

# MSA

NEWS



► ISSUE 39, 2014 | WWW.MSATRUST.ORG.UK

## Long distance caring **Hints for helping at a distance**

**NURSE  
NETWORK  
GROWS**  
*Third MSA  
Specialist  
Nurse  
appointed*

**MSA AWARENESS MONTH**  
*~ Your chance to get involved ~*



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**MEMBERSHIP AT JANUARY 2014**

Current MSA members	1,047
Carers, relatives & friends	1,679
Healthcare professionals	1,964
<b>Total</b>	<b>4,690</b>
New MSA Members since 1 October 2013	60

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



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# WELCOME TO MSA NEWS



Since the last issue of MSA News, staff and Trustees have met for our annual Awayday - an important day in our calendars as this is where we consider how the charity can best position itself to support people affected by MSA, now and in the future.

We confirmed our Vision of a world free of MSA and considered our research spend; we looked at how to extend our reach into the community and how to enhance understanding of MSA amongst the different groups of people who care for those with the disease. As part of this, we looked at how we can contribute our specialist knowledge within movement disorder clinics. Crucial to the success of our plans is, of course, building on our already successful fundraising so we can meet our future ambitions as well as securing our current activities. We're now putting budgets together and will unveil our plans in the next issue of MSA News.

Our continuing growth has led to some important changes in our infrastructure.

Since joining the Trust in 2009, I've worked on a part-time basis in the Executive Director role. I am delighted to report that to meet the demands of ongoing developments, the Trust has appointed Heather Gladman to job-share with me, also on a part-time basis. Heather, who is a qualified accountant with a strong charity finance background, will be taking on the new role of Executive Director - Operations (which includes finance), and my focus as Executive Director - Mission will cover our support services, research and communications.

This leads neatly into another appointment we have made. Franca Tranza (see page 18) has joined us from the British Medical Association in the new part-time position of Head of Communications. Together we will be working hard to move the spotlight onto MSA. On this theme, March is international MSA awareness month and we will be using social media to reach out to others. We'll also be holding our first Service of Light (see page 8) and there is some exciting news about the Californian poppy, intrigued, then turn to page 5!

At the time of going to print, MSA researchers from the UK and Europe met in London to share ideas and research findings from recent studies into MSA. It was the second symposium of this nature, the first in 2011, and demonstrate the tremendous collaboration underway within the MSA research world. John Telford, a volunteer science writer for the Trust, attended the symposium and will be writing an account of the day for the next issue of MSA News.

The commitment and dedication of these researchers was fantastic to see. They give real hope of one day finding the cause of and cure for MSA.

**MSA**

**Nickie Roberts**  
Executive Director - Mission

# SERVICES NEWS

By Neil Hunter, Head of Services

## OUR MSA NURSE SPECIALIST

We are delighted to announce that we have recruited a third Nurse Specialist. Jill Lyons started in January 2014 and covers the West of England and Wales.

“To have this kind of support [nurse helpline] is fantastic, not only for myself, but also our family”

Jill has been nursing for over 25 years, having completed a degree in nursing at Bristol University and has worked in Neurology and Care of the Elderly in various settings. Before starting with the Trust, she worked for a similar neurological charity and brings a wealth of knowledge and experience.

The very welcome appointment of a third Nurse Specialist sees the UK and Ireland now divided into three regions (see map). Which means you can now contact the Nurse Specialist who covers your region. This will help us to distribute their workload and provide a consistent service.

The MSA Nurse Specialists are the main focus of service provision for the Trust and



they provide a telephone and email advice line. They offer advice and information about MSA, from living with the illness to symptom management. They can also help explain what further support you may need and where to find it. They are not part of the NHS system and so cannot manage the treatment of someone with MSA, but they are willing to speak to the health professionals who support you. For this to happen, please ask your health professional to get in touch with them. They can also offer advice and support to carers and family and friends of people with MSA.

If you have any concerns about managing MSA, then do get in touch with them, their

details are given below.

With the Trust only having three nurses, they cannot do visits, however, they do attend many of the local support groups, so if you are able to get to a meeting it is a good way to meet them.

The nurses also run education sessions for groups of healthcare professionals and attend MSA Clinics throughout the UK. This helps raise awareness about MSA and improve the standard of care that people with MSA receive from their health and care teams.

The MSA Nurse Specialists provide an outstanding support service and if you haven't already spoken to them, their contact details are below. **MSA**



Jill Lyons

Katie Rigg (North of England, Scotland & Ireland): 01434 381 932  
Samantha Pavey (East of England): 0203 371 0003  
Jill Lyons (West of England & Wales): 01934 316 119



# NEWS ROUND-UP

## NEW CARERS APP

Developed by Carers UK, 'Jointly' is a mobile and online application designed to make caring a little easier, less stressful and a lot more organised. It combines group messaging with other useful features including to-do and medication lists, calendar and much more.



You can create a profile for the person you are caring for and use the space to record important information about the person's care, date of birth, appointment dates and so on. Then invite people into your 'circle of carers' and they will be able to see the important information too. You can create to-do lists and assign tasks to the different people in the care circle, easily track whether tasks have been done offering peace of mind.

