

MSA NEWS



▶ ISSUE 42, 2015 | WWW.MSATRUST.ORG.UK

LET'S GET

TALKING



PATRONS:

Sir Roger Bannister CBE FRCP
Professor CJ Mathias DPhil DSc FRCP

TRUSTEES:

Professor David Burn
Michael Evans
Professor Clare Fowler (Chair)
Darcy Hare
Alexander Loehnis
Hugh Matheson
Geoffrey Murray
Hon Clare Powell
Karen Walker (Vice Chair)

EXECUTIVE DIRECTOR:

Nickie Roberts

MSA NEWS EDITOR:

Andy Barrick

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.

Registered Charity Number 1137652
Company Number 7302036
Scottish Charity Number: SC044535

MEMBERSHIP AT FEBRUARY 2015

Current MSA members	1,141
Carers, relatives & friends	1,941
Healthcare professionals	2,034
Total	5,116
New MSA Members since September 2014	119

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.**



FAMILY AND FRIENDS DAY <i>Our biggest get together</i>	04
NEWS ROUND-UP	05
MSA GUIDE <i>Communication</i>	06
BUILDING AWARENESS <i>MSA Awareness Month</i>	07
MSA TRUST RESEARCH FUNDING	08
IN MEMORY	09
MEMBERS TALENT	10
CARERS CORNER <i>Pilot Days</i>	11
OUR GREAT VOLUNTEERS	12
WHEN TALKING HELPS	14
FUNDRAISING ROUND UP	16
EUROPEAN RESEARCH PROJECT	17
SUPPORTING & HELPING EACH OTHER <i>Members share tips</i>	18
UPCOMING SUPPORT GROUPS	19
AWARENESS MONTH RESOURCES	20

WELCOME TO MSA NEWS



Glancing through our latest Annual Review, it's great to see how many of our five year goals are well underway and are involving our members and their families.

Throughout this issue of MSA News we report on some of these goals, which have developed from the “open-ear” we have to your views, comments and observations.

Our goal to grow a volunteer network to help us raise awareness, develop local knowledge and fundraising, in essence - to build our “army of supporters” - is covered on pages 12-13. You can read why four new volunteers are sharing their time with us to build the network, improve understanding of MSA amongst GPs, grow our funds and our support groups.

The Trust's Vision is a world free of MSA, and in line with our goal to increase the charity's commitment to funding research and working collaboratively, we have just announced our 2014 research grant awards. We focus on one of the successful projects which can be found on page 8; we have pledged £150,000 for this year's grant round which goes live in May. There are exciting times ahead for research into MSA as we await a report from a meeting of worldwide experts in the field, who hope to define a global approach and focus to MSA research in the future. And a little pat on the back to the Trust as it has obtained membership of the Association of Medical Research Charities – the standard setting body for research grant giving and monitoring.

Increasing support for carers is another of our goals, and we have already produced a Carers Guide which signposts where to find support – emotional and practical. We recently held a pi-

lot Family and Friends day, reported on page 4, which was intended to provide people with MSA and their carers an opportunity to get together and exchange ideas and, at the same time, to hear from health professionals about managing MSA and learning about treatments. Early feedback has been very positive, so watch this space for details on future events.

Our full Annual Review can be found on our website and it details what we've been doing to, I very much hope, make life with MSA just a little bit easier. It also sets out our aspirations for the next five years, so please do take a look and share your thoughts with us.

Lastly I'd like to welcome on board our new Head of Services, Andy Barrick, who joins us from the Royal National Institute of Blind People. He has a wealth of experience in support provision, and will be reporting in the next issue of MSA News on progress across our range of services.

Nickie Roberts
Executive Director

LET'S GET TOGETHER

What if you mixed over 70 people with MSA, their family and friends and healthcare professionals in a hotel for a day in Cardiff? What would happen? **We find out.**



Increased support for people living with MSA and their carers are key goals in the Trust's five-year strategy published last year having taken on board comments from members and supporters. In October last year, we piloted a Family and Friends day which gave people living with MSA and their carers an opportunity to get together and hear from health professionals about managing MSA and learn about latest techniques.

Jill Lyons, one of our Specialist MSA Nurses and Emma Rushton, the Trust's Support Services Officer, organised the event in Cardiff, which attracted over 70 people, from Wales and from across the border.

Feedback, both on the day and after, has been extremely positive and as a consequence we will be organising future events based on a similar format.

