

# MSA

NEWS



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## “MOTHER OF GYMNASTICS”

pledges support  
to beat **MSA**



## VALENTINE FLEMING

*Founder Trustee*  
RETIREES

# HARNESSING YOUR KNOWLEDGE

WE LAUNCH OUR **MSA LOCAL HUB**



Follow us on Twitter & Facebook and help raise awareness of MSA. See our website, [www.msatrust.org.uk](http://www.msatrust.org.uk)

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Karen Walker

**EXECUTIVE DIRECTOR AND MSA NEWS EDITOR:**

Nickie Roberts

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

The Trust is financed entirely by voluntary donations.  
Registered Charity Number 1137652.  
Company Number 7302036.

**MEMBERSHIP AT FEBRUARY 2013**

Current MSA members	978
Carers, relatives & friends	1,404
Healthcare professionals	1,747
<b>Total</b>	<b>4,129</b>
New MSA Members since 1 November 2012	88

# 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.**



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# THANK YOU

## TO FOUNDER TRUSTEE, VALENTINE FLEMING



Valentine Fleming, Founder Trustee, first Trust Chairman and our invaluable and dedicated friend, retired from the Board at the end of 2012.

As an old friend of Sarah Matheson, he responded with energy and commitment when she first identified the need for an organisation that would support those living with MSA and also their families and carers. From the earliest meetings, convened some 16 years ago in Sarah's sitting room in Vauxhall, London, he has guided the Trust as it grew and expanded into the substantial and influential body it is today. There have been, inevitably, some difficult times along the way but he steered us through with sensitivity, flexibility and a steadfast commitment to the Trust's principal aim, the support of our members.

After an initial spell as Chairman, he took on the role of Treasurer. For many years he kept on top of a formidable amount of paperwork and produced regular, meticulous records of the Trust's accounts which the rest of his less numerate Trust colleagues could

readily understand – no mean feat. Valentine has rejoiced in the Trust's steady growth and success, and without his wisdom and guidance we would never be where we are today. He has been our rock, a constant and reassuring presence, and the Trust will be forever in his debt.

*EILEEN LADY STRATHNAVER OBE, Trustee*

Valentine and Elizabeth Fleming were great friends of Sarah and supported her throughout her illness, and he willingly took up the challenge to set up a charity dedicated to helping people with MSA. He excelled in the roles he undertook and wrote the most beautiful letters in longhand, both in thanks for donations and to all and sundry, such as grant-giving trusts, major donors and doctors. Nothing was too much trouble. Even the smallest donation received a handwritten letter. There were

14 members when we started; there are now over 4,000. It is thanks to Valentine's initial hard work, attention to detail and enthusiasm that thousands of people affected by MSA have benefited from professional help and advice in coping with this devastating condition.

As Sarah's sister, I will forever be grateful to Valentine. The hard work he provided has been the foundation from which the Multiple System Atrophy Trust has developed and thrived. Today, most of the Founder Trustees have retired. It is very gratifying that the Trust's future is secure and is run by a very able group of Trustees, all of whom have been touched by the sadness of MSA, supported by Specialist Nurses and a team of dedicated professional staff.

*ELIZABETH BRACKENBURY, former Trustee and East Midlands Support Group Leader*

# HELP US TO SPREAD THE WORD!

March is MSA awareness month and we need your help to spread the word.

If you use Facebook or Twitter, look out for details on how you can add a mini-MSA logo to your profile picture to show your support for the Trust and help raise awareness at the same time. You can also check out the Trust's website ([www.msatrust.org.uk](http://www.msatrust.org.uk)) to add us to your email signature so everybody you contact through email will learn about MSA and the work of the charity.

London-based GP and journalist, Dr Sarah Jarvis, has joined the Trust's campaign and says, "Multiple system atrophy is a rare disease which many people haven't heard of. I'm helping to spread the word so more people know about MSA and can be supported with their diagnosis. The work the Trust does is vital in making sure that people with MSA get the right kind of care." **MSA**



## CAMPAIGNING FOR LOCAL ACTION ON NEUROLOGICAL ISSUES

The Neurological Alliance is looking for people to help build a regional presence by helping to set up Regional Neurological Alliances (RNAs).

There are currently 16 RNAs, and the Alliance is keen to find people willing to take up the challenge of setting up more. The aim of RNAs is to bring together local people who share a commitment to improving services for people with a neurological condition. They are independent organisations deciding their own workplan, but they all share the same vision and objectives as the national Neurological Alliance.

You can find out if there is an RNA near where you live by looking at the list on the Neurological Alliance's website ([www.neural.org.uk](http://www.neural.org.uk)); if there isn't one nearby, the Alliance can help you set one up and has produced a toolkit to guide you. For more details, please contact the Neurological Alliance on 020 7584 6457 or by emailing them on [admin@neural.org.uk](mailto:admin@neural.org.uk).

# NEWS ROUND-UP

## INTRODUCING THE MAGAZINE'S FEATURE WRITER

Gavin Duncan from Scotland has very generously taken on *MSA News*' first volunteer writer role. Gavin has first-hand experience of multiple system atrophy as his dad, Johnny, had MSA and died in September last year.

