MSA NEWS

MULTIPLE SYSTEM ATROPHY TRUST MEMBERSHIP MAGAZINE

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First MSA Support Group's **10th Birthday**

NEUROLOGY NATIONAL CLINICAL DIRECTOR *Appointed*

MSA AWARENESS DAY:

~ Keep spreading the word ~

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.**

Follow us on Twitter & Facebook and help raise awareness of MSA.
See our website, www.msatrust.org.uk

MSA NEWS EDITOR:
Neil Hunter

ALL CORRESPONDENCE AND ENQUIRIES TO:
Multiple System Atrophy Trust
Southbank House, Black Prince Road
London, SE1 7SJ
Tel: 020 7940 4666
www.msatrust.org.uk

The Trust is financed entirely by voluntary donations.
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MEMBERSHIP AT AUGUST 2013

Current MSA members	1,047
Carers, relatives & friends	1,585
Healthcare professionals	1,842
Total	**4,474**
New MSA Members since 1 May 2013	113

WELCOME TO MSA NEWS

By Nickie Roberts, Executive Director

A lot's happened since the last issue of MSA News. There has been encouraging news for neurology services as NHS England announced the appointment in June of Dr David Bateman as the National Clinical Director for Neurological Services.

This is a significant move as his role will be to provide leadership for neurology at a time of continuing reform and, importantly, to champion improvements for neurological services at both a national and local level. There are around 10 million people in England with a neurological condition, so we'll be looking to see what we can do to focus attention on MSA.

We'll be looking, of course, to see how we can also influence improvements in care throughout the UK and your experience of local and national services will help us to build a picture of what's happening in other countries in the UK, so please look out for the members survey which will be sent out soon.

We have 31 support groups around the UK: 24 in England, 4 in Ireland and 3 in Scotland. The two (soon to be three) MSA Specialist Nurses we fund reach people in all these areas through email and telephone contact and by attending local movement disorder clinics and we want to find other ways of helping people at a local level. Our Services Committee has just undertaken a membership survey to get a better sense of your needs and this will be invaluable in help us plan for the future.

This year's research grant round has just closed, and our independent research panel will be reporting back with their recommendations based on areas such as the quality of the science and its relevance to research in the field of MSA. I can't tell you what we're going to fund yet as this is still being considered. However, I can tell you the panel was impressed by the quality of all the applications we received. Our annual budget for new grant applications is £100,000, so we will have to make a difficult choice as research is expensive. We'll post news of the successful applicants on our website (www.msatrust.org.uk) and will, of course, feature it in the next magazine.

Last but not least, our Head of Services, Neil Hunter, has now taken on the role of MSA News Editor. I hope you'll agree this is a fantastic issue! MSA

SERVICES NEWS

By Neil Hunter, Head of Services

FORUM ROUND-UP

We last mentioned the forum when it was first set up in early 2011. Since then it has grown considerably, with many regular posters and a lot of topics being covered.

We now have over 500 people registered on the forum and together they have created over 120 threads with over 1150 posts. There is a small group of regular posters who work incredibly hard to make everyone feel welcome. They show compassion and understanding and form the heart of our virtual community.

Say hello and you are assured a warm and friendly welcome into the forum experience. Before long, it feels like a chat over a cup of tea with dear old friends.

Reading through some of the posts, you get a real sense of what the forum is about and how it helps people who are on an 'MSA journey'. A recent post highlights the benefits of having a virtual community to call upon when needed: "sometimes you feel you're fighting this horrible disease on your own. It's good to know you are all out there".

It is not just about emotional support; the forum is also a place to have questions or concerns answered. Apart from some very knowledgeable people who understand what it is like to have MSA, or care for someone living with it, the forum is also moderated by Samantha one of our Nurse Specialists. A recent post was about concerns over eye health and MSA. Samantha explained "when we blink we moisten the eyeball, but if people have a reduced blink reflex (common in MSA) the eye can become dry and the eyelid can actually scratch the eyeball causing it to ulcerate. I would recommend you get some artificial tears from the GP and use them three times a day to prevent the eyes becoming too dry."

It isn't all serious though. The 'joke' thread is building up quite a funny collection, most of which we can't publish here. But there is an interesting thought from a science fiction fan, about how difficult it would be to put on shirts and coats if we had ten arms.

The forum is a lively place that you can visit for information, for supporting each other, to escape for a little while and most importantly a place for reassurance that you are not alone. You can join the forum by visiting www.msatrust.org.uk/our-forum and clicking register – then you can post a 'hello' and open yourself up to a group of supportive friends you never knew you had. **MSA**

HEALTH PROFESSIONAL CONTACTS

When you register with the Trust we ask for details of your Specialist and GP. We write to the GP and have just started writing to the Specialist. What we would like to do is write to all the health and care professionals who support you.

In the MSA information pack we send to new members there is a contacts sheet, which if you have filled in, could you please send us a photocopy. We will then write to each member of your team and provide them with information about MSA. This helps to increase their understanding of MSA.

