

MSA

NEWS



► ISSUE 43, 2015 | WWW.MSATRUST.ORG.UK

— SUMMER'S HERE —

Time to Relax

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**MEMBERSHIP AT
JUNE 2015**

Current MSA members 1,175

Carers, relatives & friends 2,023

Healthcare professionals 2,112

Total 5,310

Total New MSA Members

year ending March 2015 214

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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WELCOME TO MSA NEWS

After over five years at the helm the Trust says farewell to Nickie Roberts our Executive Director.

“Twelve years after its inception, the Multiple System Atrophy Trust (then called the Sarah Matheson Trust) appointed its first Executive Director, Nickie Roberts.

In 1993 the Trust’s founder, Sarah Matheson, had been diagnosed with MSA and, dismayed by the state of ignorance about the condition both in the medical world and more generally, she set up a support group. This started in the front room of her home, but then moved into a hospital’s neurology clinic and became registered as a charity in 1997.

In the early stages the charity was run by its Trustees, so when Nickie arrived in 2009 she was its first professional executive. Under her direction its dimensions have grown in every way an expanding charity needs to thrive and prosper. She introduced operational systems, policies, governance, business planning and budgeting. All the arrangements for the support the Trust provides for people who have MSA, their carers, family and friends, the system for administering medical research grants and an office employing 12 staff, have all been strategically planned, formalised and developed under Nickie’s watchful eye. The Trust is considered to be a “role model” for MSA communities worldwide, and its services and website are widely acknowledged to be an outstanding resource for those people with MSA around the world, and all this is an immense credit to Nickie: it would be difficult to overstate what a significant contribution she has made to the Trust.

As a result of all this growth, the Trustees now feel the time has come for the charity to have a full-time CEO. Nickie has family commitments that mean she cannot fulfil that role, and she has decided to stand down to allow the Trust to appoint a full-time successor.

We thank Nickie for all that she has done for the MSA Trust, and wish her well for the future.”

Professor Clare Fowler

Chair of the Board of Trustees



“I shall be so sad to leave the Trust; it really is a fantastic charity full of wonderful people working hard to change things for the better for people affected by MSA. There’s something quite special about the spirit of this charity, and I’ll miss being part of it. Love and best wishes to everyone. x”



GETTING A GOOD NIGHT'S REST

Some people struggle to get a good nights sleep and this can affect people with certain conditions, such as MSA.

Dr Sofia Eriksson and Professor Matthew Walker from the sleep neurology services team at the National Hospital have written tips on “sleep hygiene” which we hope you will find useful.

“Sleep hygiene” is another term for good sleep habits so some of the suggestions below may smooth you into a better sleeping routine. Don't feel you have to do all the changes immediately and at the same time:

- try to have regular sleep times. It is probably more important to have a fixed time you get up in the morning rather than a fixed bed time to avoid going to bed when you are not sleepy, as this may make it more difficult to fall asleep
- avoid napping during the day. Sleeping a lot during the day will affect your ability to go to sleep at night. If you need a nap, try to limit it to 15 minutes. This should also prevent you going to into deep sleep from

which it is usually more difficult to wake up

- avoid alcohol in the four hours before going to bed. Even though alcohol may make it easier to fall asleep, the effect wears off during the night making it harder to stay asleep, resulting in disrupted sleep and early awakening
- avoid caffeine four to six hours before bedtime. Remember, this includes many soft drinks and chocolate as well as tea and coffee
- make sure you sleep in a comfortable bed
- find a comfortable temperature for your bedroom
- don't watch television in bed
- avoid looking at your bedside clock to see how long you have been awake or the time it is taking for you to fall asleep. Turn it to face the other way
- try to establish a bedtime routine such as a few minutes reading or practice relaxation techniques before

bed, such as deep breathing, progressive muscle relaxation or relaxation tapes

- try not to take your worries to bed. You may find it useful to assign a ‘worry period’ during the evening to deal with problems, or create a ‘worry diary’ to write down problems which you can deal with later.

If you don't fall asleep within 20 minutes or if you wake up in the middle of the night and can't go back to sleep, then try getting up or reading for a while instead of ‘trying hard’ to go to sleep.

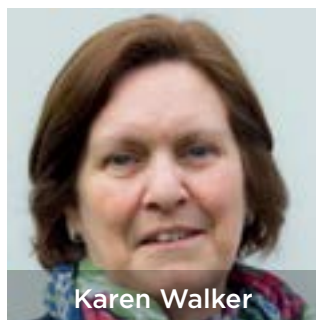
Don't try anything likely to make you more alert at this time and then, when you begin to feel tired, settle back down and try to fall asleep. If you are still not sleeping, get up again until you do feel tired.