For those who were un-

able to join us this time, this is what you missed and what type of things you can anticipate later this year:

- An introduction to the work of the MSA Trust and how we can help you
- How Parkinson's nurses can provide support in localities
- An open question and answer session with neurological consultants about MSA and latest treatments and developments in care
- Palliative care support and its role in increasing your sense of wellbeing
- How Physiotherapists can help and a taster session on movement to music

Future events will offer a great chance to network with others over lunch, speak to experts in the care of people with MSA and talk to the Trust's Specialist nurses.

As a flavour of the day this is what a couple of our members said:

"Gave me lots to think about and new ideas to try"

Ceri Luca from Newport

"Movement to music was such a positive way to end the day"

Lyn O'Keefe from Cardiff

We will be organising another day later this year in the North of England so look out for information in the next edition of MSA News as to how you can register your interest. For further information please call 020 7940 4666 or email support@msatrust.org.uk.

NEWS ROUND-UP

NEUROLOGY AND 'INVISIBLE PATIENTS'

The Neurological Alliance has released a new report, *The Invisible Patients: Revealing the state of neurology services*.

Based on a survey of nearly 7,000 patients, amongst them people with MSA, the reports key finding revealed that 58% of patients had experienced problems in accessing the services or treatment they needed.

The Trust has been given access to anonymised data and will be looking at where responses from people with MSA are different to other conditions to highlight and address any specific areas of shortcoming. **MSA**

JOB OPPORTUNITY - THE UK MSA NETWORK

Plans for the establishment of the UK's first MSA Network continue to move forward following the Trust's award of a research grant. Project leader, Professor Henry Houlden, is now looking for a research technician to join his team investigating the cause of MSA. Based within the Department of Molecular Neuroscience at the Institute of Neurology, London, the successful applicant will take on the essential role of co-ordinator of the UK MSA Network which has been designed to develop an MSA clinical and molecular bio-resource.

If you know anybody with a degree in a relevant subject area, experience in cell biology or biochemistry or a related subject area and ideally a background in neuroscience, Professor Houlden would love to hear from them; informal enquiries may be made by emailing him at h.houlden@ucl.ac.uk. **MSA**

BBC RADIO 4 APPEAL

2015 kicked off with Sir David Hare, our MSA Champion and renowned playwright, broadcasting the BBC Radio 4 Appeal for the Trust. Sir David has a special connection to the charity as his good friend, Sarah Matheson, was our founder. Sarah died from MSA in 1999.

Sir David saw first-hand Sarah's horror, once she was diagnosed, at how little information was available for people with MSA, their families, friends and carers and set about changing this. She formed the Trust in 1997 and the first support group took place in her sister's front room.

To date we've received over £10,000 in donations on the back of the BBC Radio 4 Appeal. We are tremendously grateful to Sir David Hare and to everyone who listened and donated. **MSA**

OUR NEWEST CORPORATE PARTNER - ESL

Established in 1999 when it ran its first payroll in the UK, 'esl' works with some of the best known UK companies. Following esl's annual charity partner staff vote, the Trust was unanimously chosen to become the company's 2015 charity partner.

Virginia Freeman, esl's Director of Commercial Development said: "We are delighted to have the MSA Trust as our charity of the year. It is a cause very close to our heart, providing excellent and vital support to a member of the esl family. We look forward to a successful partnership."

To learn more about esl, please visit their website www.employerservices.co.uk. **MSA**



MSA GUIDE:

SPEAKING UP, SPEAKING LOUDER

Being able to communicate with others is known to be a key issue for people with MSA. Andy Barrick, Head of Services, looks at some ideas which have enabled people to have their voices heard.

WHO TO GO TO?

A key resource for people who are having difficulty with communication are Speech and Language Therapists (SLTs). They are health professionals who specialise in treating people with speech, language and communication problems. They also work with people who have eating and swallowing needs. Through a process of observation and assessment, they can determine difficulties and potential solutions or coping mechanisms. The Trust is in contact with nearly 300 SLTs and we recognise them as being vital in supporting people with MSA, so make sure you have access to an SLT through your GP if you haven't already been referred.

WHAT EQUIPMENT MIGHT WORK?

There is a wide range of equipment that can make a real difference. Talk to your

SLT who will offer advice based on your individual needs, as well as offering guidance on what is cost-effective for you. They will also be able to advise you if any equipment can be provided at no or low cost through the NHS or social care systems.

Tips that members have told us about include:

- telephones that can amplify the outgoing voice of a softly spoken person
- voice amplifiers that can be pinned to lapels or clothing to increase volume of speech
- a simple arrangement using a basic wireless doorbell hung around the neck so that people can ring throughout the house for assistance, (the bell needs to be plugged in to work but can easily be moved)
- apps for iPads and other systems so that people can input what they want to say and have it read aloud.