The app is downloadable for free but to create a circle costs a one-off fee of £2.99. For more information please visit: [www.jointlyapp.com](http://www.jointlyapp.com) or find it in Google Play or the App Store.

## CALIFORNIAN POPPY TO BLOOM IN MSA AWARENESS MONTH

To coincide with international MSA Awareness month in March, Klondyke Garden Centres, one of our corporate partners, are donating all proceeds from the sale of Californian poppy seeds throughout their 24 stores. And it isn't just for March; the arrangement will run in perpetuity. The seed packets also contain information about MSA, so if you live near a Klondyke centre, why not pop in and get planting? This partnership will generate funds and also raise awareness of MSA.

## EVERY PATIENT IS A PERSON

Jeremy Hunt, the Secretary of State for Health, gave a speech in January at St Guy's and St Thomas' hospital proposing that every hospital patient should be given a single consultant to oversee their care and treatment while in hospital. The system has been successful overseas, reducing the time patients spend in hospital and reducing readmissions.

He stated it was about creating the right culture built around the simple truth that "the patient is a person". The plan goes on to propose that discharge from hospital should be from a named consultant to a named GP to ensure continuity of care.

It's an encouraging statement about forging better communication and better care in the NHS and is very welcome.



Jeremy Hunt MP

If you have any comments about this edition of MSA News please get in touch with Neil Hunter on 020 7940 4666 or by email at [neil.hunter@msatrust.org.uk](mailto:neil.hunter@msatrust.org.uk).

# NHS CONTINUING HEALTHCARE

## What is NHS Continuing Healthcare?

NHS Continuing Healthcare is a package of care that is funded by the NHS instead of Social Services

It becomes available if an individual has complex health care needs that could be classed as a 'primary health need'. This distinction is important, although difficult to determine, because once it is established that the need is a primary health need then the responsibility for the care moves from social services to the NHS. Care delivered by social services requires payment, or is means-tested, whereas NHS treatment is free, so being eligible could make a big difference.

### WHO IS ELIGIBLE?

To be eligible you must have a primary health need. People identified as having a primary health need are likely to:

- Have a complex medical condition requiring a lot of care and support
- Need specialised nursing support
- Have a rapidly deteriorating condition

Unfortunately it isn't simply

a case of saying yes to these, and your MSA diagnosis does not automatically qualify you. An assessment is needed and the result of that assessment will be decided by a panel, under the direction of the local Clinical Commissioning Group (CCG). This primary health need is defined through a number of key indicators:

- **Nature:** This relates to the features of the condition, how it is managed on a daily basis or the type of medical help needed.
- **Intensity:** Refers to a chronic condition which requires a certain level of care to manage (a combination of lower level needs could increase the 'intensity').
- **Complexity:** A combination of symptoms may result in a significant complexity.
- **Unpredictability:** The fluctuation in a condition may create an ever-changing care or treatment pattern.

### ASSESSMENTS

If you think you may be eligible, you need to speak with one of the health professionals in your care team; such as your district nurses or Parkinson's nurse. They will then conduct the NHS Continuing Healthcare Checklist which will flag up if a full assessment is required. If there is a need for an assessment the local Clinical Commissioning Group will identify an individual to organise one using the Decision Support Tool (DST).

The full assessment will involve a multidisciplinary team who will match, as closely as possible, your needs to the criteria laid out in the DST. These criteria are set out in 12 care domains and the tool should provide an overall picture of your support and care needs.

### WHAT HAPPENS AFTER THE ASSESSMENT?

The decision on whether or

not you are eligible for NHS Continuing Healthcare should be given to you in writing as soon as possible, and be clear and concise with details of who to contact for more information. It should include the completed DST and, if eligible, details of the care to be provided. If you have been found to be not eligible, there will be information on how to appeal the decision.

## APPEALING THE DECISION

You can challenge the decision made during the assessment by asking the CCG to look at it again, providing any additional information that may help your case. If you are still not eligible, you can ask for a review by writing to your CCG stating why you believe you have a primary health need that fits into the criteria in the DST.

## HOW THE TRUST CAN HELP

This article can only give an overview of the topic rather than detailed information. The Trust has added a page to its website with links to find more information about NHS Continuing Healthcare.

The Trust's MSA Nurse Specialists cannot conduct the checklist or be involved in the assessment; that needs to be done by a professional more directly involved with your care. However, MSA Nurse Specialists can provide a lot of support and talk you through the process so you know what will happen and what will be



asked. Importantly, they can talk to the health professionals in your care team and help clarify the kind of care that will be needed. So please give the members of your care team the MSA Nurse contact details.

The assessment process is not easy and there are no guarantees. The DST has been designed to be fair and the assessing criteria are consistent. However, the assessment against those criteria will always be a human interpretation of the way in which the individual is affected by their condition.

Finally, some practical tips for you to think about as you go through the assessment process:

- Make notes at meetings – it is too easy to forget what was said.
- Make copies – keep copies of all letters you send in support of the decision, or in relation to an appeal.

