

# MSA

NEWS



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The inside story

TEDDY BEARS  
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**MEMBERSHIP AT MAY 2013**

Current MSA members	982
Carers, relatives & friends	1,466
Healthcare professionals	1,775
<b>Total</b>	<b>4,223</b>
New MSA Members since 1 February 2013	58

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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.**



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# MSA IN THE NEWS

Thanks go to many people for helping to make March MSA Awareness Month a huge success. Over 550 people downloaded a Twibbon – a mini-MSA logo to use on their Facebook and Twitter profile pictures – social media in action.



Sir David Hare

Playwright, Sir David Hare, former Olympic gymnast Olga Korbut and media GP Dr Sarah Jarvis joined the Trust's 'Spread the Word' campaign awareness month in March.

Trust members around the UK helped raise publicity in local and regional media, such as the feature in the Manchester Evening News on Jackie Donohue and her mum, Beth Lockett, who has MSA.

Chippenham based Michael Woodman who lost his wife, Pat, to MSA last year, was featured in local press the Western Daily Press and the Wiltshire Gazette and Herald with the launch of his Wiltshire Support Group.

Ed Martin and his friends were featured in the Hereford Times and in The Ledbury Reporter.

Heather and Mick Buckel raised awareness in Morcambe with an interview for The Visitor.

We can't mention everyone here, but a big thank you to all the people who are helping to make a difference by helping to spread the word of MSA. You can find our most recent coverage in the Media section on the Trust's website, [www.msatrust.org.uk](http://www.msatrust.org.uk).

## MSA MINI-DOCUMENTARY

Mum and daughter, Sam and Rhanna Crawford from Falkirk in Scotland made a mini-documentary with national newspaper, The Guardian, which aired on the Guardian's website in May. The film called Living With MSA: Memories for my Daughter, looked at life with MSA and showed Sam creating a box of memories, hopes and dreams so a piece of her can always be by Rhanna's side. There will also be a version shown at cinemas across the country. This short film is produced in association with Zurich Insurance. The film can be watched by visiting the Trust's website, [www.msatrust.org.uk](http://www.msatrust.org.uk), in the "On Film" Media section.

If you would like to help raise awareness in the media, please contact Ellie Taylor at [ellie.taylor@msatrust.org.uk](mailto:ellie.taylor@msatrust.org.uk). If you are active online, make sure you like us on Facebook/ Multiple System Atrophy Trust and follow us on Twitter @MSAtrust.



# INFORMATION & SUPPORT



## HELPING THE HEALTH AND CARE COMMUNITY TO HELP YOU

The Trust works to raise awareness and understanding of MSA amongst the various health and care professionals associated with the disease.

As part of this work, we ask for your GP details when you register with us. We write to your GP to let them know they have a patient with MSA, enclosing a GP information pack designed to help them understand a little more about MSA and the kind of support that

might be needed by somebody with it.

Our Information and Support team have just finished working with a group of GPs to update this information, and this new pack started going out in May. It contains more detail and support materials, and should prove to be a valuable resource tool.

If you move house or change your doctor, let us know and we will send an information pack to your new GP.

In the coming months we will be piloting a similar approach with occupational ther-

apists and speech and language therapists; we will be working with relevant organisations to develop materials specific to each professional group.

## FACT SHEETS ONLINE

Trust Information Standard certified fact sheets are now available for downloading online at [www.msatrust.org.uk](http://www.msatrust.org.uk). In the orange box in the middle of the screen click “continue to download area”, and details of fact sheets covering a variety of topics will appear. Paper copies are still available from the Trust if accessing copies online is difficult. Please call Lyn Shaw on 020 7940 4666 if you would like copies to be sent to you.

## REGISTER NOW!

Are you registered with the Trust? Registration is free and is open to all people affected by MSA and includes friends, family, health and care professionals. Help us grow by encouraging those you know to register by visiting: [www.msatrust.org.uk/register-now](http://www.msatrust.org.uk/register-now) or ask people to call Lyn Shaw on 020 7940 4666. **MSA**

# NEWS ROUND-UP

## THE STATE OF CARING IN 2013

Over 3000 carers took part in the State of Caring Survey published in May this year by UK charity, Carers UK. Answers covered questions about people's experiences of caring for children and adults with a wide range of needs. Of carers responding to this survey:

- Almost a third of those caring for 35 hours or more per week receive no practical support with caring.
- Over half of carers who gave up work to care spent, or have spent, over five years out of work as a result.
- More than four in ten of carers surveyed have been in debt as a result of caring.
- 84% of carers surveyed said that caring has a negative impact on health, up from 74% in 2011-12.
- Almost half of carers surveyed have raised concerns about poor quality care services.
- Over half of those caring for someone discharged from hospital in the last year had either not been consulted about their discharge or had only been consulted at the last minute.

More details can be found by visiting the Carers UK website: [www.carersuk.org](http://www.carersuk.org).

## CALLING FOR ACTION ON HAPHAZARD NEUROLOGY SERVICES

Brain Awareness Week took place in March with the theme 'Our brains matter' and a call to action on haphazard neurology services. During the week a survey was launched to examine how people with neurological conditions get their diagnosis, the results of which will be made public later this year. The week was coordinated by the Neurological Alliance, the umbrella group for neurological charities. The Trust was represented on its steering group which set the theme for the week's activities.