THE SPOKEN WORD

People have also told us that they can sometimes find it more difficult to read. One organisation that can help with this is Calibre Audio Library. This is a national charity providing a subscription-free service of unabridged audio books for adults with disabilities who find it difficult to continue reading hardback and paper books. They can be contacted on 01296 432 339 or through their website on www.calibre.org.uk.

As ever our Specialist Nurses will be able to talk through your communication worries. You can contact them at nurses@msatrust.org.uk. **MSA**

We would also love to hear of any equipment or services that have helped you and which could help others. To share your ideas please email support@msatrust.org.uk or call 020 7940 4666.

SPRING, DAFFODILS, MARCH - IT'S MSA AWARENESS MONTH

It doesn't seem that long since World MSA Awareness Day 2014, and now the Trust is getting busy using MSA Awareness Month as a hook to raise the profile of MSA. Franca Tranza, Head of Communications, reports:

It's our aim to connect with everyone in the UK who has MSA and support them, their families, friends and carers throughout their journey. We know how isolating it can be to have a rare disease such as MSA, so it's our role to help ease this isolation and be there for the people it affects.

Social media is becoming an increasingly important tool for engaging with our members and supporters, and for MSA Awareness Month we have adopted a dedicated hashtag to mobilise support. If you're using Twitter during March, please use [#MSAAM](#) so we can make some virtual noise this year!

Many of our activities are linked to fundraising and every one of them gives us the opportunity to talk about MSA and raise awareness. It's also really important to highlight that the Trust does not work alone but with partners across the globe, and together it's our aim to spread the word about MSA.

We've got lots of events happening in March, kicking off on Monday, 2nd with Charity Chuckle for MSA, a fantastic night of laughs at the Comedy Store in London. Comedians include MC Mark Maier, Angie McEvoy, Steve Best, Pete Beckley and Dominic Holland. All proceeds from the night will be donated to the Trust.

"I alone cannot change the world, but I can cast a stone across the waters to create many ripples." Mother Teresa

After the success of last year's inaugural Service of Light in London, we will be holding two services this year to coincide with MSA Awareness Month. One is in Manchester on Saturday, 7 March and one in London on Saturday, 21 March. Last year tickets went so fast that we had a reserve list, and we were really sorry to have to disappoint some people. We hope by having two UK events in 2015 more people

will be able to come together to remember and celebrate the lives of their loved ones.

Our very exciting fundraising event, the Sahara Trek, comes to an end on Sunday, 8 March. This year we've got two people taking on the challenge, both affected by MSA and passionate about raising money for the Trust. We're really grateful to them, and hope to be able to share some of their stories and pictures later in the year.

Following on from the successful corporate partnership last March with Klondyke Garden Centres, this is being renewed this year with events and fundraising activities taking place across Klondyke stores throughout March. **MSA**

If you're interested in keeping up to date with our events, please email

melissa.tindle@msatrust.org.uk

or for further information call 020 7940 4666.

RESEARCH ROUND-UP



We know research is a key priority for our members. So with this year's awards now finalised we look at one of the two projects that have been agreed.

The MSA Trust has granted funding to a team at University College London's Institute of Neurology. Led by Professor Janice Holton, who has already carried out extensive research into MSA, the project will focus on the build-up of the protein 'alpha-synuclein' in the brains of people with multiple system atrophy.

It's entirely normal to find alpha-synuclein in a healthy brain, as well as in the heart, muscles and other tissues. The protein's exact role is still unclear but, in the brain, it's thought to act as a sort of regulator – controlling the release of the chemicals (neurotransmitters) that relay critical messages between the brain's different nerve cells (neurons).

In people with MSA, it's the sheer volume of alpha-synuclein in the brain that's the problem. In fact, a build-up of the protein has been identified in both MSA and Parkinson's patients. These clumps of excess alpha-synuclein can put a great deal of stress on the brain's neurons

and cause them to malfunction – a hallmark of MSA. But what causes the build-up in the first place?

Previous studies have revealed that no extra alpha-synuclein is being produced in people with MSA – which suggests the problem must lie in the way the protein is usually broken down and flushed out.

It has already been shown that the enzymes which usually break down and clear out alpha-synuclein aren't working properly in the brains of people with Parkinson's disease – but until now there has been no dedicated research into their effect in patients with MSA.

In this new project, the team at UCL will work closely with the Dementia Research Group at the University of Bristol to investigate how these enzymes affect levels of alpha-synuclein (both normal and mutant forms) in people with MSA. It's hoped that the project will reveal a lot about how alpha-synuclein proteins behave in the brains of MSA patients, and

whether they can be flushed out by adjusting the enzyme levels.