- Provide information – enclose copies of the Trust's MSA Guide with correspondence and have copies available when attending meetings or panels.
- Strength in numbers - have someone present with you, a carer or close friend, who understands what is involved in your care. They can take notes and speak on your behalf if needed.
- Team effort – make sure all the health professionals involved in your care have had input to the assessment.
- Be informed – speak to the MSA Nurse Specialists, they can help and advise. **MSA**

More information can be found at:

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

[www.nhs.uk](http://www.nhs.uk)

[www.gov.uk](http://www.gov.uk)

# SERVICE OF LIGHT FOR MSA

On 22 March 2014, we will be holding our first Service of Light for MSA, which we hope will offer a sensitive and meaningful way for friends and family to join together with others in the MSA community to remember and celebrate the lives of loved ones.

Our Service of Light is a time for celebration and reflection and will be held at St Paul's Church in Covent Garden, London at 4pm. Members will receive a warm welcome as we gather for readings, hymns and songs performed by a choir.

Candles will be lit during the service, with each one celebrating the life of someone we have lost to MSA, and members are invited to dedicate a light in their memory. The names of those people being remembered will be printed in the Book of Remembrance, part of the Order of Service for the day.

If you would like to attend the Service of

Light for MSA, please call us on 020 7940 5659 and ask to speak to Louise. We are asking for a voluntary donation of £10 for members to attend, with all proceeds going to MSA research.

If you are unable to attend but would still like to make a dedication to someone special, you can do this too. Simply call us on 020 7940 5659 with the name of your loved one and we will ensure they are included in the Book of Remembrance on the day.

**To ensure we are able to plan effectively, we respectfully ask you to contact us by Friday 14 March if you wish to attend and/or wish to add your loved one's name to our Book of Remembrance.**

## *In Memory*

Philip Wyatt	William Knowles	Ken Langley	Anne Sweetman	Jane Baker	Marlene Ryan
Richard Mills	Kay Drake	Michael McMillan	Bob Powell	Janet Hadfield	Georgette Bache
Maureen Broome	Denise McLean	Bill Westley	Joan Cleminson	Ron Axtell	Leonard Monk
Vanda Nicholson	Colin Nuttall	Roger Lilley	Maura McGee	Jill Marks	Jim Ward
Gladys Lowe	Peter Hurd	Ivan Manning	Richard Robinson	James Darvill	Jim Mansfield
Audrey Potts	Margaret Cann	Michael Jones	Myler Hamill	Christopher Edwards	Wendy Blundell
Richard Lees	Denzil Stones	Bob Thomas	Dorothy Howard	John Thacker	Agnes Kerr
Sue Peattie	John Darroch	Diane Bettley	Janice Gillman	Isabelle Latham	Paul Roberts
Wanda Stewart	Cathy Holland	Valerie Hayes	Geoff Laws	Freda Heasman	Ricky Chapman
Peter Baistow	Margery Simpson	Gail Kirby	Stuart MacDonald	David Karstake	David Cooper
Jacinta Hatton	Joan McLoughlin	Aubrey Mitchell	Paul Gardner	Raymond Marshall	Stephen Webb
John Smith	Paul Harris	Gayanna Kitter	Christina Haines	Thomas Mulvaney	Peter White



# MSA TRUST RESEARCH

The Trust awarded research grants to three projects in its recent grant round. Strong proposals were received from more applicants than we were able to fund.

Although disappointing not to be in a position to fund all projects, it is the first time the Trust has received more applications than it could fund, a positive sign of growing research.

## GRANTS HAVE BEEN AWARDED TO:

Professor John Hardy - Institute of Neurology, London

### **The development and characterization of a human induced pluripotent stem (iPS) cell derived oligodendrocyte model of MSA.**

This study plans to develop induced pluripotent stem (iPS) cells from patients with MSA to investigate the pathophysiology of MSA. This means that the study will investigate how cells change in the body in response to over production of alpha-synuclein, the protein known to have a strong connection with MSA. The study should therefore provide a greater understanding of how MSA develops.

*An induced pluripotent stem (iPS) cell is artificially created by genetical-ly reprogramming an adult cell such as a fibroblast.*

*The iPS cell then mimics an embryonic stem cell without the need for an embryo.*

Dr Janice Holton - Institute of Neurology, London

### **The role of CoQ2 in MSA**

This study plans to determine the role CoQ2 has in MSA. It is anticipated that the study will provide further insight into the disease mechanism of MSA and, by investigating the possibility that CoQ10 function is reduced in MSA, this could provide a target for disease intervention using a drug which is currently available and is established in clinical use for other conditions.

Professor Henry Houlden - UCL & Professor Huw Morris - University Hospital of Wales

### **The UK MSA Network: A longitudinal clinical, imaging, biomarker study and future resource for MSA.**

This project will develop a UK MSA network that brings together clinicians from movement disorder centres around the UK with a clinical or research interest in the disease. It will create the UK's first clinical and imaging database and sample biobank. The network will store detailed clinical information and imaging data from people with MSA (with their consent). This will improve understanding of the early stages and progression of MSA. It will also provide a valuable resource for future MSA research and therapy development.