Gavin's first article for the magazine is his interview with 1970s Russian Olympic medalist, gymnast Olga Korbut (see page 10).

## THE INFORMATION STANDARD

The Trust has been awarded the Information Standard kitemark. This is backed by the Department of Health and has been developed to help guide the public to accurate and trustworthy information.

In becoming certified, the Trust has had to demonstrate necessary methods and systems are in place to ensure the information we produce is accessible, accurate, appropriately researched, authoritative, clear, complete, readable, relevant, secure, up-to-date and well-designed.

The Information Standard logo, below, is evidence of certification and will be displayed on information provided by the Trust, and any other organisation, that meets the scheme's criteria. The Trust is really proud to be part of this scheme.



## MSA IN THE SPOTLIGHT

Since the last issue of *MSA News*, the Trust has been working steadily to increase media exposure of MSA as a way of building knowledge and understanding of the disease.

*Nursing Standard* magazine, the number one weekly magazine for nurses, ran a feature on Trust MSA Specialist Nurses, Katie Rigg and Samantha Pavey, which generated a significant increase in visits to our website; Samantha Crawford and her daughter Rhanna in Falkirk, Scotland were featured in a double-page spread in the *Daily Mail* over Christmas; Sue Pinfield-Wells appeared in the *Bournemouth Echo* talking about setting a support group; and Eric Armitage has had some great coverage in the *Oldham Evening Chronicle* and the *Rochdale Observer* featuring his fundraising.

If you have an MSA story you'd like to share, please get in touch with Ellie Taylor at the Trust on 020 7940 4666 or by email at [ellie.taylor@msatrust.org.uk](mailto:ellie.taylor@msatrust.org.uk).

## BRAIN AWARENESS WEEK

Brain Awareness Week takes place from 11-17 March 2013 and is the global campaign aimed at increasing public awareness of the progress and benefits of brain research. This year's theme is 'our brains matter'. Over 70 neurological conditions are taking part in the Week through umbrella organisation, the Neurological Alliance. The Trust is represented on the event's organising steering committee.

# CARING FOR YOUR BACK

Most of us will suffer back pain at some stage in our lives. Lifting the person you care for and helping them dress or move around, can place a strain on your back. However, knowing how to protect your back can help to keep it in good shape. Carer's UK share their advice.



## TRAINING AND PRACTICAL HELP

If you are regularly having to lift the person you care for, or help them in and out of bed, you may find that this can put extra strain on your back. Your

local social services, or local carers' organisation, should be able to tell you about training opportunities on how to lift and move more safely to reduce the risk of harming your back. Alternatively, your district nurse

may be able to show you ways to lift and move more safely. Ask your GP or practice manager for more information.

You may be able to get more direct, practical help. If you've not had one, ask your

local council for a carer's assessment. This will look at your needs as a carer, and is a chance for you to talk about the kind of help you need. This could include helping the person you care for to have a bath, get up in the morning or go to bed.

You may also be able to have your home, or the home of the person you care for, adapted or have equipment that will help you and them. You can ask your GP to refer you for an occupational therapy assessment. You will get advice and perhaps alterations to your house or equipment to help you.

## IMPROVE YOUR POSTURE

Poor posture can put you at increased risk of back problems by putting extra strain on your back. This can affect your muscles, ligaments, tendons and vertebrae and, in the long term, can cause painful problems such as muscle, joint and disc damage as well as constricted vessels and nerves.

Just being aware of how you are sitting and standing can greatly improve your posture. You should stand upright with your head facing forward and your back straight. When sitting, make sure you are upright with your knees and hips level and your feet flat on the floor or on a footstool. Don't hunch your shoulders or slump in your chair. When sitting down for long periods of time, be sure to keep your back well supported using the back of your chair.

## KEEP ACTIVE

Swimming, yoga, pilates, walking, running and cycling can all help to strengthen your back. If you don't have time to do a regular sport, simple changes to your daily activities can really make a difference - walking instead of using the car for short journeys, cycling to the shops, taking the stairs instead of the lift or getting off the bus a stop earlier than you usually do.

If it's been a long time since you've exercised, or if you're thinking about increasing the amount of exercise you do, discuss it with your GP first, especially if you have any health problems.

If you already have back problems, it doesn't need to stop you from being active altogether. Exercises which focus on flexibility such as yoga or tai-chi might be beneficial - but check with your GP first. These tips may also help reduce your discomfort:

- Try to lose weight if you're overweight
- Try not to make sudden movements
- Wear flat shoes with cushioned soles, as this can reduce the stress on your back

## TREATMENT

There are two types of back pain; acute back pain which comes on suddenly and lasts less than three months, and chronic back pain which develops slowly, lasts more than 12 weeks and causes long-term problems.

Acute back pain can often

be treated with over-the-counter drugs such as paracetamol or an anti-inflammatory drug like ibuprofen, but some people mustn't take these if they are taking other types of medication or have particular health conditions. If in doubt, please consult your GP. If these don't help with the discomfort, your GP might prescribe a stronger painkiller to take alongside them. For severe pain your GP might prescribe a muscle relaxant.