Dr Aoife Kiely, who will be working on the project under Prof Holton, is enthusiastic about the project.: "What I particularly like about this is its collaborative nature. Not many people research MSA and we have these little pockets of expertise dotted around. The only way we will push forward is if we all work together and share that expertise."

Previous work carried out by Prof Holton's team has focused on investigating neuro inflammation (inflammation of nervous tissue) in MSA – the findings of which have proven very informative and which are set to be published in the near future.

The MSA Trust has granted £100,000 in funding, which has only been made possible thanks to our generous supporters. The project is due to start in 2015 and will continue for around 19 months.

In the next edition we will focus on the other research project funded by the Trust. **MSA**

SERVICE OF LIGHT 2015

This year we will be holding two Service of Light events in Manchester and London. We hope the services will offer you a sensitive and meaningful way to remember and celebrate the lives of your loved ones.

Everybody will receive a warm welcome as we gather for readings, hymns and songs performed by a choir. During the service candles will be lit, with each one celebrating the life of someone we have lost to MSA. The names of those being remembered will also be printed in the Book of Remembrance, part of the Order of Service for the day.

If you would like to join us at a Service of Light for MSA, please call us on 020 7940 5659 and ask to speak to Melissa Tindle. We are asking for a *voluntary* ticket donation of £10, with all proceeds going to MSA research. **MSA**

THE EVENTS WILL BE TAKING PLACE ON:

Saturday, 7 March 2015 - 3pm

St Ann's Church, St Ann's Street, Manchester

Saturday, 21 March 2015 - 4pm

St Paul's Church, Covent Garden, London

In Memory

Donald Drummond
Richard Ward-Smith
Patricia Fox
Desmond Smith
Kath Edgeworth
Robin Galletly
Richard Bishop
Melanie O'Brien
Margaret Brothwood
Terry Pickard
Oliver Finnegan
Michael Smith
Michael Herbert
John Burke

Janet Bamford
Janet Wood-Ives
Shirley Lyon
Catherine O'Rourke
Marina Brown
Terry Clark
Malcolm Godfrey
Freda Hanvey
Pamela Weyhaupt
Derek Gill
Anne-Marie Moore
Tim Gardiner
Paul Harman
Margaret Brighton

Valarie McIlroy
Cheryl Barclay
John Wharrad
Malcolm Riddell
Joyce Baines
David Sherrington
David Neagle
Janet Byrne
Patricia Hume
Barrie Hawkins
Mohammad Akram
Bill Abbott
David Hogg
Marten Marriott

Alan Green
Jimmy Docherty
Colin Rhodes
Joan Bishop
Peter Dunsford
Janet Benford
Michael Adair
Sara Nagle
Lawrence Blackburn
Linda Bentley
John Hexter
Janet Gordon
Marjorie Hardy
Robin Alp


CREATING & COMMUNICATING

One of our members, Allison Ellerby from Surrey, has been taking part in a project looking at the benefits of creative writing at her local hospice. Here are a couple of her poems.

What every woman should carry: I Become Cat

*My bag is full of tissues,
for tears, runny nose in the cold,
I drop food down my front - more tissues!
Glasses and case, I need to read.
My diary, full of appointments, stress.
My purse, heavy with cards and slips of paper.
Oh! And some money in the purse.
Keys, colour coded and precious.
Anxious, I need to get home, safe.
Life is a challenge. Why is it so hard?
A pen, at the bottom, lost as usual.
A brush, but now I need help to brush my hair.
Frustrated, heavy bag.*

*My body lengthens, stretches out,
feels good.
My ears grow upwards, become pointed.
Suddenly I can turn them and hear so much,
Can hear high pitched sounds.
I fall onto all fours,
my arms become legs,
I feel light and agile,
I can crouch and then jump,
landing lightly, poised.
My eyes grow huge, darkness is no problem.
I am alert to movement.
Out of my bottom grows a magnificent tail,
I swish it proudly,
and in my soft paws, I have shiny claws,
meow!*



Another one of our support group attendees from Shropshire, Jill Barrow who herself has MSA, has recently had one of her photographs, "Coming Home", Highly Commended in the British Wildlife Photography Awards.

CARERS CORNER

CARER'S EVENTS

A recent Trust survey found that many carers of people with MSA, wanted to meet and share their experiences. Emma Rushton, the Trust's Support Services Officer, reports on two pilot events.

Caring for someone with MSA can often be difficult, but knowing you are not alone and that help is out there, can come as a relief to many.

Two events were held in Manchester and Kent and were the first of their kind hosted by the Trust. We wanted to provide carers with honest, practical advice on MSA, how carers could look after themselves and also give an opportunity to explore the services available to them.

