a little water and whisk gradually into the 'gravy' until it begins to thicken. Add a stock cube or similar and salt and pepper to taste.



Alternatively, gravy granules could also be used at this stage.

You can now chop the carrots before sliding the meat and carrots back into your casserole dish. Taste it and check for seasoning.

Serve with mashed potato and a green vegetable. You can buy excellent frozen mashed potato pieces which just need to be microwaved if, like me, you don't like standing at the sink peeling potatoes!

This dish works equally well if made with pieces of chicken or lamb. **MSA**

People with MSA will have different needs, and not all recipes featured in *MSA News* will be suitable for everybody, so please first check with your speech therapist and dietician. If you would like general information on food, diet or swallowing, please contact the Trust's office on 020 7940 4666.

# FUNDRAISING MEMBERS IN ACTION

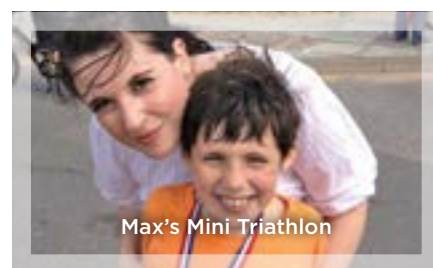
## Tony Stephens memorial golf day

On the 23rd May, 90 golfers descended on Taunton and Pickering Golf Club to take part in the Tony Stephens Memorial Golf Day. Tony, who was from Taunton, was a former Chief Inspector in the Avon and Somerset Constabulary. Friends and family took part in a three-ball Bowmaker competition and, along with an auction, raised over £4,000 for the Trust.



## Nine year old Max's mini triathlon

Max Wilson from Liverpool took part in the Sefton Triathlon in aid of his granddad, Findlay Wilson, who has MSA. Max's fantastic feat involved him swimming 150 metres, cycling 5km and running 2.5 km. Thanks to his efforts, Max raised £225 for the Trust.



## 100km around moonlit London

This June an intrepid team of cyclists took part in the 100km moonlit London Nightrider, passing the City's iconic landmarks such as Tower Bridge, the Houses of Parliament and London Zoo. Our magnificent eight were made up of: Jim Bratt, Kathryn Gilbert, Kevin DeJesus, Robert Croydon and the Trust's own Information & Support Manager, Neil Hunter, Trustee Darcy Hare, her brother, Lewis and the Trust's Executive Director, Nickie Roberts. The team raised over £2,850.



## Bridget and Norman's wedding

Norfolk-based couple Bridget Hallett and Norman Kingston tied the knot in the coffee shop of Banham Zoo. Instead of receiving gifts, the couple kindly asked their guests to make donations to the Trust. Norman has MSA, but for many years ran his own garage and still retains his enthusiasm for cars. The couple first met when Bridget was a teenager but lost touch. Then, 17 years ago, Bridget visited Norman's garage...and the rest is history! The wedding saw a total of over £550 raised for the Trust.



## Aggmore to Bruges

The Trust's Honorary Treasurer, Chris Marsden and several colleagues from his company Aggmore, cycled from London to Bruges to fundraise for the Trust. Starting out from Purley Leisure Centre in South East London, day one saw the team cycle 85 miles to Dover to catch the ferry to Calais. On day two they were back in the saddle to cycle a further 77 miles from Calais to Bruges. Although the roads were mainly flat, a strong headwind confronted the team throughout the entire day. However, when they finally arrived in Bruges they were greeted by the lovely sight of many bottles of champagne! In total the team raised over £10,500.



## Walking for Moira

Jackie Satchell, from Eastbourne, and several members of her family took part in a 10 mile walk organised by Jackie in memory of her mum, Moira. The walk began at Polegate Railway Station and went through areas that Jackie's mother knew extremely well, before finishing at the café at Holywell. Thanks to their fundraising efforts, a total of £1,595 was raised for the Trust.