In some cases, a compression pack may help. Some people find it helps to alternate between hot and cold. You can buy these or, as a homemade alternative, use a hot water bottle or a pack of frozen peas wrapped in a towel. Hold the compression pack against the painful part of your back.

Chronic back pain is often treated initially with pain killers and exercise. You should speak to your GP regarding a suitable exercise plan. Your GP may also refer you to a physiotherapist or, in certain cases, for surgery. Other options for treatment include complementary therapies such as osteopathy, acupuncture and chiropractic. **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

# *Harnessing knowledge* THE TRUST'S LOCAL HUB



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Head of Services, Neil Hunter, describes the Trust's MSA Local Hub project, designed to harness community knowledge and to offer more support at a local level.

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Multiple system atrophy is a rare disease and the fact that it is rare can sometimes have an isolating affect on the people living with it. It is an important reason why the Trust works hard to build peer support networks. Being in touch with people who are having similar experiences can help to reduce isolation, and can also provide an opportunity to share knowledge of local services.

The Trust's growing network of support groups achieves this so well. The great benefit that comes from getting people together is that knowledge is shared; this could be knowledge of helpful hints and tips about dealing with a specific problem, or the sharing of a local service that someone has discovered.

We feel there's a wealth of local information just waiting to be shared amongst members, which is why we're devel-

oping an 'MSA Local Hub'.

The Trust's MSA Local Hub is a small website, or microsite, attached to our main website that will be a portal to local information and support services. You will be able to enter your postcode into a search box and a list of services near to where you live will appear. It will include contact details and referral routes, if needed, for services that other members of the Trust have found useful or beneficial. We hope ultimately to build it into a comprehensive searchable database with all the information in one place, making it easier and quicker for people to find the support they need.

The Hub will include various sections including one on local primary care, one on regional campaigning and, of course, it will provide details of the Trust's local support groups. The aim is to develop an invaluable local resource for

people with MSA and their carers.

## **WE NEED YOUR HELP TO MAKE THIS HAPPEN**

We can build the tool, but we need help to find the information. That is how we will really capture the community feel to the Hub; the collective knowledge that all our members, all of you, have on local services is enormous. If you can help us build that knowledge into the Hub, we will have information to support so many people.

What we need is in two parts:

- The first thing we need is for you to let us know what useful services you have used or know about. It might be day care at a local hospice, a home visiting chiropodist or some hydrotherapy treatment – anything that made a difference to you. We need contact details, web ad-



dress, referral routes and any other information you feel is important to share. We have a form that you can fill in, so please contact us if you know of any service you would like to draw to the attention of others who may find it helpful.

- The second thing we need is Local Knowledge Volunteers to help us prepare the information for inclusion in the Hub. Their role will be to proof-read and check the information we receive, and to monitor it as service details change. We're looking for a couple of volunteers for each county, so if you're interested and would like to know more, then please get in touch with me on 020 7940 4666 or by emailing me at [neil.hunter@msatrust.org.uk](mailto:neil.hunter@msatrust.org.uk).

The Trust's MSA Local Hub is a really exciting development. It builds on everything the Trust stands for - greater understanding of MSA, greater support for people affected by it and a community of people supporting each other.

Together we can build an incredible resource to help everyone. **MSA**



# ARE YOU AN eBayer?

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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 Ellie Taylor at: [ellie.taylor@msatrust.org.uk](mailto:ellie.taylor@msatrust.org.uk) with the link.

# OLGA KORBUT JOINS THE FIGHT AGAINST **MSA**

A woman renowned throughout the world as the ‘mother of gymnastics’ has vowed to do all she can to help find a cure for MSA. Our new volunteer feature writer, Gavin Duncan, discovers what motivated Olga to join the fight against MSA.



The four-time gold medal winning gymnast who won the hearts of the world with her poetic displays at the 1972 and 1974 Olympic Games, found out about MSA for the first time when her ‘beloved’ friend was struck down by the rare disease.

During the 1970s Olga trained, travelled and competed in the company of Nikolai Andrianov. She became good friends with the powerful athlete, who at one time held the record for being the most decorated Olympian of all time.

However, 2011 brought the news of Nikolai’s untimely death, aged 58. The man who was revered in gymnastic circles for his strength and courage, had lost his fight against MSA.

Olga recalls her friend, saying, “As gymnasts we would see each other often during training. Nikolai was such a wonderful person; when he walked into the gym it lit up. He always made us smile and laugh.

“We travelled a lot together in the ‘70s and competed together for Russia at the Mu-

nich Olympics in 1972.

“After we both left Russia, it was hard to keep in touch, and we didn’t speak for years. When I heard of his passing, I was shocked and I cried. My immediate reaction was to grab a bottle of water and I walked for five miles at Tempe Town Lake in Arizona in his honour.

“Nikolai’s death made me think of the great times and laughs we had together. Tears came to me. I remember only the happy times.”