If you would like a new contact form, then it can be found at www.msatrust.org.uk – fact sheets. Or you can contact the office: 020 7940 4666 or office@msatrust.org.uk.

We are committed to spreading the word of MSA and promoting understanding and awareness among health and care professionals. With your help, we can reach so many more. **MSA**

NEWS ROUND-UP

FIRST MSA CLOTHING BANK

In the last edition of MSA News we told you about the exciting partnership with the Klondyke garden centre chain. This partnership features fundraising clothes recycling banks at all Klondyke stores. We are delighted to announce that the first recycling point has been installed at Klondyke's Wilmslow Garden Centre on Manchester Road in Cheshire.

Katie Heyward, the Trust's Head of Fundraising, says: "it is so thrilling to see the first of our bright orange clothing banks get set up. We are so grateful to Klondyke in supporting the Trust and look forward to a very fruitful partnership".

FEEDBACK

Your say makes a big difference to what we do. We have developed a feedback tool to make sure we capture what you think of us. Good, bad or indifferent, please let us know how the services we provide have helped you, or how they could be improved upon. The survey can be found by following the link from: www.msatrust.org.uk/living-with-msa/feedback and only takes a minute or two to complete. Thank you.

BERTIE SPOTTING

In the last edition of MSA News we launched 'Bertie Bear' upon the world.

He has become a very well-travelled bear, visiting the Sibelius monument in Helsinki amongst other places. If your Bertie Bear has journeyed far and wide, then please let us know. Send us a photo and we may include it in future editions of *MSA News*.

We still have some Bertie Bears for sale; you can order yours via the online shop at www.msatrust.org.uk/our-shop.

THE BENEFITS OF TECHNOLOGY – NATIONAL POLL SHOWS LACK OF AWARENESS

The findings of a Carers UK poll show that public attitudes to using technology to support caring for family and friends means many are missing out on "gadgets" which could make a big difference to life around the home.

The national poll highlighted that all generations are failing to switch-on to care technologies and yet technology has the capacity to save time and reduce stress for families who are caring for loved ones.

For more information about how technology may help you visit: uk.tunstall.com/carers.

HOSPICES

It is a common misconception that hospices are only about end of life care. Hospices are actually about providing care and support and improving quality of life, no matter what stage somebody with a serious illness has reached. This means that hospices could have a lot more to offer than you may have thought and it is likely that there is a service local to you.

MODERN HOSPICES

In 1967, St Christopher's Hospice in London became the world's first purpose-built hospice and cemented the modern hospice movement. Today there are over 220 hospices and palliative care inpatient units providing care for over a quarter of a million people each year. There are over 3,100 hospice and palliative care beds, almost 300 home care services and nearly 300 day care centres. It is a very large resource; it is local to you and could be a valuable form of support.

WHAT IS HOSPICE CARE?

A hospice should be seen as a way of caring for people rather than as a building. Hospice care is built around the principles of palliative care which is holistic and total care aimed at improving someone's quality of life, no matter how long that life may be.

> "Our focus is to help S care for J at home with the understanding that the option of hospice care can be considered at any stage of the illness. Home visits by the community nurse have always been appreciated by S who has great confidence that she can contact the hospice when times are a bit more difficult."
>
> **Maria, Manager of St Vincent's Hospice in Renfrewshire**

The palliative care provided by hospices concentrates on supporting people in four main areas: physical needs, emotional needs, spiritual needs and social needs. Crucially, hospices also recognise the importance of the caring unit around somebody with an illness and so they also provide support for carers and family members.

> "The hospice provided all-round support for the family and there was always someone to whom we could turn to sort out problems and give advice."
>
> **Penny**

WHAT CAN HOSPICES OFFER?

Hospice care providers offer a range of services, which may include:

- pain and symptom control
- psychological and social support

- palliative rehabilitation - helping patients stay independent
- complementary therapies, such as massage and aromatherapy
- spiritual care
- practical and financial advice

The services provided can be through longer term admission to the hospice, short stays, day centres or sometimes home visits.

> "As well as offering a number of week-long respite breaks, the hospice also arranged for my father to attend day care and provided transport."
> **Carolyn**

Hospice services are delivered by a team of health care professionals who can help you to live as actively and independently as possible. Although they may not be experts in MSA, they are dedicated and interested enough to learn all they can so that they can best support you.

The support that hospice services offer to carers is as important as that offered to the person with MSA. When the person with MSA can access a day hospice this provides them with an opportunity for interaction with others and access to therapies and support, whilst the carer has a much needed day of respite to recuperate their energy and have some mental space for themselves. In some cases you may be fortunate enough that your local hospice is able to provide longer periods of respite too. As a carer, it can sometimes be difficult to trust other people with caring for a loved one, so finding a hospice that can provide the right level of care that you would be happy with is essential for everyone's peace of mind.

> "It's reassuring for the carer knowing that the person they're caring for can have a good day out and the carer can have a bit of a break."
> **Jennifer**

Getting to know your local hospice can provide a great deal of comfort and support.