## FIRST WILTSHIRE SUPPORT GROUP MEETING

Michael Woodman of Chippenham, Wiltshire, set up the Wiltshire Support Group as a tribute to his wife Pat, who had MSA. The group held its first meeting in Chippenham in April which was attended by 24 people including Samantha Pavey, Trust funded MSA Nurse Specialist and Lyn Shaw, the Trust's Information and Support Officer. Discussion covered a wide range of topics from MSA symptoms and diagnosis, saliva control to social services' assessments and eligibility for funding. Two local Community Matrons attended and explained their roles and how they signpost people with MSA to relevant services and support.

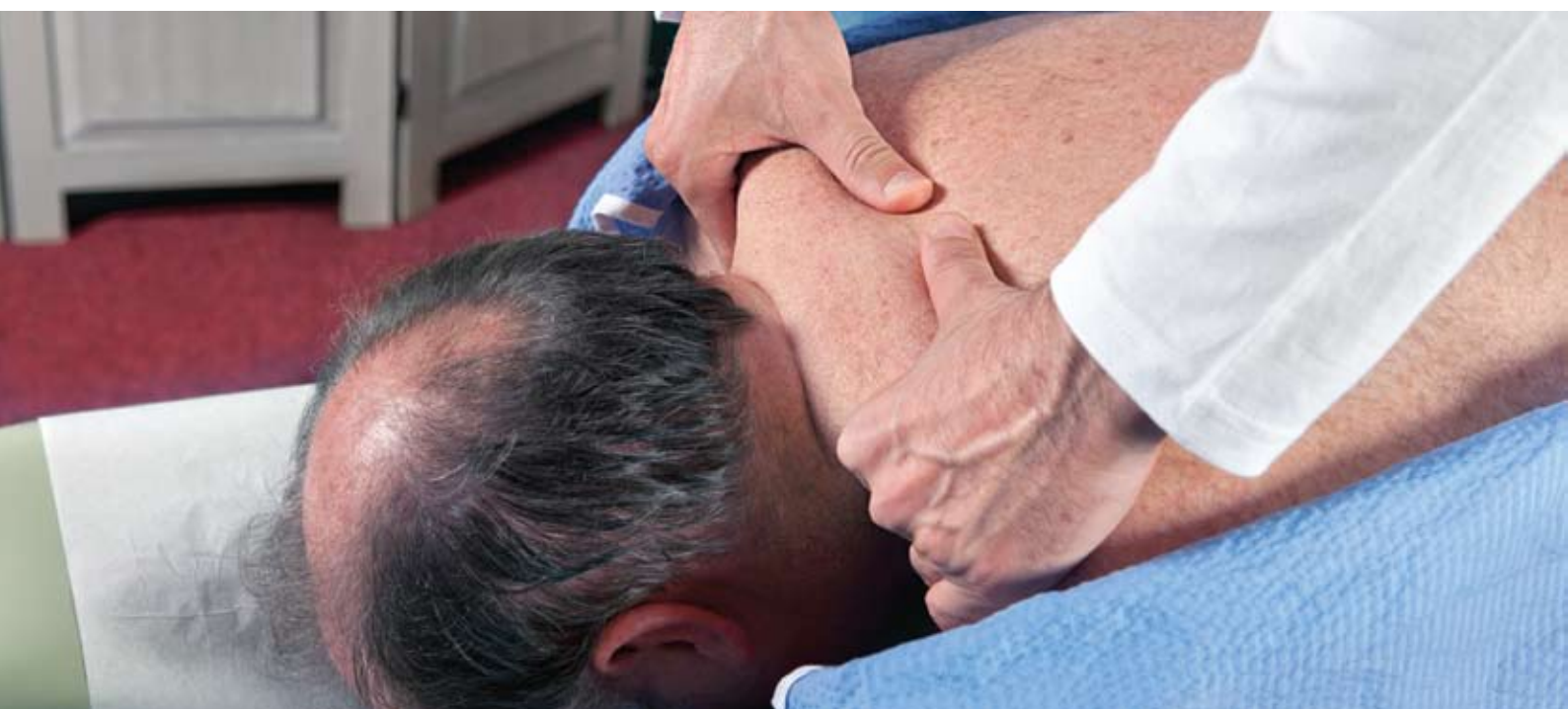
## NATIONAL GARDEN CENTRE PARTNERSHIP

The national garden centre chain, Klondyke, has named the Trust as their Chosen Charity Partner. Launching this month, the partnership will feature MSA/Trust promotions on seed packs nationwide, fundraising clothes recycling points across all stores, Trust merchandise in all Klondyke stores and an awareness campaign throughout MSA awareness month in March next year aiming to galvanise local communities around Klondyke stores.

Trust Executive Director, Nickie Roberts, says: "The widespread presence of Klondyke garden centres provides an opportunity to put MSA on the national map, raising funds and awareness. It's a fantastic twin strategy, and we're hugely grateful to Klondyke for their support."