Like Olga, Nikolai rode the wave of the gymnastics boom in the 1970s. He too made his

name at the 1972 Games when the world awoke to a new style of the discipline.

Today, he is quite rightly still recognized as arguably the greatest gymnast that ever lived. He won a total of 15 Olympic medals for the Soviet Union, including seven golds, which was a men's record until Michael Phelps won his 16th medal at the Beijing games in 2008.

Andrianov grew up in poverty, but as a teenager he was given the chance of training as a gymnast. He grabbed that opportunity with both hands, and by the age of 18 he was an important member of the strong Soviet national team.

As his reputation grew, Nikolai was renowned for possessing immense upper-body strength, for being a daring athlete who introduced new moves into his sport. He was seen by competitors as a formidable opponent.

After retiring from competitive gymnastics, Nikolai went on to train the Soviet national junior team. He was instrumental in bringing to the fore the talent of Vitaly Scherbo, whose six gold medals in the 1992 Barcelona Olympics is the greatest performance at any single Games.

In 2001 he was inducted into the International Gymnastic Federation's Hall of Fame.

Now 57 and living in the USA, Olga remembers her friend, "Nikolai was such a great competitor, so strong. I was shocked as I had never heard of MSA until he passed."

Earlier this year, Olga sent her first rallying call to her fans around the world as she joined the fight to find a cure for MSA, "Please spread this message. Let's make a differ-

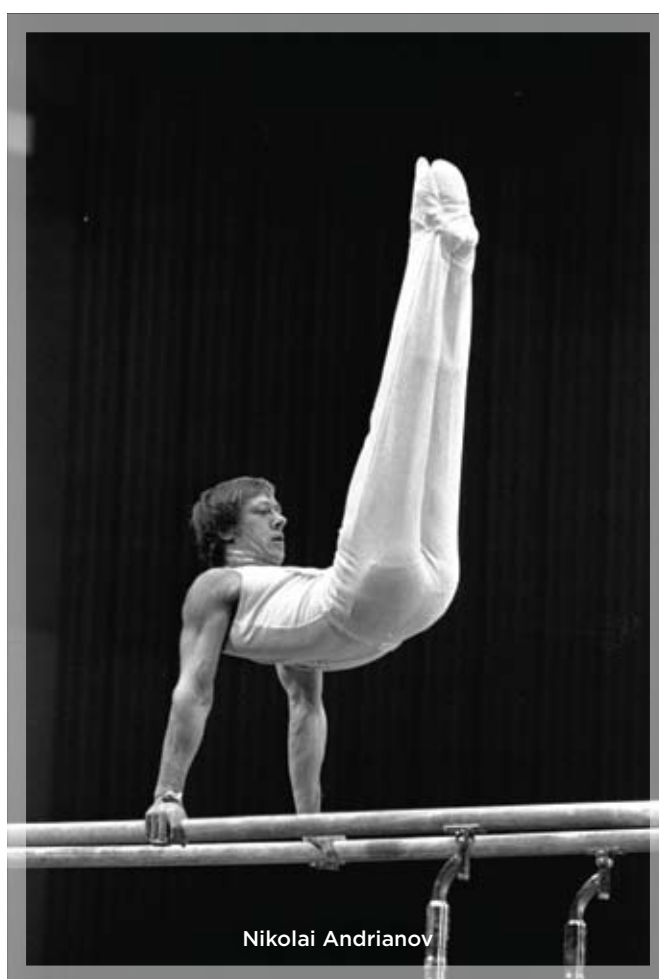
ing my help to MSA because I think I can make a difference. If a 'Cold War' can be broken, then so can anything else.

"The more people that come together, the more we can make a difference.

"My Mom was a nurse during World War II. She was a giver and provider all of her life. Today I live in her shadow, and I think she would be proud of me. I think about her every day. I always give all that I can give, and I will do that for MSA.

"I will give my support to the fight against MSA because it is what my heart was born to do. In 1972, during my last routine on the floor, I knew I had won the hearts of millions of people all over the world.

"God gave me a gift during that routine, I felt his warm hand, and delivered his message all over the world - 40 years later, millions of people still remember that magical moment. My message is peace and come together to find a cure for MSA." **MSA**



ence together."

The woman once dubbed the 'Sparrow from Minsk', also donated a month's proceeds from online sales at her website to help the cause.

Now she has vowed to help raise awareness of the rare neurological disease, "I am giv-

If you have any ideas on how to raise the profile of MSA, please get in touch with Ellie Taylor at the Trust on 020 7940 4666 or by email at [ellie.taylor@msatrust.org.uk](mailto:ellie.taylor@msatrust.org.uk).

# Easy to digest MEALS

In this issue of *MSA News* we're featuring puddings in our tasty and easy to eat recipe section.



## APPLE MOUSSE

Cut & peel 4 large apples  
Half pint of thick cream  
3 eggs

1 lemon, juice and grated rind  
2-3 oz sugar  
Half oz gelatine

Cook the apples with the lemon rind and a little water, then sieve into a basin. Melt the gelatine with a tablespoon of lemon juice (add some water if necessary); leave to cool and when it starts to thicken, add to the apple.