GETTING REFERRED

You can be referred to hospice care by your GP or hospital doctor. A district nurse may also make a referral and you may also be able to self-refer, although the hospice may wish to discuss the referral with your GP, or another health professional. Hospices generally work in a similar way throughout the country but there might be slight regional variations, so it is best to get in touch with your local hospice(s) and find out what they can offer.

COST

Hospice or palliative care is free for you, your carer and family members.

BEING REFERRED

Many people, including those in the health care professions, mistakenly equate palliative care, and thus hospice care, with end of life care; as a result many people who would benefit from hospice care are not being referred. Health and social care professionals may think it inappropriate to suggest palliative care as they do not consider the person is reaching end of life. Similarly, people with MSA may be reluctant to ask about palliative care or hospices as they do not want to think that they are nearing death. A hospice is there for care and support over the whole duration of your illness. The key to being referred to a hospice is primarily about what benefits you can gain from it rather than what stage your illness has reached. So you may be referred for hospice care as soon as a diagnosis has been made or at any stage thereafter. **MSA**

To find your nearest hospice you can visit Help the Hospices at: www.helpthehospices.org.uk or visit the MSA Local Hub www.msalocalhub.org.uk.

INSPIRED JOURNEY

By Kathryn Gilbert

The way dad faced his illness was nothing short of inspiring.

Before he started showing signs of MSA – and for some time afterwards – dad was a very active man, spending most of his spare time canoeing or cycling. And after he was diagnosed, he showed enormous courage and determination. He never let on how difficult it must have been for him to slowly watch his body stop working, and he was persistent to the point of stubbornness sometimes.

I like to think I inherited these traits from dad, which is why I started fundraising for the MSA Trust.

My fundraising journey began in 2009, when I ran the London Marathon. I'll never forget how it felt to cross the finish line. Both the training and the race were hard, but having that goal of raising money for the Trust spurred me on. And best of all, I know that dad was proud of me for doing it.

After dad passed away in November 2011 at the age of 58, I decided more or less immediately to embark on another challenge. I was inspired by his long, brave battle with MSA, and I wanted to do something really special to remember him and raise funds. So I decided to climb Mount Kilimanjaro, Africa's highest mountain.

Kilimanjaro was tough, physically and mentally. And the conditions didn't help much either (hailstorms and blizzards in Africa?!). Dad was in my thoughts a lot during the trek – not least because I kept having to remind myself why on earth I'd signed up to it! But when we finally approached the summit after eight days of trekking, I felt very emotional that I'd finished the journey. The whole experience was very cathartic and extremely rewarding.

Looking back now, I'm pleased that something good has come out of what would otherwise have been a very sad time for our family. Raising money and awareness for the MSA Trust has definitely helped me get through the last few years. What's more, I've had some amazing experiences that I might otherwise never have had. And they're all things I know that dad would have loved to do himself. **MSA**

In Memory

Michael Brien
Bob Brooks
Janet Macdonald
Karl Stokes
Eric Margison
Louise Turvey
Benjamin Rose
Edward Tothill
Eric Nye
Diana Millinship
Derek Findlay
Mark Allen
Barbara Groves
Laramie Gaster
Cecilia White
Brian Kent-Smith
Victor Warren
Carol Gretton
Nick Moss
Shirley Scouler
John Powell
Caroline Baty
Annette Stuckey
Allan Singleton
Susan Freeman
Norman Yates
John Maddock
Sarah Dyer
Barry Felton
Angela Grover
John Wilson
Christopher Peart
Yazdi Mobed
Neil Fynney
Rex Smith
William Noble
Barry Daglish
Allan Moore
Elaine Bache
Ken Cotterell
Alan Heppenstall
Tony Durkin
Tony Parsons

LATEST **RESEARCH**

We are delighted to introduce the researchers behind studies currently being funded by the MSA Trust.

COGNITION AND MSA

Katy McDonald is a researcher with a specialist interest in cognitive neuroscience and movement disorders. She is employed by the University of Manchester, through funding from the MSA Trust, and works alongside two Consultant Neurologists and Lecturers; Dr Gerhard and Dr Kobylecki. Here she explains about the current research.

"During a BSc (Hons) Psychology, I worked with children who have Attention-Deficit Hyperactivity Disorder and became fascinated by the relationship between cognition and movement (in this case, too little attention and too much movement). I completed a MSc Neuroscience, worked for the Professor of Cognitive Neuroscience, University of Oxford, and undertook a PhD in Neuroscience, specialising in cognition and Parkinson's disease, with the Professor of Anatomy and Dr Poliakoff (Senior Lecturer), University of Manchester. I have since worked on several movement disorder projects investigating pain, impulsivity and apathy, and exercise therapy.

I began working on the MSA project in May. We will examine the relationship between cognition (eg attention, memory) and areas of the brain affected by the disease. We have already had a medical student work on the project to gain specialist experience and are now recruiting an age-matched comparison group so we can look at differences between those with and without MSA.