## The West Highland Way

David McIntyre and his son Steven, both from West Myreton, walked the West Highland Way to raise funds for the Trust. Their cousin Sam Crawford has MSA, but this hasn't prevented her from spearheading a fantastic ongoing fundraising campaign among her relations and friends. Thanks to David and Steven's efforts, a total of £380 was raised.



## School Fundraising

Year six pupils from Trull School, Taunton in Somerset raised £297 for the Trust by taking part in a £4 challenge. Each pupil was lent £4 and asked to make as much money as possible from this amount; some sold plants and hair accessories, while others scored goals or charged pupils to throw water at their teachers in the stocks!

The children of Christ the King Catholic Primary School in Llanishen, Cardiff held a non-uniform day to raise a total of £126 for the Trust.

If you'd like more information about how to set up your own fundraising event or to take part in one of the Trust's challenges, please contact Mike Coffey at [mike.coffey@msatrust.org.uk](mailto:mike.coffey@msatrust.org.uk) or call him on 020 7940 4666.

# MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people who understand life with MSA. Please contact the group leader or speak to Lyn Shaw at the Trust's office on 020 7940 4666 for more details.

REGION	GROUP LEADER / CO-ORDINATORS	EMAIL	PHONE	NEXT MEETING IN 2012	VENUE
Cornwall	Jane Handy Jan Pearce	<a href="mailto:moonbeams@ymail.com">moonbeams@ymail.com</a>	01726 74792 01726 861361	TBC	TBC
Cumbria	Trust Office	<a href="mailto:office@msatrust.org.uk">office@msatrust.org.uk</a>	01434 381 932	Mon, 5th Nov 1.30 – 3.30pm	Eden Valley Hospice, Durdar Road, Carlisle, CA2 4SD
Derbyshire	Karen White Kulwant Sehmbi	<a href="mailto:karen@karenwhite7.wanadoo.co.uk">karen@karenwhite7.wanadoo.co.uk</a>	01283 735 847	TBC	Doveside Social Club, Hatton, DE65 5DT
Devon	Dennis Westrip	<a href="mailto:denniswestrip@btinternet.com">denniswestrip@btinternet.com</a>	01271 378 273	Fri, 2nd Nov 2.00 – 4.00pm	Baptist Church, High Street, Cullompton, Devon, EX15 1AA
East Midlands	Elizabeth Brackenbury	<a href="mailto:holmepierrepoint@aol.com">holmepierrepoint@aol.com</a>	01159 333 083	Wed, 10th Oct 2.00 – 4.00pm	Holme Pierrepont Hall, Holme Pierrepont, NG12 2LD
Essex	Lady Laurelie Laurie & Sir Bay Laurie	<a href="mailto:Baylaurie331@btinternet.com">Baylaurie331@btinternet.com</a>	01206 210 410	Mon, 29th Oct 12.30 – 4.00pm	Great Tey Village Hall, Great Tey, Essex, CO6 1JQ
Fife	Kim Carr	<a href="mailto:office@msatrust.org.uk">office@msatrust.org.uk</a>	020 7940 4666	TBC	Burnside Hall, Balmullo, KY16 0AW
Inverurie	Gill Campbell	<a href="mailto:office@msatrust.org.uk">office@msatrust.org.uk</a>	020 7940 4666	TBC	St Mary's Church, Inverurie AB51 3NW
Kent	Linda Nicolaides	<a href="mailto:marlin.michris@virgin.net">marlin.michris@virgin.net</a>	020 7940 4666	Thur, 1st Nov 2.00 – 4.00pm	Rm B028, University of Greenwich ME4 4TB
Lincolnshire	Katie Rigg	<a href="mailto:office@msatrust.org.uk">office@msatrust.org.uk</a>	020 7940 4666	Thur, 11th Oct 1.30 – 3.30pm	Alvingham Village Hall, Yarburgh Road, LN11 0QG
London (North)	Penny Stokes	<a href="mailto:pennystokes@hotmail.co.uk">pennystokes@hotmail.co.uk</a>	020 7940 4666	Mon, 22nd Oct 10.45 am for 11.00am start	Southgate Hockey Centre, Snakes Lane, Oakwood, London EN4 0PS
Northern Ireland	Rosemary Arbuthnott	<a href="mailto:roseyart@gmail.com">roseyart@gmail.com</a>	028 377 88386	TBC	TBC
Northumberland	Aileen Tuff	<a href="mailto:aileenlee6@hotmail.com">aileenlee6@hotmail.com</a>	020 7940 4666	Wed, 24th Oct 1.30 – 3.30pm	Blyth Library, Bridge Street, Blyth, NE24 2DJ
Oxfordshire	Sue Parnell	<a href="mailto:Sueparn@aol.com">Sueparn@aol.com</a>	020 7940 4666	TBC	Girl Guide Hall, Southern Road, Thame OX9 2EE
Shropshire	Brian Hopkins	<a href="mailto:office@msatrust.org.uk">office@msatrust.org.uk</a>	020 7940 4666	Mon, 3rd Dec 1.30 – 3.30pm	The Lantern, Meadow Farm Drive, Shrewsbury, SY1 4NG
Southern Ireland	George Hunter	<a href="mailto:george@georgehunter.biz">george@georgehunter.biz</a>	00353 872 525252	TBC	TBC
Southport	Jo Hans	<a href="mailto:hansjj@talktalk.net">hansjj@talktalk.net</a>	01253 821 693	Thur, 29th Nov 2.00 – 4.00pm	St James Church Hall, Lulworth Road, Birkdale, PR8 2BQ
Surrey	Peter Turvey	<a href="mailto:peterurvey@waitrose.com">peterurvey@waitrose.com</a>	01483 827 395	Thur, 29th Nov 1.00 for 2pm start	Shalford Village Hall, Kings Road, Shalford, Guildford, GU4 8JU
Warrington	Linda Moss	<a href="mailto:linda.moss@warrington-pct.nhs.uk">linda.moss@warrington-pct.nhs.uk</a>	0151 2826125	Fri, 30th Nov 2.00 – 4.00pm	Fairfield & Howley Neighbourhood Project, Fairfield Street WWA1 3AJ
West Midlands	Vanisha Rana	<a href="mailto:vanisha_chauhan1985@hotmail.com">vanisha_chauhan1985@hotmail.com</a>	020 7940 4666	TBC	Moxley People's Centre Charity, 3 Queen St, WS10 8TA