It may take time to get into a good routine but it's worth persevering to get that good night's sleep. **MSA**

NEWS ROUND-UP

TRUST LEADERSHIP

As you will have seen on page three Nickie Roberts is sadly standing down as Executive Director of the Trust. Until we find another exceptional person to take over her role I will be acting as interim Chief Executive Officer for the Trust. I have been actively involved in the Trust on different levels for a number of years, starting as a support group leader in Yorkshire in 2006. In 2009 I joined the Trustee board and since then I have had a number of roles including: Chair of the Services Committee, Chair of the Resources, Audit and Governance Committee and Vice-Chair of the Board of Trustees. I have stood down as Trustee in order to support the Trust through this time of change and look forward to having more direct contact with people living with MSA and their families and carers in the coming months.



We are hoping to commence recruitment later this summer, but in the meantime the Trust's work for people with MSA remains 'All Systems Go'. I very much welcome your views on the Trust's services and can be contacted at karen.walker@msatrust.org.uk. MSA

TO CAROL OR NOT TO CAROL?

The Trust is thinking of having an organised Carol Service in December but we need to know if members would like to attend. If you are interested please let us know by emailing us at fundraising@msatrust.org.uk and answer Carol Service – Yes or Carol Service – No and if possible let us know what region of the UK you live in. We would really appreciate your feedback.

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WHAT A STAR!

Elizabeth Brackenbury ran her last meeting as the East Midlands support group leader in April, after twelve years of facilitating the groups. Elizabeth, sister of our founder Sarah Matheson, started the very first support group and we are so thankful to her for helping to shape what the Trust is today. From running the initial group, our network has now grown to 34 groups throughout the UK and Ireland which is a huge testament to her work. Thank you Elizabeth. MSA



DONATING SHARES

If you have a small number of shares that would cost you more to sell than they are worth, then why not donate them to the Trust? (To give shares directly they must be listed on a recognised stock exchange).