NEUROINFLAMMATION IN MSA

Dr Aoife Kiely is a Research Fellow currently working with Neuropathologist Dr Janice Holton, at the Queen Square Brain Bank for Neurological disorders at University College London. Here she explains their study which examines neuroinflammation in multiple system atrophy (MSA) and is funded by the MSA Trust:

"I am particularly interested in looking at the brain in MSA and we can learn a lot from studies that have found that the brain's immune system is working harder in people with some of the more common neurodegenerative diseases such as Alzheimer's (AD) and Parkinson's disease (PD). Recently Dr Holton's research has shown that this might also be the case in MSA. The brain's immune system acts similarly to that of the body, and cells known as 'microglia' play an important part in helping the brain to deal with damage or toxins."

Dr Aoife Kiely

"We are now examining whether, in MSA, microglia are trying to heal the brain or are instead destroying it by damaging the brain cells. If we can find a strong link between MSA and neuroinflammation, this may mean that early treatment with anti-inflammatory drugs could help to treat people who are in the early stages of MSA."

We will bring you regular updates on these studies as they progress and we wish Katy and Aoife all the best with their research. MSA

THORA: LIVING LIFE TO THE FULL

Sometimes someone comes along that just radiates life. Despite her daughter dying from MSA and her advancing years, Thora Beddard remains a beacon of inspiration to many.

At 95 most of us would be welcoming the latter years of our lives with some well-earned home comforts.

Thora is the exception to this rule. The list of challenges she has taken on over the years is truly awe-inspiring.

One of these challenges is leading her extended family in a wide range of fundraising activities on behalf of the MSA Trust after losing her daughter, Trish, to the disease eight years ago.

Thora, who lives in Ashton-Under-Lyne, said: “I visit those in need and raise money for charity by giving speeches.

“Last year four of my great grandchildren and two of my great-great-grandchildren ran the BUPA 10k in Manchester to raise funds for MSA.

“And just a few weeks ago Trish’s husband, George, helped raise money with his singing group, entertaining at a nursing home.

“There is great love and support between us all and we have found a good cause that we can all get behind.

“Trish was a lovely girl. She was a kind and generous person and was very well organized. It’s a pleasure to do it in her name”.

Like many people with MSA, Trish was at first diagnosed with Parkinson’s but Thora said the disease “gathered momentum so quickly” that doctors changed the diagnosis to MSA. Trish died in 2005.

Thora, George and their large family learned through experience that little was known about MSA and resolved to help. Already frequent fundraisers for a range of charities, they switched their focus to MSA and have been making donations ever since.

Through her charitable work Thora was also able to add to her list of achievements last year when she was asked to carry the Olympic torch.

> *“My secret is to keep active in every way. It’s lovely to just sit in a chair but you can get too comfy.*
>
> *“At 50 I learnt to swim. At 60 I discovered yoga and took up the computer. I went abseiling at 73, and later I even modelled lingerie for the older generation on live TV!*
>
> *“When I was 83 I decided it was time I caught up on my education so I took my English GCSE.*
>
> *“There’s certainly never a dull moment”.*

She was nominated for ‘continuously supporting and inspiring those around her’.

She said: “I’ve always helped people, had a sense of humour and been a positive-thinking sort of person.

Thora was widowed 45 years ago, but has a loving, “close knit” family. Just a few weeks ago she welcomed her twelfth great-great-grandchild to the world.

Her interests include setting up a local writers group -Thora had poems about WW1 published in 2005 - a speakers’ club and has also been involved in a forum which helped improve the lives of the elderly in her area.

She credits her good health to staying active and not being afraid to take on new challenges.

“I think it is so important to have a good sense of humour. Love is also important - I live by having hugs off people. They’re better than all your doctors’ medicine.”

Gavin Duncan, volunteer feature writer. **MSA**

Please share your MSA story, get in touch with Neil Hunter at the Trust on 020 7940 4666 or by email at neil.hunter@msatrust.org.uk.

CARERS CORNER
EMERGENCIES

Sensible planning can bring peace of mind and help ease situations should an emergency happen. This guidance aims to help people with MSA and their carers should either of them become involved in an emergency.

PLANNING FOR EMERGENCIES

As a carer it is important for peace of mind that you have an emergency plan in place should something happen to you. If an emergency happens, you need to know that replacement care will be sorted out speedily and efficiently. It is advisable to have an emergency plan in place to help ease your worries about the care of the person you look after.

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

- The name and address and any other contact details of the person you look after.
- Who you and the person you look after would like to be contacted in an emergency – this might include friends, family or health and care professionals.
- Details of any medication the person you look after is taking.
- Details of any on-going treatment they need.

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

EMERGENCY "CARER CARD" SCHEMES

Some areas operate local emergency carer schemes. These could be set up by the local council, trusts or carers centres. The carer is usually asked to register and, with help from a skilled worker, draw up their emergency plans. The plans are held by the scheme which provides a 24-hour response service. Carers carry a card with the scheme's telephone number and a unique identification number to avoid any personal details appearing on the card.