Whisk the eggs in a bowl over boiling water until thick and creamy; cool, stirring all the time. Add to the apple mixture, sweeten to taste then fold into the cream. Pour into an 8-inch cake tin and leave to set, then turn out.

## CHOCOLATE BLANCMANGE

1 pint milk  
Vanilla extract  
2 tbs sugar

2 heaped tbs cornflour  
1 tbs cocoa

Mix together the cocoa, cornflour and sugar with a little of the milk to form a paste. Boil the rest of the milk, add the mixture and cook until it thickens. Add the vanilla extract and stir. A ripe banana, sliced thinly, can be added to the blancmange. Serve with custard.

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.

If you have your own favourite recipe you'd like to share, please email [robin.toomey@msatrust.org.uk](mailto:robin.toomey@msatrust.org.uk) - thanks to the MND Association for letting us reproduce these recipes from their cookbook.

# TRUST PLANS: SUPPORTING THE HEALTH AND CARE COMMUNITY

Over the past few months the Trust has been conducting a survey of health and care professionals to find out what they know of MSA, and their expectations of the Trust in supporting them.

Nearly 250 responses have been received, and of these 93.5% had heard of MSA. This was not surprising because the survey had been targeted at professionals we already knew, and we asked them to help spread the word about the survey. However, less than half of those who responded were registered with the Trust, and almost a quarter of those who replied had not heard of the Trust.

Raising awareness of MSA amongst the health and care community is a priority for the Trust, so the survey asked if health professionals believed it was up to charities to help educate; the response was staggering with 100% of respondents saying they do believe it is the role of charities to help educate professionals regarding a disease. The Trust's two MSA Nurse Specialists already deliver education and awareness sessions to various groups of professionals, and we will

be looking to further develop this.

Survey results also suggested that health professionals would find it beneficial to have downloadable learning materials accessible from the Trust's website, with 86% indicating so.

Working with professional bodies was also a recommendation, with 71% of respondents indicating collaborative working on the development of learning materials as a good idea. Again, this is something the Trust will be developing over the coming months and, as an example, work is already underway with the British Association of Occupational Therapists. If successful we will try to develop similar arrangements with other organisations.

The survey also found that charity websites are the first place health professionals visit when looking for information. There will be considerable work

over the next few months to re-vamp the professionals' section of the Trust's website to include fact sheets for specific professions, a new GP section and a series of interviews with experienced health professionals to guide those encountering MSA for the first time.

Not only has the survey provided greater insight into the Trust's role in guiding the many health and care professionals who support people with MSA, but it has also recruited a number of volunteers from the medical community happy to help us develop the materials needed. Good news all round! **MSA**

# 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.

REGION	VENUE	DATE & TIME
Manchester	Mayo Building, Salford Royal Hospital, M6 8HD	Monday, 18 February - 1pm
Northumberland	Blyth Library, Bridge Street, Blyth NE24 2DJ	Wednesday, 27 February - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Friday, 1 March - 2pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Monday, 4 March - 2.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thursday, 7 March - 2pm
West Sussex	Field Place, The Boulevard, Worthing BN13 1NP	Tuesday, 12 March - 2pm
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wednesday, 13 March - 1.30pm
Yorkshire (West/ North)	Darley Village Memorial Hall, Sheepcote Lane, Harrogate HG3 2RP	Thursday, 14 March - 1.30pm
Oxfordshire	Girl Guide Hall, Southern Road, Thame OX9 2EE	Thursday, 14 March - 2pm
London (North)	Southgate Hockey Centre, Snakes Lane, London EN4 OPS	Monday, 18 March - 2pm
Dorset	Heathlands Hotel, Grove Road, Bournemouth BH1 3AY	Tuesday, 19 March - 12.30pm
Fife	Burnside Hall, Balmullo KY16 0AW	Wednesday, 20 March - 2pm
Inverurie	The St Mary's Centre, St Mary's Place, Inverurie AB51 3NW	Friday, 22 March - 1.30pm
Derbyshire	Doveside Social Club, Hatton DE65 5DT	Thursday, 28 March - 2pm
Warrington	Fairfield and Howley Neighbourhood Project, WA1 3AJ	Friday, 5 April - 2pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6	Monday, 8 April - 2pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Monday, 8 April - 2pm
Armagh	Venue TBC	Tuesday, 9 April - 2.30pm
Limerick	Classroom 1, Nurses Home, Midwestern Regional Hospital, Dooradoyle	Wednesday, 10 April - 2.30pm
Longford	The Civic Suite, The Temperance Hall, Longford	Thursday, 11 April - 1.30pm
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	Thursday, 18 April - 2pm
Wiltshire	St Paul's Church Hall, Malmesbury Road, Chippenham SN15 1PS	Friday, 19 April - 2pm