**We will bring you news and updates as the projects progress. MSA**

# 2013 MEMBERS SURVEY

Thank you to everybody who completed our 2013 Members' Survey. The response rate was high with over 230 people completing the questionnaire. Results are being analysed and a full report will be available on the Trust's website in late March. Until then, here are key findings.

## INFORMATION AT DIAGNOSIS

A major area of concern for the Trust is the level of information people are provided with at the point of diagnosis. In 2010 49.4% of respondents said they received nothing from their neurologist following a diagnosis. Over the last three years, the Trust has worked hard to address this concern by communication and awareness activities. We have conducted mailouts to all neurologists letting them know we are here and willing to support, and we have asked them to let their patients know about the Trust. These activities seem to be having an impact as 35.8% of respondents reported receiving no information in the 2013 survey, a reduction of

13.6% compared with the 2010 survey. This is still too high, and we will continue work to reduce this. Additionally in 2010, 41.6% of respondents said they were given information about the Trust and this has now risen to 50.2%.

## AWARENESS OF SERVICES

We asked you about your knowledge of the services we offer, and again the results are encouraging when compared with the 2010 data. The chart below shows the percentage of respondents who are unaware of the services we offered. As you can see the figures have dropped considerably in the last three years.

## USE OF THE SERVICES

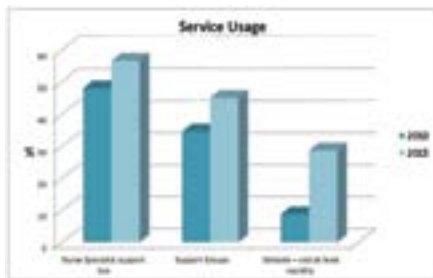
With the greater awareness of the services we provide comes greater usage of those services. More of you are getting support from the help we offer, with big increases in the percentage of people using the nurse support line and attending support groups. This is really encouraging; the nurses provide invaluable information and advice about coping with day-to-day issues affecting someone living with MSA and the support groups offer the chance to meet others in similar situations. We are therefore delighted to report the expansion of these key services: we have added a third nurse (see page 4) and almost trebled the number of volunteer-led support groups in the last three years.

## WERE THEY OF USE?

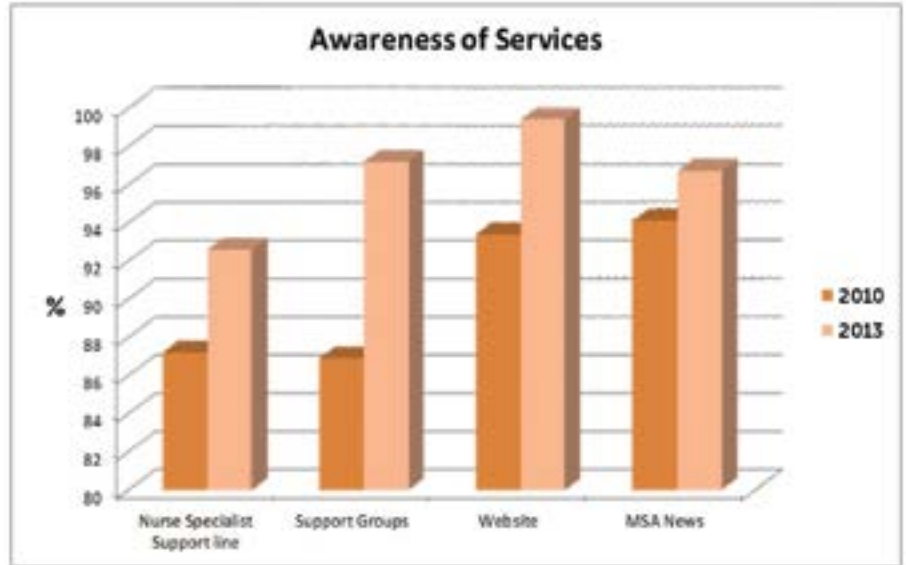
The benefit people received from services was an important part of the survey. We need to know what we are doing right, and wrong, in order to improve the support we deliver. Overall, the figures are extremely encouraging. The nurse support line either fully or partially met 85% of users' needs. The support groups either partially or fully met the expectations of those attending in 96% of respondents. Our fact sheets were considered partially or fully useful by 86% of respondents, and the information presented in MSA News was considered fully or partially useful by 98% of respondents.

## NEED TO IMPROVE

There is always room for improvement. This survey can-



vassed views on how the Trust and the health community support carers. Of the respondents, 55.6% of carers said they received nothing in relation to their caring role at the time of diagnosis, and 75.6% said information about the specifics of caring for someone with MSA would be helpful. We will be developing a Guide to Caring for Someone with MSA over the coming months



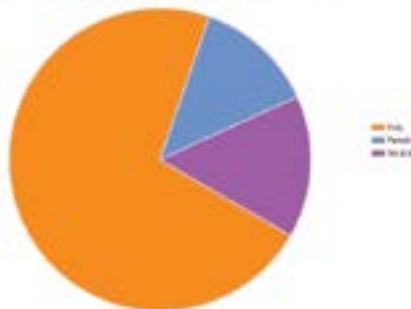
and it should be available in the summer.