We were delighted with the feedback from both days and especially on how well received the presentations were from our Specialist Nurses.

Sue Smith an attendee at the Kent event said "Excellent! Thank-you very much. It was good to hear what MSA is in plain language". MSA is a complex condition and members have told us it is often confusing when difficult language is used, so hearing it put in layman's terms proved very useful.

Some useful tips we picked up on both days included:

- practical issues such as employment rights and the benefits system. These can be overwhelming topics, but are an important part of making sure that people with MSA and their carers get the right financial support. For instance, you may be entitled to council tax reduction if you have a room specially adapted so contact your local authority about this
- a key tip given by the representatives at the Manchester Carers Centre was that every carer has a right to a Carers Assessment from their local authority even if they live separately to the person they are caring for. Contact your local authority social care team to look at carers needs, as well as that of the person they are looking after, and note that this can also include looking at the home to see if any

adaptions or equipment can help

- information was given on local support available by Carers First Kent and Medway. Carers centres can provide counselling sessions, befriending services, courses including first aid and peer support activities. To find your nearest carers centre visit the Carer's Trust website www.carers.org where you will find information about local resources.

We are hoping to incorporate parts of the carers days into our Family and Friends Day later on this year, so look out for information on this in the next edition of MSA News. **MSA**

If you have any comments or questions about the carers events or the topics covered please email emma.rushton@msatrust.org.uk or call 020 7940 4666.

SPOTLIGHT ON VOLUNTEERING

The Trust couldn't do all the things we do without our volunteers. Here Emma Myers, our Volunteer Co-ordinator, puts the spotlight on some of our stars and reports on the progress in building the Trust's volunteer network. It would be impossible to feature everyone but here is a small selection of some of the things members are doing to support our work:

Tony Regan



Tony Regan from Liverpool, is the Trust's first Regional Lead Volunteer working in North West England. Tony wanted to volunteer for the Trust in memory of his wife, Delia, who sadly passed away in May 2014 from MSA.

Tony said, *"This is a bit of a crusade for me. I want to use the knowledge and experience I have of caring for someone with MSA to help improve the lives of other people affected. I hope the role will enable me to increase awareness of MSA, offer support to families in accessing services at a national and local level, and raise funding for research and patient care."*

Regional Lead Volunteers help the Trust by supporting, motivating, inspiring and managing groups of volunteers who are raising funds and increasing awareness of MSA in their local areas, and we are delighted to have Tony on board and leading the way in the North West.

Greig Shute



Greig Shute from Nuneaton, has been raising funds to support the work of the Trust by using his contacts to host a fundraising golf day event. Greig's father was diagnosed with MSA around three years ago, and Greig has since found the Trust to be a great source of support and advice. By

hosting the event Greig felt he was doing something positive to support the charity and to show support for his father. The event was a huge success, surpassing an initial fundraising target of £1,500. The final total raised was £4,154 and people are asking when the next event is going to be held. Greig said, *“The fight against MSA is not just with the person who has it, the fight is with everyone involved and together we can make a difference.”*

Julie Marriott



Julie Marriott from Nottingham, has been making contact with GP surgeries in her local area to help raise awareness of MSA and the work of the Trust. After losing her mother to MSA, Julie wants to help increase the knowledge of health and care professionals so they can provide better and more timely treatment and care. She is now in regular contact with her local GP training surgery, and provides leaflets and information on MSA and the work of the Trust which is passed on to all new GPs during their

training. *“I felt so frustrated by having to explain what my mother’s condition was to the people who were treating her; I want to do anything I can to help other families avoid that upset.”*

Rosemary Arbuthnot



Rosemary Arbuthnot from County Armagh, has been helping the Trust to co-ordinate its Northern Ireland support groups since 2010 when she lost her husband to MSA. Rosemary is often contacted by people affected by MSA and is very good at putting people in contact with the Trust for help, advice and support. She also engages support from local politicians and policy makers for people with MSA, eg, attending the Lord Mayor’s parlour in Belfast, lobbying policy makers and ensuring MSA is on the agenda across Northern Ireland’s relevant health and care groups. *“At the time my husband and I needed support there was nowhere to turn for people affected by MSA, so I am keen to support the Trust*

in developing its presence in Ireland so others are able to access the crucial support they need.”

We are always keen to find out what our members are doing in the local community and would love for you to share with us the innovative, creative and inspirational ways in which you help to raise funds and increase awareness. **MSA**

Thinking about volunteering for the Trust? We have some great opportunities, so please email Emma Myers, Volunteer Coordinator volunteer@msatrust.org.uk or call her on 07951 740332 for more information.