West Sussex	Gwen Yates Amanda Woodhall	<a href="mailto:gyates1602@aol.com">gyates1602@aol.com</a> <a href="mailto:amandashort82@hotmail.com">amandashort82@hotmail.com</a>	020 7940 4666	TBC	Field Place, The Boulevard, Worthing, BN13 1NP
Yorkshire (East)	Katie Rigg	<a href="mailto:office@msatrust.org.uk">office@msatrust.org.uk</a>	020 7940 4666	Wed, 31st Oct 1.30 - 3.30pm	Etton Village Hall, 37 Main Street, Beverley, HU17 7PG
Yorkshire (North)	Katie Rigg	<a href="mailto:office@msatrust.org.uk">office@msatrust.org.uk</a>	020 7940 4666	Tue, 9th Oct 1.30 - 3.30pm	Oswaldkirk Community Hall North Yorkshire
Yorkshire (West)	Katie Rigg	<a href="mailto:office@msatrust.org.uk">office@msatrust.org.uk</a>	020 7940 4666	Wed, 21st Nov 1.30 - 3.30pm	Community Centre, Leeds Road, Howden Clough, Birstall WF17 0HY

Groups shown as 'TBC' are still running but the date of the next meeting has not been confirmed.

## BEHIND *the* SCENES

Working tirelessly behind the scenes of all the Trust's support groups are a network of volunteer leaders who organise meetings across the UK. Our group leader in Kent, Linda Nicolaides, describes her meetings:

The organisation of our support group meeting starts two months before the event. A date is chosen and a room is booked on or close to that date, and I then let Lyn Shaw at the Trust's office know and she prepares paperwork and informs Trust members. We have a core group which is growing with a new member or two, plus their carer(s), arriving each meeting.