In the event of an emergency you, or someone with you, would call the scheme. An operator would look up your emergency plan and make arrangements for replacement care. This could be contacting friends or family, or putting in professional help. Plans will have been shared with them so they know the individual requirements of the person requiring care, such as medication.

If you would like to know more about emergency planning, please contact our MSA Nurse Specialists who may be able to help or signpost you to further advice and support.

IN CASE OF EMERGENCY

The MSA Nurse Specialists are often asked: “What should a carer do in the event of an emergency?” The answer is quite simple really: the same as you would do if the person you are caring for didn’t have MSA.

If the person you are caring for collapses, you should not automatically assume that the problem is caused by MSA.

If the person is unresponsive but breathing, lie them down in the recovery position whilst talking to them in a calm manner; they will be able to hear you and will be reassured by a familiar voice. If, after a few minutes, they don’t start to respond you should call 999 and ask for an ambulance. If they aren’t breathing, call 999 first, then attempt CPR.

If the person is not alert, then do not give them anything by mouth as their swallow may be compromised.

If they are talking to you, and are not confused, you can give them some water to drink as this will raise their blood pressure. The commonest cause of blacking out in MSA is low blood pressure, postural hypotension, so if you know this is a symptom, ask for our information leaflet on how to manage low blood pressure.

It can be very alarming if the person you are caring for collapses but in most cases they will recover in minutes. **If they do not, you should call 999.**

When the paramedics arrive, give them a quick overview of MSA as it may be something they are not familiar with. They won’t have time to read through any information but you could tell them that the MSA nurses are happy to talk them about MSA at a convenient time if they want more information.

MORE TIPS

There are a few measures you can take to help should an emergency arise:

ICE

Put a contact number on your mobile phone under the name ICE - this is recognised as ‘In Case of Emergency’ - the person then offering assistance can contact your chosen next of kin or friend rather than look through an address book and not know who to contact.

BOTTLE IN THE FRIDGE

The Bottle in the Fridge initiative is an emergency information scheme that provides emergency services with vital health information and details of someone you wish to be contacted in an emergency. The bottle pack consists of:

- A bottle
- A basic medical information form
- Green and white emergency data link stickers, which are unique to the scheme

You should complete the form with all of your relevant medical and personal information and put this in the bottle. Also include emergency contact names and phone numbers.

You place the filled bottle in your fridge. The reason for choosing the fridge to store message bottles is that 95% of all households have one and it is generally easy to find. You put one of the stickers just inside your front door, so that it’s clearly visible to any of the emergency services, and one of the stickers goes on your fridge. The green and white stickers are recognised by the emergency services.

Bottles are free of charge and can usually be found in your local chemist, doctor’s surgery, Age UK, council offices and many other places, including police stations. **MSA**

LifeBook

Age UK has developed a LifeBook so you can record all sorts of useful details, from who insures your car, to where you put the TV licence. The LifeBook will not only help you to be more organised but could also be invaluable to a family member or a friend if they need to locate important information about you in an emergency. Simply follow the step-by-step instructions to fill in the various sections with your details, contacts and locations of important documents. For more information, visit: **www.ageuk.org.uk** and search for Lifebook

FUNDRAISING ROUND-UP

We are incredibly grateful to all our fundraisers nationwide; here are just a few highlights from the hundreds of supporters who have recently helped us.

EVENTS

Lauren Goodyer aged 13, swam a magnificent 132 lengths in one hour at her local swimming pool in Bedfordshire, in aid of the Trust. This imaginative fundraising challenge was for her grandpa, who has MSA.

Tracey Williams, Andrew Ladd and Sara Downes took part in the UK's first RideLondon event, following the 100-mile Olympic cycling route through London and the Surrey Hills. Between the three of them, they raised a mightily impressive £2,160 for the Trust.

When Peter Shelley and David O'Brien decided to fundraise for the Trust, they wanted to do something a bit different. Enter Hell & Back, a running event involving seven-foot walls to scale, barbed wire to crawl under, and mild electric shocks before the finish line. The chaps completed this challenge in style, raising £412.

Freya Donald from Dumfries and Galloway held a bake sale as part of her Guides badges, raising £50 for the Trust in memory of her grandpa.

Barnaby Kean, Sarah Bishop and Debra Dean-Chadwick formed our first Superhero Team, dressing up as their favourite childhood heroes and taking to the skies to jump out of a plane. Between the three of them, our wonderful superheroes raised £2,592.

Charlotte Harris became the Trust's first ever London to Paris cyclist, completing the gruelling 300 mile trip in just four days. Charlotte raised over £1,600 and says: "*it was a privilege to undertake this trip on behalf of people who can no longer manage activities such as this, in the hope that the money raised will find a cure and also vitally provide support for everyone affected.*"

Chris Kerss took to her motorbike for a novel fundraising challenge, completing 888 miles on the return journey between her home in Norfolk and Fife, home of the Knockhill Racing Circuit.