We are always on the lookout for volunteer support group leaders so if you are interested in finding out more about the role please contact us at support@msatrust.org.uk. We are aware that it is difficult for some people to get to support groups, especially those in rural areas, so we are keen to get your thoughts on starting digital support group meetings. Let us know what you think by emailing us or calling 020 7940 4666.

WHEN YOU NEED TO TALK



There are times when things may seem to be overwhelming. This is where talking therapy and counselling can help. Amanda Hawkins Past Chair of the British Association for Counselling and Psychotherapy, explains how:

Around any long term and life limiting health condition there is a sequence of feelings that run alongside the diagnosis and adaptation into the illness, not just for the person with the condition, but also for those around them. All too often it's easy to focus on the physical effects of any illness, and easy

to lose focus on the psychological impact. However, it will be there.

Many people rely on their families and friends to talk through difficult feelings, but when everyone is affected in the family it's difficult to support each other. With any diagnosis there are some clear stages for

all involved, and quite often it is useful to talk these through with a counsellor who is independent and who can listen impartially.

SHOCK AND DENIAL

Whether the diagnosis comes on suddenly or a diagnosis is confirmed after experiencing gradual change, shock is often

the first reaction. It can be hard to take in the news, and you can find yourself carrying on as if nothing was different. You may also disbelieve the news, or think the doctor has made a mistake. Of course, it's reasonable to seek a second opinion and look for more information about treatments. But you may find yourself frantically seeking further diagnoses, or trusting in "miracle" cures that have no evidence to support them. This is called denial, and it may be the mind's way of buying time to get used to a new experience. It should fade over time as you find ways to adjust to your situation.

ANGER

You may get angry with the people around you, or with the services provided by official organisations. Sometimes you can feel angry when there's no obvious target. You might wonder "why me?" and get caught up in searching for explanations even though they may not change anything. Anger can be a natural response to unwelcome changes in circumstances. In questioning how the situation happened, you're searching for ways to make things better. You may need time to explore whether you have the power to change things before you can feel ready to move on.

HELPLESSNESS, FEAR, ANXIETY

These feelings are part of the process of accepting what cannot be changed. This can be scary, and may even send you back into denial. Common fears

include worries about income and having to be dependent on others to do things. Not being able to do things that others can do can feel intensely embarrassing, even shaming, and can cause strong anxiety. Learning how to do things differently can sometimes help with these feelings.

SADNESS AND GRIEF

These may be obvious reactions, but you might be surprised by the strength or depth of what you feel. This can be especially difficult for people who see themselves as "practical" and "good at coping". It's true that coping in an emergency can mean getting on with things without stopping to take notice of our feelings, but major life events such as an MSA diagnosis require a longer, slower process of management. Allowing space for what you feel actually strengthens your ability to cope with change.

DEPRESSION

When sadness lasts a long time you can get depressed. This is a normal response to loss, but if it lasts for more than a few weeks and stops you getting on with normal life you may need professional help, especially if you get so low you have thoughts of harming yourself.

Seek help from your GP or a counsellor if you:

- know it is not a physical thing but you persistently feel unable to get up
- don't want to eat but, again you know there is nothing physically wrong

- have disturbed sleep, often waking early and are unable to go back to sleep
- cannot "be bothered" to see friends or family, or otherwise do what you would normally do.

It can sometimes be necessary for your doctor to prescribe anti-depressants which can be used to lift your mood, and this can help you engage in some therapeutic work. Anti-depressants lift the symptoms but counselling deals with the cause of your depression, so a combination is usually advised.

All of these stages are important to all people that are affected by MSA and you may find yourself in any one, or multiple stages, at any one time. It's important to realise that these are common reactions to a very difficult and life-changing experience for all involved, and having time and space to help you think about what is going on not only helps you cope better in the moment, but also frees up time to spend with people that you love and get the most out of each day. **MSA**

You can ask to be referred to a counsellor via your GP, or else you can find a private counsellor via BACP (British Association of Counselling and Psychotherapy) who have a directory of therapists on their website:

www.itsgoodtotalk.org.uk.

FUNDRAISING ROUND-UP

As always our fundraisers have been busy supporting the Trust across the UK and Ireland. From tractor runs to golf days, our fundraisers did not let the winter cold stand in their way. Below are a few highlights from our calendar of events and ways you can get involved:

Thirteen year old twins Matthew and Beth Mulvey, from County Durham took on the Junior Great North Run in memory of their grandmother. Collectively they raised £300 and their family couldn't be prouder.

Jane Lightfoot from Wiltshire successfully raised over £3,600 after completing the Great South Run 5K in October.