# PAIN IN MSA

It is not uncommon for people with Parkinson's and related movement disorders such as MSA to have some level of pain, although this is not the case for everyone. Pain can generally be categorised into five main types: Musculo-skeletal, neuropathic, dystonia, akathitic or central pain and each of these is considered in this article, along with treatment options.



## **MUSCULOSKELETAL PAIN**

Aching muscles, postural strain, repetitive movements, injury and prolonged immobilization.

Initially you should be assessed by your doctor or physiotherapist who can advise on suitable treatment options which may include:

- Injections with anaesthetic or anti-inflammatory medications in, or around, the painful sites
- Exercise that includes muscle strengthening and

- stretching
- Physiotherapy/occupational therapy
- Acupuncture/acupressure
- Relaxation/biofeedback techniques
- Chiropractic care
- Therapeutic massage/aromatherapy

## NEUROPATHIC PAIN (ALSO CALLED RADICULAR PAIN)

Caused by a problem with one or more nerves. The function of the nerve is affected leading it to send pain messages to the brain. Neuropathic pain is often described as burning, stabbing, shooting, aching or like an electric shock.

Common painkillers may not be effective, but there are specific drugs that can relieve neuropathic pain:

- Antidepressants in the tricyclic group, for example amitriptyline. They are not used in this instance to treat depression, they work by interfering with the way nerve impulses are transmitted.
- Anti-epileptic medicines are another type of pain relief used for neuropathic pain, for example gabapentin. These medicines are commonly used to treat epilepsy but they have also been found to ease nerve pain. As with antidepressants, a low dose is usually started and built up gradually if needed. It may take several weeks for maximum effect as the dose is gradually increased.
- Opiate painkillers are stronger traditional painkillers,

for example codeine, morphine and related drugs. As a general rule they are not used as first-line for neuropathic pain.

- Tramadol is a painkiller that is similar to opiates, but has a distinct method of action that is different to other opiate painkillers and is often used for treating neuropathic pain.

## DYSTONIC PAIN (INCREASED MUSCLE TONE)

This type of pain can occur from stiffness and rigidity in the muscles and Parkinson's medications, for example Sinemet or Madopar can often improve dystonic pain for many people with MSA.

## AKATHIC PAIN

Described as a sense of restlessness, often accompanied by an urge to move, akathic pain may improve with Levodopa, such as Sinemet or Madopar, or dopamine agonists such as Mirapexin.

## CENTRAL PAIN (ALSO CALLED PRIMARY PAIN)

Often described as burning, tingling, formication (a sensation that feels as if ants are crawling over the skin). Parkinson's medications may be helpful, as may neuropathic medicines (see above).

Pain can be made worse by stress, anxiety and depression. Our perception of pain can vary depending on how we react to pain and circumstanc-

es. Where relevant, treatment for anxiety or depression may help. Treatments such as stress management, counselling, cognitive behavioural therapy and pain management programmes sometimes have a role in helping people with chronic (persistent) neuropathic pain.

In all instances you should discuss pain with your neurologist or Parkinson's nurse specialist who can refer you to a pain clinic if appropriate. A combination of medications and treatments may be required, and you should report any unwanted side effects to your specialist. The Trust's MSA specialist nurses are available to discuss any pain issues you may have, and advise you on a suitable course of action.

The Trust is also producing a more in-depth fact sheet on pain in MSA, and copies can be requested by contacting Lyn Shaw at the office on 020 7940 4666 or by email at [lyn.shaw@msatrust.org.uk](mailto:lyn.shaw@msatrust.org.uk). **MSA**

Our MSA Specialist Nurses are here to help:

[nurses@msatrust.org.uk](mailto:nurses@msatrust.org.uk)

**Samantha Pavey** (South England and Wales):

020 3371 0003

**Katie Rigg** (North England, Scotland and Ireland): 01434 381 932

# MSA RESEARCH PAST, PRESENT & FUTURE

It's safe to say that every reader of MSA News is desperate for a cure to be found. But how many of us know what's happening on the front line in the fight to find that cure? Our volunteer feature writer, Gavin Duncan, reports.



## **The Trust funds research with the hope of finding that so far elusive cure.**

Professor Huw Morris (HM) and Professor Niall Quinn (NQ), members of the Trust's Research Committee, are at the forefront of the MSA Trust-backed research. They talked to MSA News to give us all a little more insight into what's being done to find a cure.

## **WHAT RESEARCH IS CURRENTLY BEING DONE INTO MSA?**

**NQ:** "There has been a huge increase in the research carried out in MSA over the last few years. Research into MSA is taking place in many countries - there are MSA Study Groups in Europe, Japan and North America. These groups can also mount multi-centre studies which are important with a rare disease such as MSA."



## WHY IS RESEARCH INTO MSA AND YOUR FINDINGS IMPORTANT?

**HM:** “A lot of the early research in the last 25 years was directed at laying down the framework for future studies. We needed to develop criteria to diagnose cases, then apply these criteria to find out how common the disease is. It was important to also know whether there are variations between different populations that might give us additional information.

“We had to establish the natural progression of the disease and its variability between cases so we could counsel patients and family about what to expect in the future. This would give us a yardstick against which to compare any treatments that might hopefully modify the underlying disease.

“Finally, we needed to develop a specific rating scale to clinically assess the severity of the disease and how it changes over time. This was essential for clinical trials.”