East Midlands	Holme Pierrepont Hall, Holme Pierrepont NG12 2LD	Wednesday, 24 April - 2pm
Lincolnshire	Alvingham Village Hall, Yarburgh Road LN11 0QG	Thursday, 25 April - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thursday, 2 May - 2pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Monday, 3 June - 1.30pm
West Sussex	Field Place, The Boulevard, Worthing BN13 1NP	Tuesday, 18 June - 2pm
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wednesday, 19 June - 1.30pm
Yorkshire (West/ North)	Darley Village Memorial Hall, Sheepcote Lane, Harrogate HG3 2RP	Thursday, 27 June - 1.30pm
Fife	Burnside Hall, Balmullo KY16 0AW	Wednesday, 3 July - 2pm
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Warrington	Fairfield and Howley Neighbourhood Project, WA1 3AJ	Friday, 5 July - 2pm
Cumbria	Carlisle - venue TBC	Monday, 8 July - TBC
London (North)	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Monday, 8 July - 2pm
Lincolnshire	Alvingham Village Hall, Yarburgh Road LN11 0QG	Thursday, 11 July - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thursday, 15 August - 2pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Monday, 2 September - 1.30pm
West Sussex	Field Place, The Boulevard, Worthing BN13 1NP	Tuesday, 24 September - 2pm
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 - 2pm
Warrington	Fairfield and Howley Neighbourhood Project, WA1 3AJ	Friday, 23 October - 2pm
Lincolnshire	Alvingham Village Hall, Yarburgh Road LN11 0QG	Thursday, 31 October - 1.30pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6	TBC, October - 2pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Friday, 1 November - 2pm
Cumbria	Carlisle - venue TBC	Monday, 4 November - TBC
Fife	Burnside Hall, Balmullo KY16 0AW	Wednesday, 6 November - 2pm
Inverurie	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 - 2pm
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 - 2pm

*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 Robin Toomey at [robin.toomey@msatrust.org.uk](mailto:robin.toomey@msatrust.org.uk) or drop him a line at the Trust's office: Southbank House, Black Prince Road, London, SE1 7SJ.

# FUNDRAISING ROUND-UP

## EVENTS

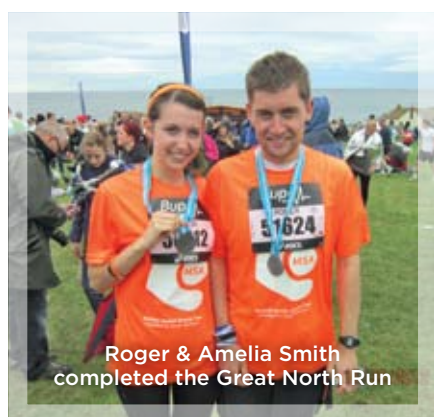
Since the last edition of *MSA News*, our brilliant fundraisers have been out in force taking part in a variety of grueling, tasty and fun events. To name just a few: Matt Handy from Cornwall drove across ten

athon... the list goes on!

This year sees a record-breaking number of people taking part in either organised events or their own, and to help our fundraisers we've recently launched our brand new supporter pack which provides

raised more than £2,000. Global service retailer, Daymon Worldwide, also showed great Christmas spirit by making a generous donation of £8,000 to support our work.

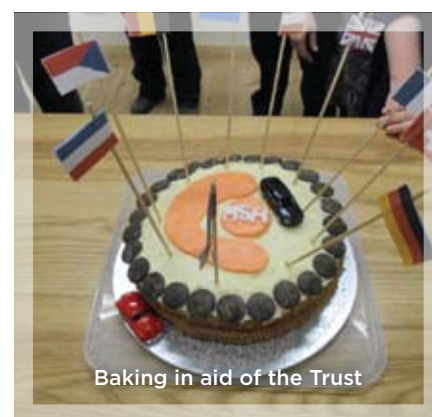
We've also had a wonderful response to our plea for com-



Roger & Amelia Smith completed the Great North Run



Matt Handy took part in an intrepid trip across Europe



Baking in aid of the Trust

countries in ten days to raise both awareness and funds for the Trust; the Hughes family from Norfolk staged a sponsored walk; Alice Herbison from Edinburgh held a bake sale; the Old Owens football club in North London organised an MSA match; Jackie Rough from Kent took part in a Santa Dash; Josh Vallis, resident of Miami Beach, took part in the Miami Marathon. We've also had fundraisers taking part in the Great South Run, the Great North Run, Preston Marathon, Wokingham Half Marathon, Brighton Half Mar-

fundraising advice and tips. So, if you're setting up your own event or taking part in an organised event such as a marathon, 10k, cycle ride or swim, please download the pack from our website ([www.msatrust.org.uk](http://www.msatrust.org.uk)) and get in touch – we're here to help.

## COMPANIES HELP TOO!

Christmas 2012 saw the Trust expand its choice of Christmas cards by offering our traditional format and, for the first time, our own e-card donated by Wish-a-wish Cards, which

panies to donate goodie bags to our marathon runners this year, securing gifts from Unilever, High5 sports nutrition, Maximuscle and Nike.

If your organisation supports charities through fundraising activities, or if it has a Charity of the Year partnership you think the Trust might be eligible for, our Head of Fundraising, Katie Heyward, would love to hear from you ([katie.heyward@msatrust.org.uk](mailto:katie.heyward@msatrust.org.uk) or call on 020 7940 4666).