## PRIORITIES FOR THE FUTURE

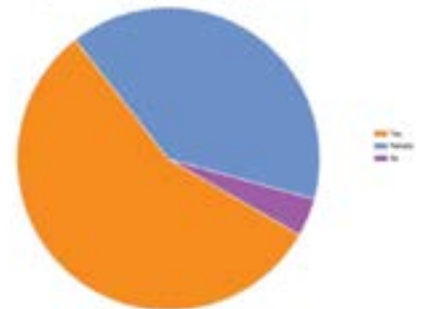
Education and increasing awareness among health professionals was the key priority, with 81.3% flagging it up as es-

Again, thank you to all those who completed the survey. The survey is one of the ways we listen to you; we welcome feedback on all our services and you can always drop us an email or call us. Good or bad, the stories we hear about our services and how they sup-

If you have used the Trust's Nurse Specialist helpline (telephone or email), did it answer your questions?



If you've been to a support group, did it meet your expectations?



essential. We will be developing materials for educating members of the multi-disciplinary team supporting you. With the appointment of our third nurse, we can increase the education we provide to HCPs.

Funding research was also a major priority with 70.3% rating it essential. We are hoping to further increase research grant funding and several new projects are reported on page 9.

port you, or how they could be improved, help us improve what we do. And remember to look out in March for the full survey results. **MSA**

# CARERS CORNER

## CARING AT A DISTANCE

For many reasons we may end up living far from those we care about, and if those we care about have a condition like MSA, then the distance can feel even further.



**W**hether you live across town or across the country, if you're not the one primarily responsible for the care of someone with MSA, it's not unusual to feel helpless or guilty.

The following tips may provide practical ideas on how to get involved or help.

### LEND AN EAR

The emotional support offered by a listening ear can help those who need to offload. The relationship between the person with MSA and the primary carer can often become intense, so speaking regularly with both of them can help. If you live a long way away, try and arrange a weekly call, or perhaps use video calling, such as Skype.

### BE INFORMED

Find out all you can about MSA and the type of care and support the person with MSA will need. It will make a big difference to the primary carer knowing that someone understands what is involved. The Trust has a great deal of information about MSA, to help you understand it. If you have any questions, call the MSA



Nurse Specialists, who will be happy to talk through any concerns with you or to explain anything in more detail.

### **STAY IN THE LOOP**

If the person with MSA gives their legal permission, and if the primary carer is happy for you to do so, get copies of their medical records and names and contact details of the health professionals involved in their care. Keep track of appointments and follow-up visits. Know what is happening and when, and call to find out how appointments went. It will be an enormous emotional support to them and will help to make you feel more involved.

### **FINANCIAL SUPPORT**

This might be an obvious one but the cost of equipment can be expensive; can you help financially? Or can you help with finding out about grants and benefits to which those living with MSA, or their carer, may be entitled?

### **INVESTIGATE TECHNOLOGY**

The primary carer may be too involved in the day-to-day issues of caring for someone to have the time to explore how gadgets, equipment and other aids may help. Why not volunteer your 'tech-support services' and find out what might help? Knowing about MSA and the types of problems it can throw up will help you understand what gadgets might be useful.

### **KNOW THE ROUTE**

You probably already know this, but work out the route to get to see the people you care about. Having it already planned will ease a lot of pressure should you need to make the journey at short notice.

### **PLAN VISITS**

If you are going to visit, then try and arrange it beforehand to make maximum use of your time there. Think about the needs of both the person with MSA and the primary carer, and plan individual time with both. Can you spend a couple of days there and provide a little respite for the carer? Also, think about spending time alone with the carer, give them the chance to use your listening ear in person, and make sure they are alright and looking after themselves. Give the person with MSA the chance to see and interact with someone different. Someone with MSA can tire quickly – agree a signal they can use when they want a visit to end.

### **LITTLE GESTURES (CAN HAVE A BIG IMPACT)**

Could you pick up the monthly prescriptions? Or do the weekly shop? Or help out with the washing or cleaning?

### **PLAN A HOLIDAY**

You could research possible holidays with access to necessary equipment. The Trust has a 'Travelling with MSA' leaflet. Could you offer to go with them and spend some quality time together to assist and to

allow the carer some time to themselves while away?

### **LOOK AFTER YOURSELF**

Try not to get so caught up in worrying about those you care about that you neglect yourself. You need all your strength and wits about you, so a good diet and plenty of exercise are essential. Keep your own doctors' appointments and don't put any concerns about your own health on the back burner.

### **GET INVOLVED**

If you have the time and the energy then why not run a Trust support group, do some fundraising or local awareness raising? Channelling your energies into positive action will have a huge beneficial effect on you. You will feel like part of the fight and that you are making a positive difference.

**MSA**

For more information about MSA visit our website. We have many fact sheets available for downloading that will help you understand MSA. If you want to talk any of the above through, then please get in touch with our MSA Specialist Nurses; see page 4 for details.

# FUNDRAISING ROUND-UP

Since our last issue of *MSA News*, our members have been out in force raising vital awareness of MSA and funds to further our work. As is always the case, we have FAR too many eventers to allow us to feature everyone. Here is just a very small selection of our recent fundraising stars...