## HAVE THERE BEEN ANY BREAKTHROUGHS SINCE THE TRUST STARTED FUNDING RESEARCH?

**NQ:** “A very important part of the research has been the opportunity to study the brains of MSA patients after death. Some patients have generously agreed to be brain donors. This has enabled us to understand the different clinical patterns of disease that relate to MSA pathology.

“Understanding how nerve cells are damaged in the brain is an important part of pathological research into MSA.

“Dr Janice Holton at the National Hospital for Neurology and Neurosurgery in London is currently carrying out research, and is looking at the way MSA pathology leads to, or is associated with, inflammation of the brain.

“This research is funded by the Trust and may lead to an improved understanding of the ways in which anti-inflammatory drugs might be used in future therapies for MSA patients.”

## WHAT DIFFERENTIATES MSA RESEARCH FROM OTHER NEUROLOGICAL RESEARCH?

**HM:** “Much of the research carried out in Parkinson’s disease (PD) also has relevance to MSA. The symptomatic drugs that we use are the same as those used in PD.

“There has been a lot of genetic research into both diseases, largely based on blood samples donated by patients. A number of important genes modifying the risk of developing disease have been found in PD, but not so far in MSA.

“There may be genetic factors that slightly increase the risk of the disease, perhaps in conjunction with environmental factors.

“If we could understand these factors in more detail, this would help us piece together the pathway that leads to the disease. A worldwide collaborative study of genetic factors in MSA has been led by Professor Henry Houlden at the Institute of Neurology, Queen Square, London with the support of the Trust.”

## WHAT ARE YOUR HOPES FOR THE FUTURE OF MSA RESEARCH?

**NQ:** “What we all want is a treatment that could slow, halt or, best of all, prevent the disease.

“A number of different potentially disease-modifying drugs have been trialled in MSA, but none of those tested have so far proved effective. Nevertheless it’s very encouraging that university researchers and drug companies have been able to set up and complete these studies, some of which have included over 350 MSA patients.

“One big hope is that by studying the brains of people with MSA, we can understand better the way the disease progresses. We are moving from understanding the different clinical patterns of disease, to learning about how damage to nerve cells happens.

“The million-dollar question is how and why the changes in the brain begin, and how they spread and become more severe over time.” **MSA**

# THE “BEDROOM TAX” - CHALLENGING A DECISION

The way the Government provides support to people who need help with their rent through Housing Benefit has changed.

One of these changes is called the Housing Benefit Size Criteria Rules, commonly referred to as the “Bedroom Tax”. The change means that social housing tenants of working age who get help towards their rent through Housing Benefit, will have the amount they receive restricted if they are considered to have too many bedrooms. Carers UK has produced a toolkit to help if you decide to challenge a decision. Here’s what they say:

If you are affected you will by now have received a letter from your council telling you about the decision. You have one month from the date of the letter to challenge the decision, and we’ve put together a toolkit to help.

The kit consists of a standard letter and six arguments from which you must choose the reason, or reasons, why you think the decision is wrong. You may choose one or more of these arguments - whichever are relevant to you. The arguments are as follows:

**Argument 1:** *If you or your partner need overnight care from someone who does not usually live with you, and so need an extra room.*

**Argument 2:** *If an adult son or daughter, a parent or another adult needs overnight care from someone who does not usually live with you, and so you need an extra room.*

**Argument 3:** *If you or your spouse or partner needs their own room.*

**Argument 4:** *If a member of your household needs an extra room for other reasons.*

**Argument 5:** *If your home has been specially adapted to meet the needs of a disabled person.*

**Argument 6:** *If someone in the household has mental or physical health problems.*

It’s important to know that these arguments are all untested at present. However, there are already ten judicial review cases in England on some of these arguments and, if these are successful and you have not appealed, you could be affected by what is known as the ‘anti-test case’ rules. This

means that you cannot benefit from the success of any court case for past loss unless you appealed yourself.

While it is possible that these arguments may be successful, we cannot guarantee this will be the case.

## USING THE TOOLKIT

To use the toolkit you should download the draft letter and one or more of the arguments - whichever are relevant to you - from our website: [www.carersuk.org](http://www.carersuk.org). You will also find guidance on personalising your letter.

Carers UK would like to thank Govan Law Centre for suggesting the Human Rights Act 1998 arguments and the format of this toolkit. **MSA**

For more information on challenging the “Bedroom Tax”, please visit [www.carersuk.org](http://www.carersuk.org) or call their offices on 020 7378 4999.

# BUILDING THE MSA VOLUNTEER ARMY

**The past year has seen the Trust grow considerably.**

Our support groups have almost doubled in number, we are providing more web-based help for people irrespective of where they live and awareness of MSA is steadily growing.

With our Vision of “A World Free of MSA” very much in mind, we have made a commitment to spending a minimum of **£100,000 per year** to fund research with the hope, one day, of finding the cause of, and a cure for, MSA.

We want to keep up the momentum, and we need your help to build a volunteer army! **Here's how you can get involved:**

## FUNDRAISING & AWARENESS

The Trust relies entirely on donations as we receive no statutory income. Including our research funding, the current annual cost of running the Trust's services is around £450,000 and this figure will grow in line with our service and research developments. Much of our income comes from people volunteering to take part in fundraising activities, by remembering us in legacies and in memoriam donations.