LEGACIES

The Trust has recently been fortunate to receive a total of £20,000 in legacy donations, kindly left to us by Sara Young and Bob Gault. Both Sara and Bob had MSA, and once their families had been taken care of they both chose to leave gifts in their Will to the Trust. We are hugely indebted to Sara and Bob, and their families. If you are considering updating your Will and would like to remember the Trust, we would be happy to give you all the information you need. Please contact Katie Heyward on 020 7940 4134 or email katie.heyward@msatrust.org.uk.

CHARITABLE TRUSTS

The following charitable trusts have chosen to support the work of the MSA Trust since the last edition of MSA News:

- The Grimmitt Trust
- The Paul Bassham Charitable Trust

Peter Shelley and David O'Brien - Hell and Back 2013

Charlotte Harris sets off to Paris

Superhero Barnaby takes to the skies

- Miss D B Simpson Charitable Trust
- The February Foundation
- The Geolyn Trust
- The Childwick Trust
- The Joseph & Mary Hiley Trust
- The W O Street Charitable Foundation
- The Sir James Reckitt Charity

AMBASSADORS

Do you sit on your children's school committee? Does your employer hold dress-down days in aid of charities? Would you be willing to go into your local Waitrose or Nationwide Building Society and ask them to consider the Trust as a Community Matters beneficiary? If so, we would LOVE to hear from you! Please call Katie Heyward on 020 7940 4134 or email katie.heyward@msatrust.org.uk.

NEW ADDITION TO OUR FUNDRAISING TEAM

We are delighted to welcome Louise Trott to the fundraising team here at the Trust. Louise joins us from a local hospice in London, and will be concentrating on growing our thriving fundraising events. If you have an events idea you would like to discuss, or if you would simply like to introduce yourself, please email Louise at louise.trott@msatrust.org.uk.

We really could not continue our work if it wasn't for our fantastic supporters. Thank you for all you continue to do. MSA

Louise Trott our new Community and Events Fundraiser

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. For all enquiries regarding fundraising events, please contact Louise Trott, Community and Events Fundraising Officer on 020 7940 4666 | louise.trott@msatrust.org.uk.

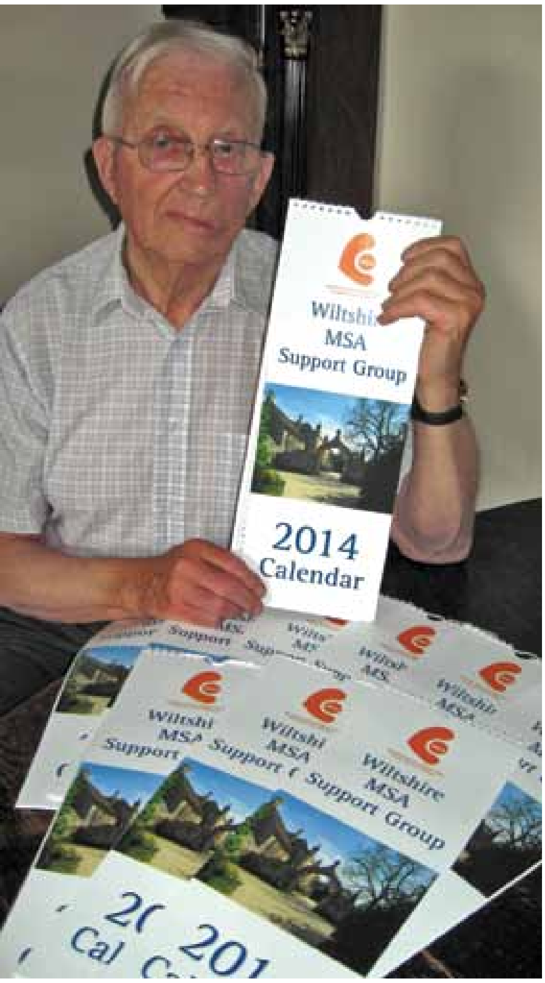
MSA SUPPORT GROUP DIRECTORY

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 for more details.