Once this is done, I invite a local medical person who is working with MSA on a daily basis to come along to share their experiences with the group. In the past we have been honoured with the pres-

ence of Laura Daniels, speech therapist, Dr David Oliver, consultant in palliative care at the Wisdom Hospice in Rochester and, of course, Samantha Pavey, one of the Trust's treasured specialist MSA nurses. With this done I can relax until the day of the meeting.

The day of the meeting is always one to look forward to; meeting friends, new and old, to see how they are meeting the challenges that life has thrown at them since the previous meeting. Folk arrive to the welcome of a traditional cup of tea or coffee, or other refreshments. We spend a little time renewing acquaintances

and chatting before the MSA specialist takes the floor. A brief overview of their specific area is presented, followed by a question and answer session.

It's amazing how quickly the time passes swapping tips on different medication (to be verified by their own doctors of course) or how specific symptoms are managed, until we have to end the meeting. Once all the members have started their journey, back to the meeting room for....the washing up! And thoughts of an afternoon spent sharing ways to combat our lives living with MSA. **MSA**

# CARERS CORNER

## SLEEPING WELL

Sleep is something that's supposed to come naturally to us, yet it can still be difficult to achieve. There are many reasons why people don't find it easy to get a good night's sleep and caring for somebody can be one, so it's important to help yourself get a more restful night. The second part in our Carers Corner series looks at how to get a good night's sleep.



## HOW MUCH SLEEP DO I NEED?

Different people need different amounts of sleep depending on what is happening in their lives. It's the quality of sleep you're getting that matters most. Adults and older adults generally need about eight hours sleep. A few nights of poor sleep isn't harmful, but over longer periods of time this can have an impact on you physically and mentally, reducing energy, concentration, mood and your general ability to function.

Getting a good night's sleep will sometimes be out of your control, but there are ways of improving your sleep environment that will help you to relax and feel more comfortable.

## MAKE YOUR ROOM SLEEP FRIENDLY

Making small adjustments to your surroundings will help to improve the quality of your sleep.

- Use blackout blinds to make your bedroom dark and take away all distractions such as TVs and/or computers.
- If you've had your mattress for a long time, it might be worth investing in a new one to help make your bed more comfortable.
- Adjust the temperature in your room so you don't feel too hot or too cold.

## GET INTO A ROUTINE

Establishing a routine and giving the person you're caring for clear cues that it is time to rest, will help both of you sleep better.

- Try to go to bed and get up at the same times each day, even at the weekend.
- Don't nap during the day (unless it's practically impossible for you to get a full night's sleep – then it's a good idea).
- Make time to unwind before you go to bed. Have a warm bath or read a few chapters of your book.

## CARING THROUGH THE NIGHT

Getting a good night's sleep will be out of your control if you're caring for someone who needs medication or other help through the night. If this is the case, try and compensate with a nap during the day.

If, however, you're kept awake because you're worried about the person you're caring for, then it might be a good idea to invest in equipment that will let you know if there's a problem (eg, a monitor). Your local council may offer telecare and telehealthcare packages specifically designed to monitor disabled and older people, and give family members peace of mind.

It might also be helpful to talk to the GP or specialist of the person you're caring for to see if anything can be done about their sleeping habits which could help you both. You can also call the Trust's office on 020 7940 4666.

## LOOK AFTER YOURSELF MANAGE YOUR STRESS

If you're stressed then sleep is often the first thing to suf-

fer. It can turn into a vicious cycle where you get even more stressed about the fact that you can't sleep.

- If you're kept awake because you're worried about the person you're caring for, then it might be a good idea to invest in a monitor so you will know if there's a problem.
- Keep a notepad by your bed and write down your worries or the tasks you need to do the next day. This will help you to put them out of your mind until the morning.
- If you're feeling anxious, get up and do something else for 20 minutes like reading a book or watching TV. Try to get back to sleep later.