Building awareness of MSA to help target isolation and improve knowledge of the disease relies very much on people opening up their lives by sharing their MSA story and the impact it has on them and their families. Working with people in this way has resulted

in MSA receiving more traditional and new media exposure.

## SUPPORT VOLUNTEERING

We are also looking to increase our support volunteer network through support groups and our online MSA Local Hub ([www.msalocalhub.org.uk](http://www.msalocalhub.org.uk)). If you have a spare hour or so a week, you could consider, eg, helping us by searching for local services or by checking the accuracy of information already added to the Hub.

Whether it's an hour now and then or something more regular, we can work together to find a volunteer opportunity to best meet your needs. We will also provide you with materials and support to help you. For more information, please call us on 020 7940 4666. **MSA**

# PEER SUPPORT

MSA can be an isolating condition and sometimes people feel they are the only ones who have ever heard of it. We know this isn't true, but at times it may feel like it's you against the world. That's why so much of the work we do at the Trust is about trying to reduce that sense of isolation, and a really effective way of alleviating this is by putting people in touch with each other. **Neil Hunter, Head of Services, explains:**

Through our peer support activities we are trying to create a community, an 'extended MSA family', built upon sharing and mutual support. We provide help through the nurse specialist helpline and through our broad range of fact sheets. We also try and make it easier for you to support and share information with each other, and to reassure you that you aren't in this alone.

We provide several things to help people connect with each

other.

The online forum available through our website, [www.msatrust.org.uk](http://www.msatrust.org.uk), is an easily accessible support tool. It started slowly, but is fast becoming an active community with several people posting regularly - feedback we get shows it makes a big difference to people's lives. If you haven't used the forum before, why not try it? You can register by following the link to 'forum' on our website. Once registered, you can post a "hello" and

meet a whole group of people who can relate to what you are going through, who will be happy to share their experiences and offer practical and emotional support.

Our local support groups go from strength to strength. Thanks to our incredibly committed volunteer support group leaders, the Trust now has 30 groups running throughout the UK and Ireland. New groups in Norfolk, Dorset and Wiltshire have recently started, and Gloucestershire will start

this month (June). More and more people are attending the groups, sharing experiences and stories and offering understanding and strength to each other. This growth is driven by the desire of people affected by MSA to help and support one another in an environment where for once you don't have to explain what MSA is! Support groups may not be for everybody, but if you haven't yet been to one why not go along to the next one in your area? Details of future group meetings can be found on our website at [www.msatrust.org.uk](http://www.msatrust.org.uk).

The MSA Local Hub directory is now up and running, [www.msalocalhub.org.uk](http://www.msalocalhub.org.uk), and the number of services listed on it is growing steadily. It is a really easy way to let other people know what you know about local support services. Our goal is that one day soon, anyone diagnosed with MSA will run a search on the Hub



and get an instant picture of what help is available to them in their area. For this to happen, we need you to let us know what is out there. Let us know of your local support services and we will add them to the Hub; it can be any service that you have found helpful, whether a local hospice or a home-visiting chiropodist. The Hub is a really simple way to share knowledge and build a supportive MSA community.

We also run a contact scheme which aims to put people in touch for mutual support and information sharing. You can choose to be in contact by email, letter or telephone - whatever works best for you. We try to match you with someone who suits your preferences, which could be someone newly diagnosed, a fellow carer, someone living alone or with an interest in

research.

Peer support can build a stronger, closer MSA community. A problem shared may not always be a problem halved, but it will help to reassure you that you aren't alone. There are other people who understand what you are going through, other people always prepared to listen and other people prepared to offer some helpful thoughts, advice or knowledge.

So why not get on line, give us a call or attend your next support group meeting? **MSA**

More information about any of the schemes in this article can be found on our website, or by contacting Lyn Shaw, Information and Support Officer on 020 7940 4666 or [office@msatrust.org.uk](mailto:office@msatrust.org.uk).



# MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people who understand life with MSA. Please contact Lyn Shaw at the Trust's office on 020 7940 4666 or email at [lyn.shaw@msatrust.org.uk](mailto:lyn.shaw@msatrust.org.uk) for more details.