GROUP	VENUE	DATE AND TIME
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 9 Oct - 1.30pm
Yorkshire (West/North)	Darley Village Memorial Hall, Sheepcote Lane, Harrogate HG3 2RP	Thur, 10 Oct - 1.30pm
Oxfordshire	Girl Guide Hall, Southern Road, Thame OX9 2EE	Fri, 11 Oct - 2.00pm
East Midlands (10th Anniversary)	Holme Pierrepont Hall, Holme Pierrepont NG12 2LD	Tue, 15 Oct - 2.00pm
Northumberland	Blyth Community Centre, South Beach Estate, Blyth NE24 3RJ	Wed, 23 Oct - 3.30pm
Warrington	Fairfield and Howley Neighbourhood Project, WA1 3AJ	Fri, 25 Oct - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Mon, 28 Oct - 2.00pm
Gloucestershire	Whitminster Village Hall, School Lane, Gloucester GL2 7NT	Tue, 29 Oct – 2.30pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6 1JQ	Wed, 30 Oct - 2.00pm
Lincolnshire	Alvingham Village Hall, Yarburgh Road LN11 0QG	Thur, 31 Oct - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 1 Nov - 2.00pm
Cumbria PSP/MSA	Junction 44 Premier Inn, Parkhouse Road, Carlisle CA3 0HR	Mon, 4 Nov - 1.30pm
Fife	Burnside Hall, Balmullo KY16 0AW	Wed, 6 Nov - 2.00pm
Aberdeenshire	The St Mary's Centre, St Mary's Place, Inverurie AB51 3NW	Fri, 8 Nov - 1.30pm
London (North)	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 11 Nov - 2.00pm
Manchester/Oldham	Link Centre for Independent Living, 140 Union Street, Oldham OL1 1DZ	Wed, 20 Nov - 2.00pm
West Midlands	Moxley People's Centre, 3 Queen Street, Moxley WS10 8TA	Wed, 27 Nov - 2.30pm
Dorset	TBC	TBC
Kent	TBC	TBC
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 2 Dec - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 5 Dec - 2.00pm
	2014	
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 3 Mar - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 6 Mar - 2.00pm

Information for meetings in Cornwall, Dorset and Kent will be available in the coming months.

WILTSHIRE CALENDAR



A huge thank you goes to Michael Woodman for creating a 2014 Wiltshire Support Group calendar. The calendar features some stunning images of the beautiful Wiltshire countryside and is a great way of raising funds for the Trust. It sells for £7.50 plus postage and packing and makes an excellent birthday present or Christmas stocking filler. For more information about the calendar, please contact Lyn at lyn.shaw@msatrust.org.uk or on 020 7940 4666.

FIRST LANARKSHIRE SUPPORT GROUP

By Lyn Shaw, Information Officer

For some time now, the Trust has been hoping to set up a support group for members who live in the Glasgow and Edinburgh area. So we were delighted a few months ago when Georgene Wilson, whose mother has MSA, volunteered to help with setting up a new support group in Lanarkshire.

The group held its first meeting in Hamilton in August and was attended by 24 people, including Katie Rigg, Trust-funded MSA Nurse Specialist, Katie Heyward, Trust Head of Fundraising, and Lyn Shaw, the Trust's Information and Support Officer.

Katie (Rigg) led an informative and wide-ranging discussion that covered such topics as pain management; the benefits of drinking plenty of water to raise blood pressure, improve balance and clear headfog; and the benefits of moderate exercise, especially swimming and exercise bikes. Katie also spoke about the importance of guarding against making automatic assumptions that all new symptoms are MSA-related. There is a tendency to attribute all symptoms to MSA and thus resign yourself to thinking there is little that can be done. People with MSA are still susceptible to other illnesses that might be treatable. Katie reminded the group that anyone who is concerned over a symptom should consult the medical professionals looking after them or get in touch with the MSA Nurse Specialists.

We were fortunate to have Chris McBrearty, Parkinson's Neuro Nurse Specialist, attending the meeting. Chris explained her role and also encouraged members to contact her if they were having difficulty accessing local services.

We welcomed the family of the late Bob Gault, who had MSA. Bob established the national garden centre chain, Klondyke, who have named the Trust as their chosen charity partner. We owe thanks to Bob's family for their tireless work in support of the Trust and for their generous donations.

Everyone agreed that the meeting was useful and said that they would like to have another one in a few months' time. We're hoping to fix a date for that some time in March 2014.

AWARENESS OF **MSA**

Professor Gregor Wenning, consultant neurologist at Innsbruck and member of the Trust's Research Advisory Panel, was recently quoted at an MSA meeting in Sydney that MSA is just as common (or rare) as Huntington's Disease, a disease more widely known to the general public than multiple system atrophy. He said, "*With MSA we are a few years behind in our awareness.*"

The Trust, with its members around the UK, is working hard to raise the profile of MSA and, with that, increase understanding of the disease and its impact on people's lives. Here's what our members have been doing:

Clair Madonald featured in the Paisley Daily Express as part of Carers' Week. Throughout her teenage years, 19 year old Clair helped care for her mum, Janet, who had MSA. Clair was keen to focus attention on MSA and, importantly, to raise awareness too of the role of young carers.

In Falkirk in Scotland, Sam Crawford appeared in an article featured in Pick Me Up and, following in mum's footsteps, Sam's daughter Rhanna also appeared in a later edition of the magazine.

Jean Clarke, whose husband Ed had MSA, featured in the Gloucestershire Echo. The article focused on raising awareness and the importance of MSA support groups – Jean has now also helped to set up a support group in Gloucester.

Ashley Latham and Catherine Herron were featured in the Sunderland EcWho along with their mum, Isabelle Latham, who has MSA. The family are determined to raise the profile of MSA so they don't have to explain what it is to people.