## EAT AND DRINK WELL

What you choose to eat and drink, and when, affects your energy levels. Your sleep will suffer if you eat and drink the wrong things before you go to bed.

- Don't drink too much caffeine through the day or in the evening.
- Cut down on alcohol and try not to drink it before bed. You might feel like it helps you to relax, but it could end up waking you up in the middle of the night.
- Eating sugary foods or a heavy meal just before bed will make it harder to sleep, so try having your meal earlier in the day.
- Feeling hungry can also stop you getting to sleep at night, so have a light snack before you go to bed such as cereal and milk or crackers.

## MOVE MORE

If you're active in the day then you'll sleep better at night. Exercise releases chemicals in your body which promote more restful sleep.

- Aim for 30 minutes of physical activity on five days of the week, or as much as you can manage.
- It might be hard at first, but once you get into an exercise routine you'll feel fitter and less tired throughout the day.
- Try not to exercise too close to bed time, as it can leave you feeling more awake.

## MORE INFORMATION AND RESOURCES

The Trust's specialist nurses can be contacted at [nurses@msatrust.org.uk](mailto:nurses@msatrust.org.uk).

## THE CAREWELL HANDBOOK AND WEBSITE

Carewell is a partnership between Bupa, Carers UK (of which the Trust is an affiliate member) and nutritional body, MEND. The handbook and website have been produced to help carers and the people they care for. The handbook can be ordered by calling 0800 011 4777. The website can be accessed by visiting [www.carewelluk.org](http://www.carewelluk.org).

## DEEP SLEEP CD

A copy of the Deep Sleep CD, designed to help ease you into a natural sleep by using a range of relaxation techniques, is provided with copies of *The Carewell Handbook*.

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# CARERS' TIPS FOR STEPS TO BETTER SLEEP

“

*I have blackout blinds in my bedroom, and instead of turning the bright bedroom light on when I get up during the night to look after Dad I light a candle. It's less disruptive for both of us, and means I can get to sleep again quickly afterwards.*

”

“

*A regular bedtime routine helps me sleep. I get up and go to bed at the same time every day, even if the opportunity of a lie in ever happens.*

”

“

*I'm often kept awake trying to think of all the things I have to do the next day. Keeping a notepad by the bed allows me to write things down as I think of them, and then forget them as I go to sleep. Everything always seems much more worrying in the middle of the night and often the things on the list are quite pointless when I read them in the morning, but it still gets them out of my head for the rest of the night!*

”

More tips can be found by visiting [www.carewelluk.org](http://www.carewelluk.org).



# Memorial WALL

We are pleased to launch our Memorial Wall set up on our website: [www.msatrust.org.uk](http://www.msatrust.org.uk) to provide our members with an opportunity to remember their loved ones in a very public way.



The first person to be remembered on the wall is our founder, Sarah Matheson who, disillusioned with the lack of knowledge of multiple system atrophy when she was diagnosed, drew on her previous experience of charity work to set up the Trust in 1997. She passed away in 1999.

Sarah's brother and Trustee, Hugh Matheson, said of the memorial wall's launch, "Sarah founded the MSA Trust to help bring relief to people suffering from a disease few knew anything about. This Memorial Wall helps to keep her memory alive." **MSA**

To find out more about the Memorial Wall, please contact Katie Heyward at the office: [katie.heyward@msatrust.org.uk](mailto:katie.heyward@msatrust.org.uk) or call 020 7940 4666.