GROUP	VENUE	DATE AND TIME
West Sussex	Field Place, The Boulevard, Worthing BN13 1NP	Monday, 10 June - 2.00pm
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wednesday, 19 June - 1.30pm
Derbyshire	Doveside Social Club, Hatton DE65 5DT	TBC
Gloucestershire	Quedgeley Village Hall, 208 Bristol Road, Quedgeley GL2 4PE	Tuesday, 25 June - 2.30pm
Yorkshire (West/ North)	Darley Village Memorial Hall, Sheepcote Lane, Harrogate HG3 2RP	Thursday, 27 June - 1.30pm
Dorset	TBC	TBC
Kent	TBC	TBC
Fife	Burnside Hall, Balmullo KY16 0AW	Wednesday, 3 July - 2.00pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Friday, 5 July - 2.00pm
Aberdeenshire	The St Mary's Centre, St Mary's Place, Inverurie AB51 3NW	Friday, 5 July - 1.30pm
Warrington	Fairfield and Howley Neighbourhood Project, WA1 3AJ	Friday, 5 July - 2.00pm
Cumbria (PSP/ MSA)	Junction 44 Premier Inn, Parkhouse Road, Carlisle CA3 0HR	Monday, 8 July - 1.30pm
London (North)	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Monday, 8 July - 2.00pm
Lincolnshire	Alvingham Village Hall, Yarburgh Road LN11 0QG	Thursday, 11 July - 1.30pm
Oxfordshire	Girl Guide Hall, Southern Road, Thame OX9 2EE	Thursday, 11 July - 2.00pm
Bristol	The Withywood Centre, Queen's Road, Withywood BS13 8QA	Tuesday, 16 July - 2.00pm
Northumberland	Blyth Library, Bridge Street, Blyth NE24 2DJ	Wednesday, 24 July - 2.00pm
Lanarkshire	TBC	TBC
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thursday, 15 August - 2.00pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Monday, 2 September - 1.30pm
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	TBC
Wiltshire	St Paul's Church Hall, Malmesbury Road, Chippenham, SN15 1PS	Friday, 20 September - 2.00pm

West Sussex	Field Place, The Boulevard, Worthing BN13 1NP	Tuesday, 24 September - 2.00pm
Northern Ireland	TBC	TBC
Republic of Ireland	TBC	TBC
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wednesday, 9 October - 1.30pm
Yorkshire (West/ North)	Darley Village Memorial Hall, Sheepcote Lane, Harrogate HG3 2RP	Thursday, 10 October - 1.30pm
East Midlands	Holme Pierrepont Hall, Holme Pierrepont NG12 2LD	Tuesday, 15 October - 2.00pm
Northumberland	Blyth Library, Bridge Street, Blyth NE24 2DJ	Wednesday, 23 October - 2.00pm
Warrington	Fairfield and Howley Neighbourhood Project, WA1 3AJ	Friday, 25 October - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Monday, 28 October - 2.00pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6 1JQ	Wednesday, 30 October - 2.00pm
Lincolnshire	Alvingham Village Hall, Yarbrough Road LN11 0QG	Thursday, 31 October - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Friday, 1 November - 2.00pm
Cumbria PSP/MSA	Junction 44 Premier Inn, Parkhouse Road, Carlisle CA3 0HR	Monday, 4 November - 1.30pm
Fife	Burnside Hall, Balmullo KY16 0AW	Wednesday, 6 November - 2.00pm
Aberdeenshire	The St Mary's Centre, St Mary's Place, Inverurie AB51 3NW	Friday, 8 November - 1.30pm
London (North)	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Monday, 11 November - 2.00pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Monday, 2 December - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thursday, 5 December - 2.00pm

Information for meetings in Cornwall, Kent and West Midlands will be available in the coming months. If you've attended a support group, why not share your experience with others? Please email Neil Hunter at [neil.hunter@msatrust.org.uk](mailto:neil.hunter@msatrust.org.uk) or drop him a line at the Trust's office: Southbank House, Black Prince Road, London, SE1 7SJ.

## STRENGTH IN NUMBERS - HELP TO GROW THE TRUST

The Trust wants everybody affected by MSA - friends, family members and health and care professionals - to become a member. There's strength in numbers, and a larger membership base will:

- Give us a bigger campaigning voice - we can shout louder if we speak for more people.
- Increase awareness of MSA and the Trust's services - the ripple effect of more people talking about MSA and sharing experiences.
- Help us to invest more funds into research and our services by reaching more people who will support our fundraising activities.



Help the Trust to grow by encouraging people to register at [www.msatrust.org.uk/register-now](http://www.msatrust.org.uk/register-now) or by calling Lyn Shaw at the Trust's office on 020 7940 4666. Membership is free. **MSA**

# FUNDRAISING ROUND-UP

It's been a busy few months since the last issue of MSA News. Donations have been received from charitable trusts, the Trust has been the beneficiary of a generous legacy and runners have represented the charity in marathons across the world. **Head of Fundraising, Katie Heyward, reports:**

## EVENTS

**The support you have shown us since the beginning of 2013 has been phenomenal, with over 120 people so far signing up to take part in events throughout the year. As a small summary:**

In March, Ed Martin and his good friends Ben and Paul from Brighton took on the South Wales Three Peaks Trial in just one day. The climb was inspired by Ed's father, Peter, who was recently diagnosed with MSA, and raised £1,953 for the Trust.

Another March event, organised by Olivia Van de Werff from Bristol, was a 150-mile cycle ride from Bristol to London, undertaken by a group of energetic ladies. Each day of the three-day trip meant cy-

cling between 9-11 hours in extremely cold weather, raising in excess of £3,000.

On Easter Sunday, Alexandra from Wetherby held an Easter Egg Hunt in her garden which attracted 60 children who unearthed 250 eggs and raised £230 for the Trust.

In April, a total of 14 runners took part in the London and Brighton Marathons raising a staggering £18,500. If you, or somebody you know, would like to take part in either Marathon in 2014, please get in touch for details of how you can register your interest.