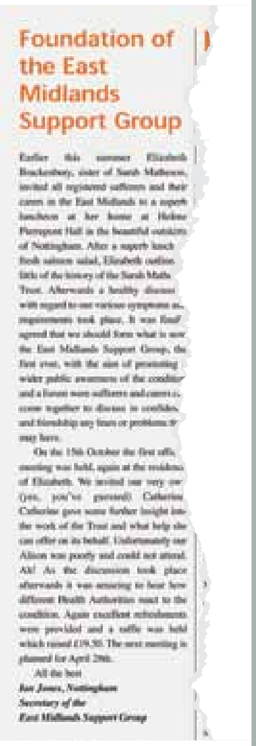
And on a global level, on 3 October MSA communities around the world joined forces on MSA Awareness Day by lighting a candle at 8pm local time to create a wave of constant light with the very emotive message of shining out hope into the world. An important message for 365 days of the year. **MSA**

FACEBOOK & TWITTER

Did you know the Multiple System Atrophy trust is on Facebook? The Trust's page keeps you updated with all our latest news, fundraising and awareness activities. Oncee you find us on Facebook, make sure you 'like' us so you stay up-to-date with what's going on. We are also on twitter, and you can follow us at @MSAtrust.

HAPPY ANNIVERSARY

On Wednesday 15th October 2003 China launched its first manned space flight, called 'Shenzhou 5'.



Foundation of the East Midlands Support Group

Astronaut Yang Liwei 'flew' for over 21 hours before landing safely in Mongolia. Meanwhile, several thousand miles away in Holme Pierrepont, on the outskirts of Nottingham, a far more momentous event was happening.

That day, ten years ago, the East Midlands Support Group met for the very first time. And it wasn't just their first meeting; it was the first meeting of any MSA support group. Elizabeth Brackenbury, sister of the Trust's founder, Sarah Matheson, opened her doors and welcomed people affected by MSA to join together in support, friendship and information-sharing. The Trust's Nurse Specialist at the time, Caroline Best, attended and gave a short talk about MSA and took questions about symptom management.

The group is still running and on October 15th this year, it will be celebrating its tenth anniversary. It is an incredible achievement and we wish the East Midlands group a very happy anniversary and offer a huge thank you to Elizabeth and her team of helpers for all they have done in the last decade to support those affected by MSA in the East Midlands area. MSA

ARE YOU AN eBayer?

If you regularly sell on eBay™ you can now choose to donate some of your profit to the Trust through the eBay for charity scheme.

STEP ONE:

Once you're ready to sell your item, go to the Sell hub and select 'Advanced Sell'. As you're filling out the details, look out for the charity box just below where you set your price.

STEP TWO:

Select a charity to support and the percentage (10%-100%) of your final selling price that you'd like to donate. Note: The minimum donation is £1 per listing.

STEP THREE:

Three weeks after your item sells, PayPal Giving Fund (eBay's partner charity) will automatically collect the donation from you. You can also manage your donations through the My Donations section of My eBay, under the My Account tab. Any fee credits will appear on your next invoice.

GIFT AID

Remember to add Gift Aid, as this means that for every pound you give the Trust will receive an extra 25p from the Government.

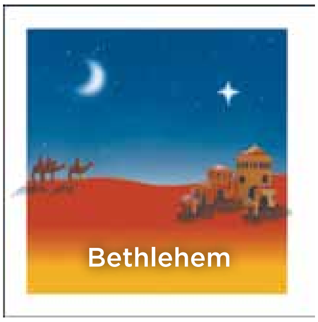
Happy Selling!

If you'd like a "shout" on Facebook and Twitter, please email us at: office@msatrust.org.uk with the link.

TRUST CHRISTMAS CARDS 2013 NOW AVAILABLE!

We're pleased to introduce our new line of Christmas cards, designed to raise both funds and awareness for the Trust.

With three to choose from, each design comes in a pack of 10 and costs £3.50 plus postage and packaging. Please see our price table for reduced costs if you purchase multiple packs or visit our online shop, www.msatrust.org.uk/our-shop to purchase these cards. Alternatively, fill in this form and return it to us enclosing a cheque made payable to: MSA Trust, and send it to: MSA Trust, Southbank House, Black Prince Road, London SE1 7SJ. **Thank you for your support!**



Our three designs measure 108mm x 108mm and each have a greeting inside reading:

"With Best Wishes for Christmas and the New Year."

Pk(s)	1	2	3	4	5	6	7	8	9	10
COST	£4.00	£8.00	£11.90	£15.80	£19.60	£23.40	£27.20	£31.00	£34.80	£38.60

MULTIPLE SYSTEM ATROPHY TRUST CHRISTMAS CARD ORDER FORM

Name:……………………………………

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Postcode:…………………… Telephone:……………………

Bethlehem (Qty):………… Friends (Qty):………… Skating (Qty):…………

Total payment enclosed £……………………

To order, please visit www.msatrust.org.uk/our-shop. Alternatively, please fill in this form and return it to us by **Friday 6th December**. WHILE STOCKS LAST!

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