## SUPPORT FROM CHARITABLE TRUSTS

Our thanks to the following charitable trusts who have supported us in the past few months:

- The Thoresby Charitable Trust
- The Constance Travis Charitable Trust
- The Family Rich Charities Trust
- Royal Naval Association
- Stonewall Park Charitable Trust
- The Coutts Charitable Trust
- The Swire Charitable Trust
- The Tadpole Trust



Team Pardoe abseiled down the Trafford Centre

the cause and a cure for this devastating disease.

Here's how your monthly gift can help:

- £10 could supply detailed information to 12 healthcare teams per year, each caring for one person with MSA
- £20 could provide Trust welcome support packs to 36 families a year

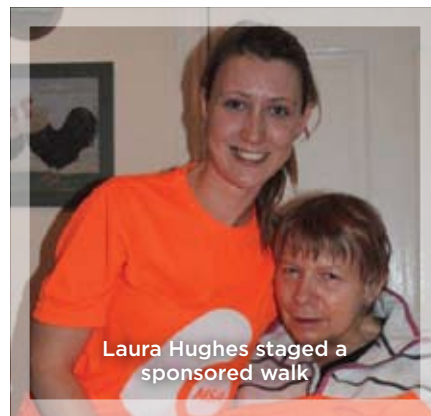
## REMEMBERING THE MSA TRUST

In January of this year, we received a generous legacy of £10,000 from Miss Leaf. Miss Leaf was a member of the

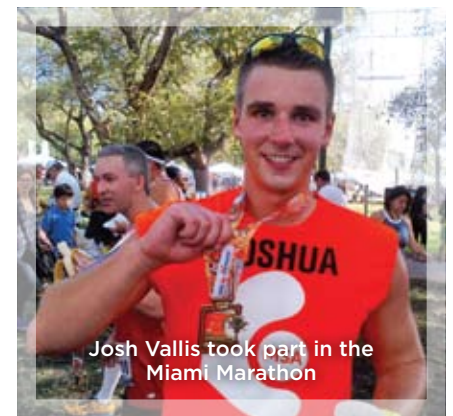
to plan ahead with confidence. If you have chosen to remember the Trust in your Will, or if you would like further information on how you can leave a lasting legacy to people affected by MSA, please get in touch with Head of Fundraising, Katie Heyward.

## ONGOING APPEAL

We're delighted to report that in 2012, with your support, we raised over £400,000 which allows us to plough more funds into research as well as continuing to develop much needed services for people af-



Laura Hughes staged a sponsored walk



Josh Vallis took part in the Miami Marathon

## REGULAR GIVING

Making a regular gift to the Trust is a great way of helping us to plan our future work with confidence, knowing we can continue to support those people affected by MSA in the UK and Ireland, while also funding research into finding

Trust and wished to support our work by remembering the charity in her Will. We are extremely grateful for the opportunity her bequest provides to continue our support and research activities.

Legacies of all values really are vital, and enable the Trust

affected by MSA. As a growing organisation, we've also looked at our infrastructure, and now have in place a structure which will help us to meet ongoing demands. We look forward to keeping you posted on our developments, and to updating you with our progress. **MSA**

### The fundraising team at the Trust are here to help:

For enquiries about company support, regular giving, leaving a legacy or charitable trusts, please contact Katie Heyward, Head of Fundraising on 020 7940 4666 | [katie.heyward@msatrust.org.uk](mailto:katie.heyward@msatrust.org.uk).

For all enquiries regarding fundraising events, please contact Mike Coffey, Individual Giving & Events Fundraising Officer on 020 7940 4666 | [mike.coffey@msatrust.org.uk](mailto:mike.coffey@msatrust.org.uk).

# BENEFIT CHANGES

## WHAT DO THEY MEAN FOR YOU?

In March of last year, the Government's Welfare Reform Act received Royal Assent. The Act will produce the biggest change to the welfare system in over 60 years.

Spearheading this change is the introduction of Universal Credit which offers support for those in work on a low income, as well as those out of work. It will combine several existing benefits into one complete package. The benefits it replaces include: Income Support, income-based Jobseekers Allowance, income-based Employment Support Allowance, Housing Benefit, Child Tax Credit and Working Tax Credit. It will be introduced in a few pathfinder areas in April 2013 with a wider launch in October 2013. Entitlement is based on a number of criteria, but applicants must be between 18 and state pension age and be in Great Britain. More information about Universal Credit can be found at [www.dwp.gov.uk/policy/welfare-reform/universal-credit](http://www.dwp.gov.uk/policy/welfare-reform/universal-credit).