This summer seems set to be the busiest ever for fundraising at the Trust. In the coming months we have a wealth of events coming up, including: Dublin Mini-Marathon, a sponsored bake-a-thon, a motor-cycle challenge spanning

the length of the country, a fancy-dress superhero skydive, the London to Paris cycle, a cycle tour of South Africa and a climb up Snowdon. Amazing challenges by amazing people.

## COMPANIES SHOW SUPPORT FOR MSA

Toby Churchill Ltd, the UK's main manufacturers of Light-writers, has kindly contributed towards the cost of our new running vests, now available. We're sticking to our bright orange to ensure our runners and cyclists can be seen as they spread the word of MSA – see page 20 for details on how to get your vest.

If your organisation fundraises, or if you feel your company could sponsor a certain line of our work, then please get in touch – we would love to hear from you.





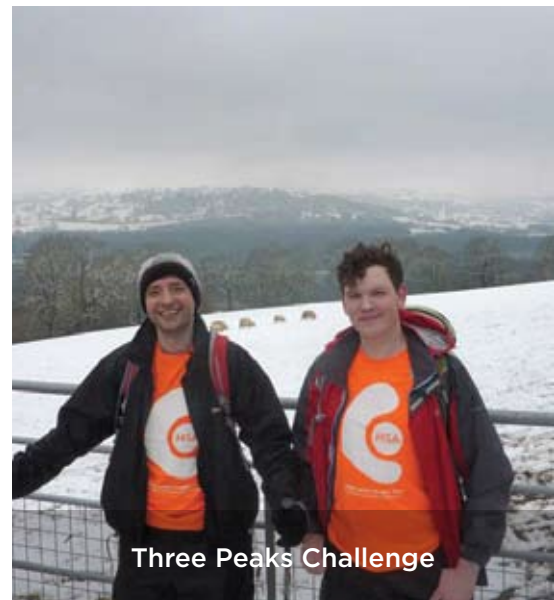
The Hans family after the Paris Marathon



Anthony Haikney after completing London Marathon, with cousin and MSA Trust member Peter Small



Bristol to London cycle ride



Three Peaks Challenge

## CHARITABLE TRUSTS

Our thanks to the following charitable trusts who have chosen to support the work of the Trust since the last issue of MSA News:

Florence Shute Millennium Trust  
The P F Charitable Trust

The D'Oyly Carte Charitable Trust  
The Lennox & Wyfold Foundation  
The Stonewall Charitable Trust  
The Steel Charitable Trust  
The Peter Barker-Mill Memorial Charity  
The W G Edwards Charitable Foundation

### The fundraising team at the Trust are here to help. Please contact us:

For enquiries about company support, regular giving, memory giving, leaving a legacy or charitable trusts, please contact Katie Heyward, Head of Fundraising on 020 7940 4134 | [katie.heyward@msatrust.org.uk](mailto:katie.heyward@msatrust.org.uk). For all enquiries regarding fundraising events, please contact Mike Coffey, Events Fundraising Officer on 020 7940 4666 | [mike.coffey@msatrust.org.uk](mailto:mike.coffey@msatrust.org.uk). **We really could not continue our work if it weren't for our fantastic supporters. Thank you for all you continue to do.**

# SUPPORTING TRUST MEMBERS *in* IRELAND

Lyn Shaw, the Trust's Information and Support Officer, accompanied Katie Rigg, MSA Nurse Specialist, on a three-day visit to Ireland in April with the aim of supporting people with MSA and raising awareness of the disease. **Lyn Shaw relives the hectic schedule:**

## TUESDAY

### **MSA TEACHING SESSION, DUNGANNON**

At a very early hour on the morning of Tuesday, 9th April, an impressive group of healthcare professionals gathered together at South Tyrone Hospital's Day Hospice all intent on learning more about MSA. Katie Rigg, visiting MSA Nurse Specialist, gave a comprehensive teaching session on MSA looking at the incidence, gender, age and diagnosis and research into the disease, through to symptom management, the role of the multi-disciplinary team, palliative care and the services provided by the Trust. The session could well have carried on for several hours but for the fact that Katie was booked to attend two successive MSA Support Group meetings later in the day.

### **MSA SUPPORT GROUP MEETING, DUNGANNON**

The first Tyrone Support Group meeting was held at Ranfurly Arts Centre and it was good to see Trust members and prospective members there, as well as GP Dr Aine Abbott and a number of physiotherapists, all with a keen interest in MSA. Dr Abbott circulated copies of the pilot version of a new healthcare passport she has been helping to develop, and invited feedback on its design and content.

Northern Ireland Support Group Leader, Rosemary Arbuthnot, distributed booklets on the Northern Ireland Rare Disease Partnership (NIRDP) of which she is a Director. Rosemary's husband, Michael, had MSA and is the motivation for the great things that Rosemary is now doing to raise awareness in Ireland.

### **MSA SUPPORT GROUP MEETING, ARMAGH**

After a short car journey from Dungannon, we arrived at the venue for our second support group meeting of the day where we talked about holidays and cruises, wheelchairs and wheelchair services, level access bathrooms and bathroom adaptations, managing involuntary closing of eyes and iPad communication apps.