## IN MEMORY

Alan Price  
Margaret Beake  
Kevin Nutt  
Janet Robertson  
Martin Olive  
Alan Edwards  
Pauline Page  
Owen McCarthy  
Stephen Pardoe  
Kathleen McIlhinney  
Catherine Hopkins  
Bryan Purdey  
Michael Gould  
Dee Hawksworth  
June Fox  
Susan Barritt  
James Walker  
Malcolm Hoyland  
Jennifer Smith  
Eric Rapsey  
John Lord  
Carol Hayman  
Sidney Burrows  
Peter Youngs  
Francis (Frank) Strange  
Peter Shilling  
Eileen Norris  
William (Bill) Stewart  
Amber Wills  
Joyce Lancaster  
Lorraine O'Shea  
Daphne Jennings  
Betty Shore  
Tony Mills  
Rita Saul  
Lorna Sundström  
Jos Young  
Thomas Allinson  
Peter Kerby  
June Ball  
Bill Colligan

Jane Pardoe  
from Stourport  
on Severn,  
Worcestershire,  
has shared with  
us the poem she  
wrote for her  
husband, Steve:

### *My Husband*

*We had lots of happy years  
Without too many tears  
Laughter was the main stay  
That kept those demons away*

*I'll Always Love You  
Whitney sang to rhyme  
And when it came to fruition  
We knew it was time*

*I'll miss you Pard's\*  
More than anyone will know.  
But we both knew  
It was the right time to let go*

*God Bless You Steve xxx*

(\*Pard's was a family  
nickname for Steve)

# RAISING THE PROFILE OF MSA

Building awareness of MSA amongst health professionals and the general population is an ambition of the Trust, and a sentiment shared by many of our members.

In simple terms, the more people hear about MSA the more informed and educated they become on the care and welfare issues of those living with it on daily basis. More knowledge and understanding of MSA in the community will hopefully also reduce the isolation many people feel from having a rare disease.

The Trust has recently employed a part-time freelance public relations professional to help bring MSA out into the open, and Ellie Taylor describes here how we can all help to make MSA more visible.

There are many individuals and families across the UK who are very successful in getting publicity for the Trust and MSA. Often this is because they are undertaking a fundraising activity and, as part of this, want to promote their event. The Trust will be working hard to get MSA in the national media and on social media networks, but if you're

tempted to try your hand at getting some publicity too, perhaps alongside your fundraising events, here's a quick guide on how to go about this.

## PROMOTING YOUR EVENT

Facebook and Twitter are good places to start. Make sure you let the Trust and all its supporters know what you're up to by putting it on the Trust's Facebook page and by "tweeting" us. Whether you're Facebooking or tweeting, make sure you get your friends on Facebook to share and like what you put on, and your followers on Twitter to retweet (RT).

## FACEBOOK

Most people have a Facebook account and it's a great way to let people know what you're up to. Make sure you update your Facebook status regularly. You can also link to your justgiving.com page.

## TWITTER

A tweet is a bit like a text message and is 140 characters long. You can send a generic message to all your followers, as well as messaging people that aren't following you. Tweets are also a good way to tell people what you're up to.

## GETTING INTO THE MEDIA

Any publicity (as long as it's accurate!) you can get for your event is great, and often stories that end up in the national newspapers and on television started out in a local paper, including the free ones. Getting in contact with your local paper is a good place to start. Try to keep your information to one page and include things they'll want to know about:

## WHAT & WHY

Write a few lines about what you're doing and why. Make sure you include a couple of sentences on MSA (please con-

tact me on 020 7940 4666 or by email at [ellie.taylor@msatrust.org.uk](mailto:ellie.taylor@msatrust.org.uk) and I can help you with this).

### WHEN

Make sure you tell them when you're doing it. Often the local newspaper will want to cover your fundraising when you do it; they may also want to come along and take a photograph (remember, this is a great opportunity to wear your MSA t-shirt!).

### WHO

Tell them who you are and make sure you include contact details, including your mobile number, and Twitter and Facebook details if you have them. Please give them the Trust's contact details too (020 7940 4666, [www.msatrust.org.uk](http://www.msatrust.org.uk)).

### CHASE!

Once you've sent them information about your event, don't be afraid to call up (ask for the planning or news desk) nearer to the time to check they've received your information and to find out if they're interested in covering it. Don't be surprised if they didn't receive it the first time round, just explain what your event is on the telephone and then send them the information again.