Another key change under the Welfare Reform Act will see the Disability Living Allowance (DLA) stopped and replaced with a Personal In-

dependence Payment (PIP). An assessment will be needed for PIP payments. It will provide financial support for extra costs caused by ill-health or disability. The payments are based around 'need' and to ensure the right level of support is in place, need will be assessed regularly. From 8 April 2013, new claimants in the North West and North East of England will be put onto the PIP scheme. The rest of the UK will be included from June 2013. Existing DLA claimants will be moved over to PIP in 2015. However, any adjustment to existing DLA claims from October 2013 will prompt an invitation to be moved over to PIP. If you are already claiming DLA you do not need to do anything, the Department for Works and Pensions will contact you in 2013. More information about PIP can be found at [www.gov.uk/pip](http://www.gov.uk/pip).

April 2013 will also see the launch of the much talked about benefit cap. This is a

limit on the amount of benefit that most people between 16 and 64 receive. The cap's level has been set at £500 a week for couples and single parents whose children live with them, and £350 a week for single adults who don't have children or whose children don't live with them. The cap will apply to the total amount that people in your household receive from a range of benefits.

The benefit cap does not apply to all; you will not be affected by the cap if you qualify for Working Tax Credit or any of the following: DLA, PIP (from April 2013), Attendance Allowance, Industrial Injuries Benefits or Employment and Support Allowance. More information about the benefit cap can be found at [www.gov.uk/benefit-cap](http://www.gov.uk/benefit-cap).

The Trust has produced a guide to benefits and support. If you would like a copy, please contact us by calling Lyn Shaw on 020 7940 4666 or emailing [office@msatrust.org.uk](mailto:office@msatrust.org.uk). MSA

# MSA CLINICS UPDATE

Issue 35 of *MSA News* carried an article on MSA clinics; there have been a few changes since the magazine was published:

## **Southampton General Hospital in Hampshire and The Royal Gwent Hospital, Gwent**

Clinics are not yet up-and-running. Further details will be published as soon as they become available.

## **Plymouth**

Apologies to Professor Zcyicek at the Derriford Hospital who does not run an MSA clinic. However, there is a six-monthly clinic in Plymouth at the Mount Gould Hospital run by the Trust's MSA Specialist Nurse, Samantha Pavey and Parkinson's Specialist Nurse, Fiona Murphy. Telephone: 01752 268 011.

# TRUST-FUNDED RESEARCH INTO COGNITIVE ISSUES

Trust funded researcher Dr Kathryn McDonald will be joining Dr Christopher Kobylecki and Dr Alex Gerhard at the University of Manchester's neurology department this April to start work on imaging studies aiming to identify which areas of the brain cause problems associated with MSA. Dr McDonald, who has assessment experience of people with parkinsonian disorders, has recently held the post of Senior Research Practitioner in the Department of Neurology at the Salford Royal NHS Foundation Trust. She has a PhD in Neuroscience and is a Professional Member of the Institute of Clinical Research, UK as well as the British Association for Cognitive Neuroscience.

## *In Memory*

Gloria Pearce  
Stanley Goldsmith  
Joan Prytherch  
Dianne Calladine  
Kathleen Parkin  
William (Bill) Cherrington  
Bill Ward  
Patricia Woodman  
Alan Sackwild  
Brian Royle  
George Graham  
Stephen Booth  
Della Berryman

Bernard Dowd  
Tony Salkeld  
William Brooks  
Siven Doorghen  
Doris Williams  
Jack Conway  
Irene McIntosh  
Michael Perry  
Michael Bromley  
Raksha Devi  
Peter Moore  
Ronald Lummis  
Gordon Morgan

Robert Boyall  
Susan Tait  
Ron Daniels  
Joe Peake  
Jean McHale  
Lorna Whitehead  
Christine Cross  
Margaret Sadler  
Fred Darnell  
Pamela Wait  
Marian McArragher  
Reen Pilkington  
Margaret Bridges

Linda Michael  
Audrey Broughton  
James Grant  
Rose Mary Page  
Julia Reay  
Sara Young  
David McCormick  
Maureen Collinge  
Rosemary Bamber  
Alistair (Ally) Connor  
Evelyn Harman  
Iskra Veneva-Kantchev  
Olive Augustine

# MSA TRUST T-SHIRTS STAND OUT FROM THE CROWD!

Our t-shirts are a brilliant way of raising awareness. Whether you're cheering on somebody fundraising for the Trust or popping down the shops, put on your MSA t-shirt and be noticed wherever you go!

If you wear one of our t-shirts out and about, please take a picture of yourself and send it to us. We'll publish them on our website and social media, and together we can spread awareness of MSA. To order a t-shirt, please complete and return the form below. T-shirts cost £10 each, plus £1.75 P&P.



## MULTIPLE SYSTEM ATROPHY TRUST T-SHIRT ORDER FORM:

Name:.....

Address:.....

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

Email address:.....

**T-shirts cost £10 each plus £1.75 for P&P.**

Quantity required:..... Size(s): (S, M, L, XL).....

Total payment enclosed £.....

Please make cheques payable to: **Multiple System Atrophy Trust** and send to:

Multiple System Atrophy Trust, Southbank House, Black Prince Road, London, SE1 7SJ

For more information contact Mike Coffey on 020 7940 4666 or email at [mike.coffey@msatrust.org.uk](mailto:mike.coffey@msatrust.org.uk).