## WEDNESDAY

### **MSA SUPPORT GROUP MEETING, LIMERICK**

After another early start and a seven-hour journey from Armagh by car, train and bus, Katie and I reached the Mid-Western Regional Hospital in Limerick. Many Trust members and their families, as well as healthcare professionals, joined us for a lively question and answer session covering the Trust's MSA Local Hub,

MSA presenting symptoms and diagnosis, research studies, medication, pain relief, DVT socks and foot exercises, swollen feet, diet and nutrition, diuretics and frequency and duration of suitable exercise programmes.

We owe very special thanks to Mags Richardson (Parkinson's Disease Clinical Nurse Specialist) and Pauline Conway (Administration Officer, Parkinson's Association) for their help with the meeting.

### MSA SUPPORT GROUP MEETING, LONGFORD

Another day, another bus journey! Eight Trust members attended the Longford meeting and discussed circulation, postural hypotension, foot and leg exercises, temperature control, complementary therapies and false claims about MSA cures on the internet.

We are grateful for the generous donations from everyone who attended the meeting.

### SO WHAT DID THIS THREE DAY TRIP DEMONSTRATE?

There is a great swell of activity in support of people living with MSA in Ireland. The excellent work of Rosemary and the tireless work of MSA Specialist Nurse, Katie Rigg, in supporting both the people affected by MSA and the health and care community in Ireland, provides a real sense of belief that good things can be achieved. **MSA**

## ONLINE MEMORIAL GARDEN LAUNCHES

We've been working with an external company to create a new online memorial website, and we're delighted to now launch our MSA Tribute Garden. This new service, which can be found at [tribute.msatrust.org.uk](http://tribute.msatrust.org.uk), gives our members the opportunity to remember loved ones using an online memorial garden. You can set up a garden or tribute and use it to remember a birthday, anniversary or other date important to you. **MSA**



## *In Memory*

Lorna Lennox  
Alan Brownless  
Henry Preston  
Mary Kean  
Alan Fairbrass  
Jeremy Harrison  
Graham Battle  
Shirley Hargrave  
Catherine Maxwell  
Ron Evans  
Lee Giles

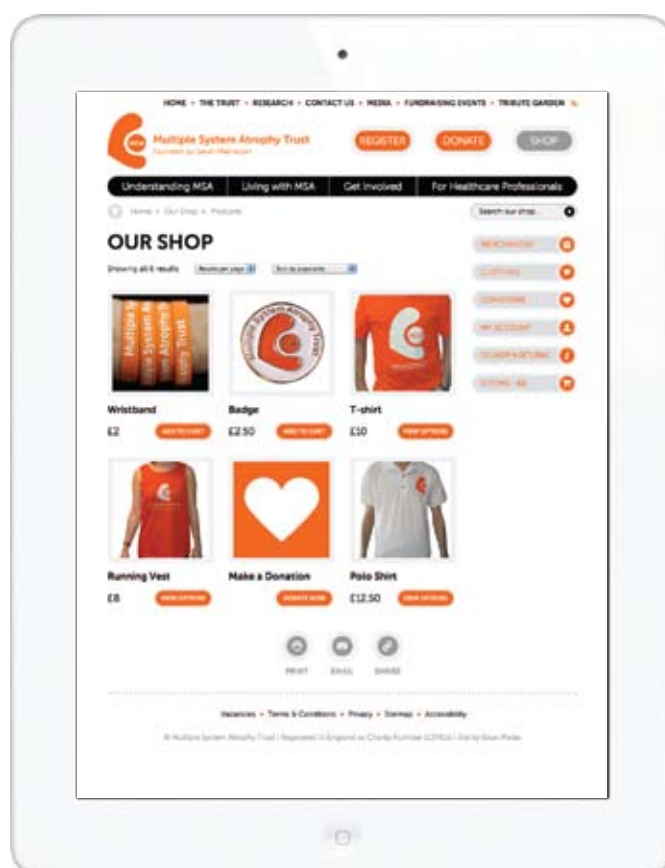
Carole Osborne  
Henry Wood  
Linda Stuart  
Teresa Montella  
Keith Challis  
Lucy Strauss  
Philip Adey  
Avril Scott  
Elise Loxton  
Peter Shorter  
Reginald Dadds

Lois Kemp  
Keith Attenborough  
Edward Johnson  
Nigel Dixon  
Cathy Aubin  
Godfrey Reid  
Phil Marriott  
Roger Lorenz  
Neville Tortice  
Valerie Verity  
Jeffrey Nelson

Herbert Cassidy  
Leon Cooper  
Anne Speak  
Graham Lester  
David Chapman  
Andrew Wilson  
Jennifer Kitchen  
Roy Blackburn

# TRUST'S ONLINE SHOP NOW OPEN!

The charity's online shop has opened making it even easier for you to purchase your Trust goods. We've also launched some new lines of stock - running vests for those summer events - and Bertie Bear.



A beautifully crafted Guernsey bear, Bertie comes with his very own embroidered Trust sweater. He is the ideal mascot for all your fundraising events, as well as being a wonderful gift for children - or perhaps for particularly generous event sponsors. He is 19cm high when sitting and on sale for £10 plus £2.50 P&P. *Not suitable for children under 36 months.*

For more information and to order, please visit the Trust's shop at:  
[www.msatrust.org.uk/our-shop](http://www.msatrust.org.uk/our-shop)