### LET US KNOW

It would be great to know if your local media are intending to cover your event, and if there's any chance of having a photocopy of any coverage, fantastic!

## RECENT MEDIA COVERAGE

Our members are always busy fundraising and many also manage to get some publicity. Here's a few examples:

In August Sam Crawford in Falkirk who has MSA, was featured in a double-page spread in the Scottish newspaper, *The Sunday Post*. The interview was very moving and really explained what it's like to live with MSA. Sam talked very openly about the impact it has had on her and her 16-year old daughter, Rhanna. Sam is putting together a memories box for her, "It's filled with old pictures, notes and little keepsakes I'd like her to have."

Over in Norfolk, Martha Hughes was in the *Eastern Daily Press* when she did her first skydive in aid of the Trust, watched by mum, Helen, who has MSA. As well as raising the profile of MSA in the local paper, Martha also raised more than £1,900 for the Trust. She says, "It was brilliant - the best bit was the freefall!"

The Ketteringham family from Lincolnshire appeared on ITV's *This Morning* show in July. Colin, his wife Louise, and four young children were interviewed by presenters Kate Thornton and John Barrowman. The interview was very emotional and talked about MSA and how it affects people. Colin and his family received a surprise gift of holiday vouchers from Thomson Holidays to go towards the holiday fund

the family have set up to allow them to go on a holiday and create some wonderful memories. Colin said, "It was a very nice and emotional surprise. The presenters were in tears. The programme has touched a lot of people. On Thursday I had 23 followers on Twitter and now I have more than 700, just from being on the show."

This is the first time MSA has been featured on national television. The show had over a million people watching and the impact of appearing on such a popular television programme was felt on the Trust's website with unique visits up by over 1,000 for the month of July. The power of good publicity! **MSA**



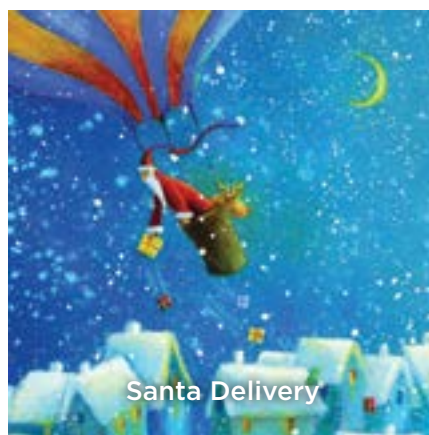
If you'd like to know more about getting publicity for your fundraising events, or to find out how to help raise the profile of MSA more generally, please get in touch with Ellie Taylor at the Trust on 020 7940 4666 or by emailing her on [ellie.taylor@msatrust.org.uk](mailto:ellie.taylor@msatrust.org.uk).

# TRUST CHRISTMAS CARDS 2012 NOW AVAILABLE!

We're pleased to introduce our 2012 Christmas cards, designed to raise both funds and awareness.

Each design comes in a pack of 10, and costs £3.50 plus postage and packaging. Please see our cost table for prices if buying multiple packs.

Please fill in this form and return it to us enclosing a cheque made payable to Multiple System Atrophy Trust, and send to: MSA Trust, Southbank House, Black Prince Road, London SE1 7SJ.



Our two designs are 108mm x 108mm and each have a greeting inside reading:  
**With Best Wishes for Christmas and the New Year.**

**Thank you for your support!**

Pk(s)	1	2	3	4	5	6	7	8	9	10
<b>COST</b>	£4.00	£8.00	£11.60	£15.10	£19.50	£23.00	£26.50	£30.50	£34.00	£37.60

## MULTIPLE SYSTEM ATROPHY TRUST CHRISTMAS CARD ORDER FORM

Name:.....

Address:.....

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

Santa Delivery (Qty):..... Christmas Tree Village (Qty):.....

Total payment enclosed £.....

Please either cut here or photocopy and return to us by **5 December**. Thank you!

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