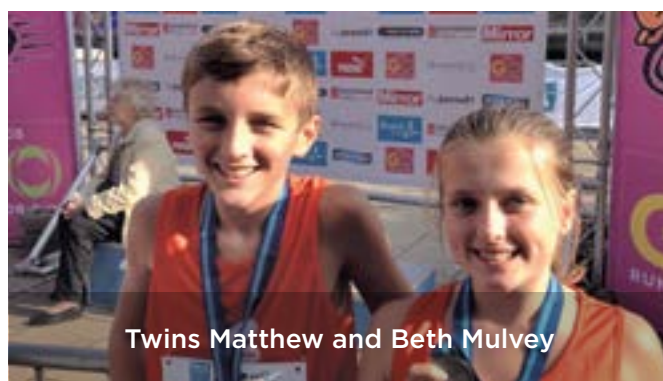
Alongside her family and friends, Nerys Hughes from Gwynedd held a tractor race in North Wales in honour of her husband, Emlyn Hughes who has MSA; £3,248 was raised in aid of the Trust.

In response to MSA Awareness Day in October, Vicky Duffy decided to go grey for MSA. Vicky is committed to showing off her grey hair and has beaten her target of £1,000, raising over £1,600.

The Roberts family from Merseyside took on many challenges to raise funds for the Trust - Marc even threw himself out of a plane. Together, with friends, they raised £4,400, all in memory of their husband, dad and granddad - Paul.

We want to say a massive thank you to each and every one of our fundraisers. Your support goes a long way to help people affected by MSA.

MSA



Twins Matthew and Beth Mulvey



Jane Lightfoot from Wiltshire (left)

If you would like to know how you can fundraise for the Trust, please contact Melissa Tindle, Events and Community Fundraising Manager at fundraising@msatrust.org.uk for an enquiry pack. No matter what you do, we will support you every step of the way.

RESEARCH IN THE WIDER WORLD

As well as funding vital research (see page 8) the Trust keeps tabs on new research happening throughout the world. Jill Lyons, one of our Specialist nurses reports on a new research project taking place in Europe.

Clinical trials are about to begin on a new vaccine that could offer patients significant improvements over current treatments for multiple system atrophy (MSA) and Parkinson's disease. The vaccine, developed through a collaborative project called SYMPATH, may actually be able to stop or slow disease progression, rather than simply providing symptomatic improvement. The primary objective of the clinical trials is to analyse the safety of the vaccine candidates in humans.

In MSA, alpha-synuclein builds up in the brain cells, called oligodendroglia, which provide support and protection to the nerve cells. As the disease progresses, the affected cells die off, eventually leading to the onset of symptoms.

The collaborative research project SYMPATH aims to forward the clinical development of vaccines that target alpha-synuclein.

AFFiRiS - an Austrian vaccine manufacturer, is coordinating the project together with renowned medical scientists in the fight against alpha-synuclein driven neurodegenerative diseases. The study unites eight institutes from three European countries, Austria, Germany and France. The trials will test the vaccine to evaluate safety and explore its activity in both conditions.

The cause of both Parkinson's disease and MSA are not fully understood and currently there are no treatment options available for either that can alter the course of the disease. Both

diseases are a type of synucleopathy, which are characterized by the clumping together of alpha-synuclein in the brain. In the healthy population, alpha-synuclein is normally soluble, but in the case of disease it forms clumps within and among neighbouring cells in the brain, eventually leading to cell death. Synucleopathies all share these unusual structures, but in different regions leading to different illnesses.

Vaccines have already demonstrated their disease modifying potential in numerous pre-clinical model systems. The project has received funding from the European Union.

The trials are not currently in the UK but the Trust will keep members informed of any further results or trials. **MSA**

You can find further information at:

www.medicalxpress.com/news/2014-12-tackling-parkinson-therapeutic-vaccines.html

www.sympath-project.eu/DL/sympath_factsheet_EN.pdf

SUPPORTING & HELPING EACH OTHER

Our Support Services Officer, Emma Rushton looks at some of the helpful tips and hints picked up by our members that have attended support groups recently. To join in on discussions and share some useful tips of your own, find your local group on the next page.

We currently have 33 regular support groups running around the UK and Ireland. Our aim is to extend these to other areas and to have at least 35 groups running from 2015.

Support groups offer a way for people with MSA, carers, family and friends and health-care professionals to meet and share much needed advice and support in a friendly and supportive atmosphere.

Our MSA Specialist Nurses try to get to as many support groups as possible and will attend at least one of each support group every year. The support group leaders will often try to organise speakers to attend the meetings and discuss topics such as benefits advice, occupational therapy and local services.