Three thousand miles across the pond, Esther Berkowitz set her family the challenge of swimming 100 miles for MSA. Esther's mum, who lives in London, has MSA and they wanted to do something to support the Trust. The boys took to swimming like ducks to water (excuse the pun!), and as a family they raised a phenomenal \$9,500!

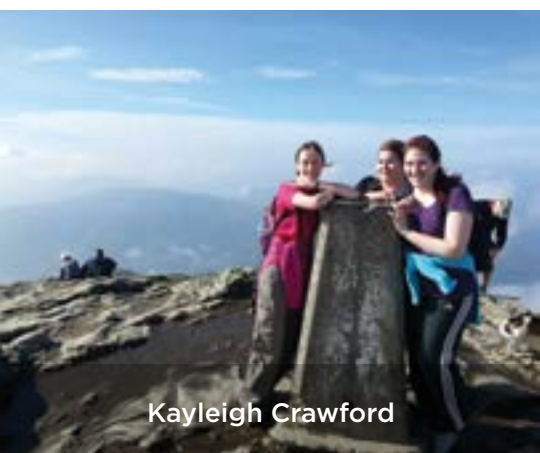
In memory of Sean Kelly, the Kelly Family organised a spon-

sored cycle or run in November 2013 in Ireland. Eighty people took part and, despite the treacherous conditions, raised a staggering €7,000 for the Trust.

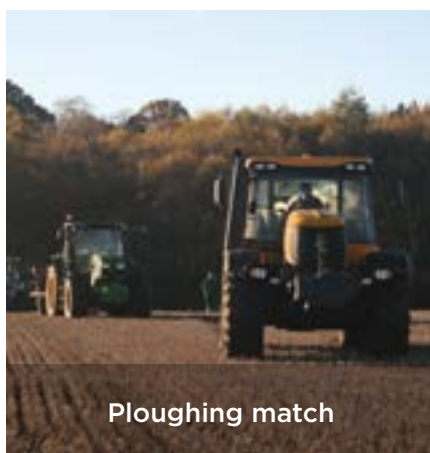
To support her auntie who has MSA, Kayleigh Crawford and colleagues climbed Ben Lomond in Scotland and raised over £1,700! Kayleigh's employer match-funded her donation which helped them reach this amount. Many companies

will match your donation, so remember to ask them when you are doing your own fundraising.

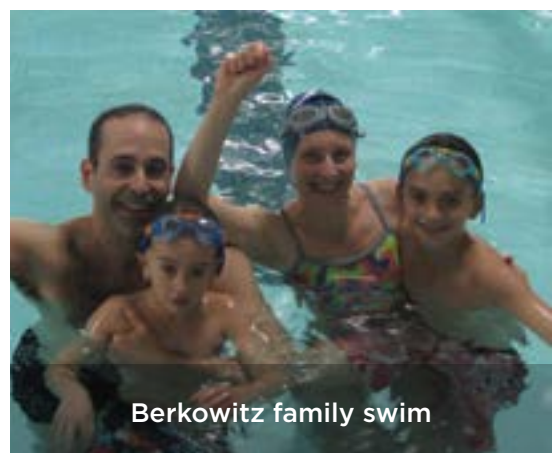
A slightly more unusual fundraising event was organised by Nick and Anna Hood in Norwich; a ploughing match. It was a close contest and a great time was had by all, resulting in £3,000 being donated to the Trust. **MSA**



Kayleigh Crawford



Ploughing match



Berkowitz family swim

# SARAHHA TREK FOR MSA

## FEBRUARY 2015

Have our eventers inspired you? Why not take on an intrepid fundraising event with a difference?!



There is no landscape on earth like the desert! From stony flat expanses scattered with ancient fossils, to perfect wind-blown sand dunes, trekking in the Sahara Desert transports you to another world.

The desert and its incredible night skies provide a feeling of space and of solitude, of nature's power and the transience of mankind that is both awe-inspiring and humbling.

This will be an unforgettable and life-changing challenge in support of the Trust.

We are looking to recruit a team to take on this 100km trek over ten days in February/March 2015.

By taking on this challenge you will not only push yourself to your limits and have amazing experiences, you will be raising vital funds to help the Trust continue supporting those who have MSA, like our first sign-up Heather, whose husband was diagnosed in 2012. Heather says, "When I saw the post on the MSA Trust Facebook page, I knew that the Sahara Trek was something that I needed

to do. If you are still undecided but like the idea, please get involved. I'm not super fit (yet) but this is further motivation for me on a personal level and such a fantastic way to raise much needed funds for the trust. It is going to be a really incredible life experience and a great chance to pay it forward, I can't wait **MSA**

For more information contact Louise on: 020 7940 5659.

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

For enquiries about company support, regular giving, memory giving, leaving a legacy or charitable trusts, please contact Katie Heyward, Head of Fundraising on 020 7940 4134 | [katie.heyward@msatrust.org.uk](mailto:katie.heyward@msatrust.org.uk). For all enquiries regarding fundraising events, please contact Louise Trott, Community and Events Fundraising Officer on 020 7940 5659 | [louise.trott@msatrust.org.uk](mailto: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](mailto:lyn.shaw@msatrust.org.uk) for more details.