Here is a taster of the useful advice people have shared at support groups over the past few months that I was keen to pass on to other members:

- Carers can sign up with their local GP as a carer and most surgeries will then allow you to gain quicker appointments.
- The Surrey support group discussed the herbal remedy, Co-enzyme Q10 which is claimed can help with tiredness. Parkinson's UK did some research on this, and although there was no actual proven evidence that it worked, some people who take it feel it has been beneficial to them.
- One member at our South Yorkshire group reassured others that travelling to go on holidays wasn't a problem. She had found airlines to be very helpful and accommodating to medical needs. We have a fact sheet on travelling and MSA which you can download from our website, www.msatrust.org.uk.
- A member from the North London support group spoke about the Taxicard scheme

which enables residents in London to get subsidised travel through most London boroughs. You can find out more information about this on our Local Hub.

- The importance of finding and accessing your local hospice has been discussed at many of our support groups. Hospices offer a wide range of services including complementary therapies, respite and emotional support, to both people with MSA and carers. To find out more please visit the Hospice UK website, www.hospiceuk.org.

MSA

If you have any questions about these suggestions, or you have any of your own, please contact me at emma.rushton@msatrust.org.uk or 020 7940 4666.

MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people who understand life with MSA.

Please contact Emma Rushton at the Trusts office on 020 7940 4666 or email her at emma.rushton@msatrust.org.uk for more details. These groups are subject to change, so please check the Trust's website or ring the office for up-to-date information.

GROUP	VENUE	DATE & TIME
West Sussex	Worthing Quaker Meeting House, 34 Mill Road BN11 5DR	Thur, 10 Mar - 2.00pm
Inverurie	St Mary's Centre, St Mary's Place, Inverurie AB51 3NW	Wed, 11 Mar - 1.30pm
Cambridge	Barton Bowls Pavillion, High Street, Barton, Cambridge CB23 7BG	Thur, 12 Mar - 2.00pm
Oxfordshire	The Girl Guide Hall, Southern Road, Thame OX9 2EE	Mon, 16 Mar - 1.00pm
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 18 Mar - 1.30pm
West Midlands	Moxley People's Centre, 3 Queen Street, Moxley WS10 8TA	Thur, 19 Mar - 11am
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 19 Mar - 2.00pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6 1JQ	Wed, 8 Apr - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 8 Apr - 2.00pm
Surrey Carers	Contact the Trust office for more information	Thur, 9 Apr - 12.30pm
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Mon, 13 Apr - 1.30pm
Wiltshire	St Pauls Church Hall, Malmesbury Road, Chippenham SN15 1PS	Mon, 13 Apr - 2.00pm
Dorset	Trinity Methodist Church Hall, Southbourne Road BH6 5AQ	Mon, 20 Apr - 11am
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	Thur, 23 Apr - 2.00pm
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Tue, 28 Apr - 2.00pm
East Midlands	Holme Pierrepont Hall, Holme Pierrepont NG12 2LD	Wed, 29 Apr - 2.00pm
Kent	Room B208, University of Greenwich, Chatham Maritime ME4 4TB	Thur, 30 Apr - 2.00pm
Somerset/Bristol	Locking Castle Church, Jasmine Way, Weston-Super-Mare BC24 7JW	To be confirmed
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 1 Jun - 1.30pm
Gloucestershire	Whitminster Village Hall, School Lane, Gloucester GL2 7NT	Thur, 4 Jun - 1.30pm
Oxfordshire	The Girl Guide Hall, Southern Road, Thame OX9 2EE	To be confirmed
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 17 Jun - 1.30pm
Kent	Room B208, University of Greenwich, Chatham Maritime ME4 4TB	Thur, 18 Jun - 2.00pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 18 Jun - 2.00pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 3 Jul - 2.00pm

DO YOUR BIT FOR MSA AWARENESS ORDER FORM



T-shirt



Bertie Bear



Running Vest



Lapel Badge



Cotton Tote Bag



Wristband



Mug



Fundraising

Name:.....

Address:.....

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

Email Address:.....

P&P: Please add 50p for badges, wristbands and tote bags (£2.50 if ordering 10 or more of these items in any combination) - £2.50 for t-shirts, vests and the bundle (£4.40 if ordering 5 or more of these items in any combination) - £4.40 for a mug or a mug + other merchandise.

T-shirt (XS/S/M/L/XL) - £10, Qty:..... Running Vest (XS/S/M/L/XL) - £8, Qty:.....

Bertie Bear - £10, Qty:..... Tote Bag - £5, Qty:..... Wristband - £2, Qty:.....

Badge - £2.50, Qty:..... Mug - £5.60, Qty:..... Bundle - £15, Qty:.....

Total payment enclosed £ (please make cheque payable to 'MSA TRUST'):.....