GROUP	VENUE	DATE AND TIME
Republic of Ireland	Our Lady's Hospice, Harold's Cross, Dublin	Tue, 25 Feb - 2.30pm
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
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 7 Mar - 2.00pm
Northumberland	TBC	Wed, 12 Mar
Yorkshire (South)	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 12 Mar - 1.30pm
Derbyshire	Doveside Social Club, Jinny Close, Hatton DE65 5EZ	TBC
West Sussex	Field Place - Pavilion Room, The Boulevard, Worthing BN13 1NP	Tue, 18 Mar - 2.00pm
Greater Manchester	TBC	TBC
West Midlands	Moxley People's Centre, 3 Queen Street, Moxley WS10 8TA	Wed, 19 Mar - 1.30pm
Oxfordshire	The Girl Guide Hall, Southern Road, Thame, Oxfordshire OX9 2EE	Fri, 21 Mar - 2.00pm
Warrington	Fairfield and Howley Neighbourhood Project, WA1 3AJ	Fri, 21 Mar - 2.00pm
London (North)	Southgate Hockey Centre, Snakes Lane, London EN4 OPS	Mon, 24 Mar - 2.00pm
Cornwall	Echo Centre, Barras Place, Liskeard PL14 6AY	Mon, 24 Mar - 1.30pm
Lincolnshire	TBC	TBC
Gloucestershire	Whitminster Village Hall, School Lane Gloucester GL2 7NT	Wed, 2 Apr - 1.30pm
Cambridge	St Mary's Church, Church Street, Buckden, St Neot's PE19 5TL	Fri, 4 Apr - 1.30pm
Essex - 10th Anniversary	Great Tey Village Hall, Great Tey, Essex CO6 1JQ	Mon, 7 Apr - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 9 Apr - 2.00pm
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	Thu, 10 Apr - 2.00pm
Wiltshire	St Paul's Church Hall, Malmesbury Road, Chippenham SN15 1PS	Fri, 11 Apr - 2.00pm
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 16 Apr - 1.30pm
East Midlands	Holme Pierrepont Hall, Holme Pierrepont NH12 2LD	Wed, 23 Apr - 2.00pm
Lanarkshire	Hill House Parish Church, Clarkwell Road, Hill House, Hamilton ML3 9TQ	Fri, 25 Apr - 2.00pm
Republic of Ireland	Dublin - TBC	Mon, 28 Apr - 2.00pm
Republic of Ireland	TBC	Tue, 29 Apr - 2.00pm



A short story from Trust member Allison.

## ALLISON IN MSALAND

As my husband Nick and I walked away from the neurologist, I could still hear the words “progressive and life limiting neurological condition called Multiple System Atrophy”.

We clung to each other in the corridor of the hospital and I, metaphorically speaking, started to tumble very quickly down a long dark tunnel.

For days I tumbled and rolled, desperately trying to keep hold of my darling husband’s hand as he tumbled too. My parents reached out to help and started to fall with me, it was terribly frightening.

Like in ‘Alice in Wonderland’, during my tumble I tried to grab at things and people along the way, desperate to be rescued. I flung open doors as I fell, trying to ask for help, I grabbed phones and shouted down them to people that didn’t seem to hear me.

Further and further I fell



and was aware that my loved ones were falling behind trying to catch me. All of us getting hurt and bruised along the way.

Help! I shouted into the darkness.

After some time, little bright lights started to appear. Then I realised they were people. Special people!

I met a new GP called Lucy

who helped me open the right doors. Very quickly, bright and sunny doors were opened and I stopped falling, landing in a crumpled heap.

Where did these doors lead?

The MSA Trust, the local MSA support group and Working Hospice. Suddenly there was a support network at last!

MSA

## SUPPORT GROUP VOLUNTEERS

We are always on the lookout for more support group leaders to set up and run MSA support groups. If you have some time to spare and want to make a big difference to people living with MSA, then why not run a local support group?

We are looking for leaders in the following areas: Somerset, Northamptonshire, Peterborough,

Bedfordshire, Edinburgh and South Wales. We are also looking for someone to run:

North Yorkshire, East Yorkshire, Fife and Inverurie. If you would like to know more about what is involved then please get in touch with Lyn. E: [lyn.shaw@msatrust.org.uk](mailto:lyn.shaw@msatrust.org.uk) | T: 020 7940 4666

# MSA AWARENESS

## HELP US SPREAD THE WORD, SOME MORE

By Franca Tranza, Head of Communications

Following on from the theme of last year's *MSA News* about spreading the word about MSA, as the new Head of Communications at the Trust, I'm using this issue to urge you to help us to keep spreading it!

I started at the Trust in November 2013 and I have been learning about multiple system atrophy (MSA) and how the organisation works. The dedication of families, friends and carers of people with MSA who are busy fundraising, raising publicity and doing what they can to support their loved ones.

It's so important. What I've learnt very quickly is that, apart from those directly involved, too few people know about MSA.

You'll be receiving this issue of *MSA News* at the beginning of MSA Awareness month (March 2014). This gives us a good opportunity to raise the profile of the disease and the Trust, but we need your help. We are going to use Twitter to post a fact about MSA every day – please favourite and retweet our posts so as many people as possible find out more about MSA.

We have also put a call out for short videos to be aired during MSA Awareness Month. We are asking the questions:

- What MSA means to you?
- And how the Trust has helped/impacted on your experience of MSA

If you would like to help us with this and are happy to be featured on our social media pages, please record your video (no more than 60 seconds) on your mobile phone or tablet device and email it to my colleague Louise ([louise.trott@msatrust.org.uk](mailto:louise.trott@msatrust.org.uk)).

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

We are also putting together materials to support you in your fundraising and awareness-raising efforts – these include a template press release, letter for your local paper and your local MP. We have tried to save you as much time as possible, but if you need any more information, get in touch; my contact details are below. The materials will be on our website very soon.

Journalists who want to cover health issues are always after case studies. Nothing brings a story alive as much as someone's personal journey. So if you think you would be happy to talk to the media, please let me know. I assure you I will never give a journalist your contact details without your prior permission.

We are particularly keen to find out about difficulties anyone has had accessing NHS care or, equally, anyone who has fantastic care and wants to praise their doctor or nurse. Please feel free to ring or email me if you think you might want to talk to the media to raise awareness about MSA, but feel unsure.

I look forward to getting to know more of you throughout 2014 and hope, together, we keep spreading the word.

Franca Tranza - E: [franca.tranza@msatrust.org.uk](mailto:franca.tranza@msatrust.org.uk) | T: 07718 426078 **MSA**

# MEET YOUR CARE TEAM

This is the first in a series of interviews with members of your health and care team. Today we meet Sukhi Aujla, a Speech and Language Therapist in London.

## 1. How do you help people with MSA?

I work with people who have MSA to provide assessment, therapy and advice on changes that may help in speech, communication and swallowing. I try to work proactively with clients to set goals and plan for future changes. I also think there is an important role in signposting services that people might find useful (e.g. the MSA Trust!)

## 2. How did you come to work in this specialisation?

I have worked as a speech therapist for over ten years and knew from early in my career that I wanted to work with adults. I was given an opportunity to work in the community, and this is where I started working with a gentleman with MSA. Working in partnership with him, I have learnt about the day-to-day impact of this condition, and how it influences all aspects of his life. I have seen how his condition has changed over a number of years. He has inspired me to develop my knowledge of MSA, and my clinical skills in treating the symptoms of this condition.

## 3. What are the positive and negative aspects of your role?

The positive aspects are obvious - working closely with someone who may be going through a number of different challenges and being able to support and advise them. Being able to make a tangible difference to a person's quality of life is so rewarding. MSA can be an understandably difficult diagnosis to accept and whilst this isn't a negative aspect of the role, it can be challenging.

## 4. How do you think msa care has changed during the time you've been involved?

I think there is growing awareness of MSA. The National Service Framework for Long-Term Conditions made a really positive impact in our service delivery, and I continue to use it as a framework for the service I provide.

## 5. What difference do you think the msa trust has made?

I think the MSA Trust has made a difference at the personal level for people with the condition, but also in a broad-



er sense by funding research, raising awareness and through supporting therapists who work with people who have MSA.

## 6. Regarding MSA, what are your hopes for the future?

My hope for the future is that interest in this condition will grow with greater awareness amongst the public. I also hope for more joined up specialist services working together with charities such as the Trust. I look forward to more effective treatment regimes for people with the condition. **MSA**

# REGULAR GIVING

Regular gifts allow us to plan our work with confidence, knowing we can continue to support families across the UK affected by MSA, while also funding vital research into finding the cause of, and cure, for this devastating disease.

## £10 A MONTH

Will supply vital information to the medical team caring for one MSA patient.

## £20 A MONTH

Will provide welcome support packs to three families affected by MSA.

## £100 A MONTH

Will pay for our support line to run for one whole week.

Making a regular gift will enable us to plan our activities with confidence. If you would like to donate a regular gift, please fill out this form and

return it to the Trust:

**MSA Trust, Southbank House, Black Prince Road, London SE1 7SJ.**

Once we receive your form, we will keep a photocopy and forward the original to the bank to process your payment.

To the Manager:..... (Bank/Building Society)

Address:.....

Bank Sort Code:..... Account number:.....

Starting on:...../...../..... I would like to set up a standing order, to be paid monthly/annually (please delete as appropriate), of £..... to the account below:

Bank: CAF Bank Charitable banking

Account Name: Multiple System Atrophy Trust

Sort Code: 40-52-40

Account Number: 00096281

Bank Address: 25 Kings Hill Avenue, West Malling, Kent ME19 4JQ

Your name (please print):.....

Address:.....

Postcode:.....

I wish the Multiple System Atrophy Trust to treat this donation as a Gift Aid Donation. OR

This gift plus all future gifts as Gift Aid donations. OR

All gifts of money that I have made in the past 4 years and all future gifts of money that I make from the date of this declaration as Gift Aid donations

*giftaid it*

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