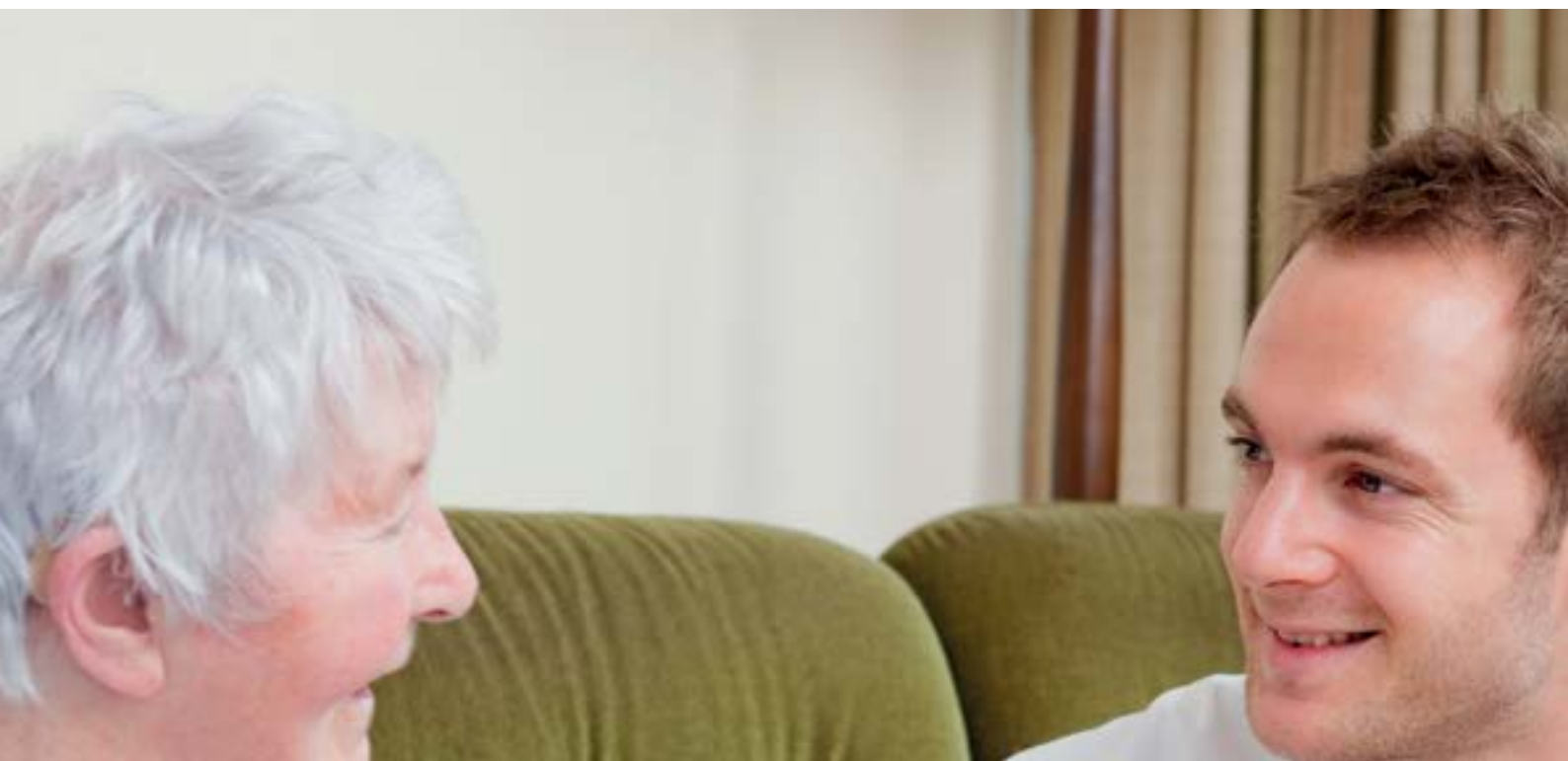


Giving shares is highly tax effective as donors who give shares directly can get full tax relief on any capital gains tax paid. You can also claim income tax relief on the market value of the donated shares.

Selling small amounts of shares can be time consuming and expensive, but making use of ShareGift is easy and hassle-free. For more information on donating a small number of shares, please visit their website at www.ShareGift.org.

MSA

KNOW YOUR RIGHTS



Members often tell us that they find it hard to know what services and support they should be entitled to. Andy Barrick, the Trust's Head of Services looks at the new Care Act and explains what it might mean.

WHAT IS THE CARE ACT?

The first part of the Care Act came into force in England this April and replaces most current law regarding carers and people being cared for. It outlines the way in which local authorities should carry out carer's assessments and needs

assessments; how local authorities should determine who is eligible for support and defines the new obligations on local authorities.

The Care Act applies to England only. There are separate laws about social care elsewhere in the UK. Here is a brief outline of the current situation

in our other UK nations:

In Wales, the Social Services and Wellbeing Act (Wales) became law on 1 May 2014, and will start to take effect from April 2016. In Northern Ireland, changes have also been made to the social care system and in Scotland, the Public Bodies (Joint Working) Act

about the integration of health and social care was granted royal assent on 1 April 2014 and the NHS and councils are beginning to work towards this.

The Care Act (2015) is mainly for adults in need of care and support and adult carers who have been given significant new entitlements under the Act.

People living with MSA will still be entitled to their own 'needs assessment' and a key emphasis of the Act is to focus on preventing or delaying the need for support.

If you have been refused help in the past it may be worth asking for an assessment again, as the criteria for getting help has changed.

From April 2015 there will be national eligibility criteria for both carers and the person being cared for. This will introduce a minimum threshold and if a carer or the person being cared for meets this threshold, they will have 'eligible needs'. Following a financial assessment, the local authority will then have to agree with the person which of their eligible needs they will meet and how.

This will be the first time that local authorities will be required to meet carer's eligible needs directly, and national criteria should make assessments for both carers and the people being cared for more uniform around the country and less like a 'postcode lottery'. Having said this, local authorities will

still have the option of meeting needs that fall below the national minimum threshold.

Obviously few decisions have yet been made under the new eligibility criteria, but it is considered by most 'experts' that many more people could be eligible for care and support.

The Care Act introduces a general duty on local authorities to promote an individual's 'wellbeing'. This means that they should always have a person's wellbeing in mind when making decisions about them or planning services.

If you haven't already you should ask your local authority social services department for an assessment.

It is very important that you fully explain your situation during your assessment, so the impact that your care needs have on your life is spelt out. This is one reason that you may want to think about having someone else with you during the assessment – this could be an independent advocate if you need one.

'Wellbeing' covers a lot of different areas, including: your personal relationships (eg, whether you have a need for more social contact), your physical and mental health, your safety, your financial wellbeing (such as whether there are any benefits you could be claiming), your housing situation and the control you have over your daily life. If your care needs could have a big effect on at least one of the areas of wellbeing mentioned above, then this could be considered a 'significant impact'. Or, if your

care needs have a bit of an effect on several of these areas of wellbeing, this could add up to having a significant impact on your wellbeing as a whole. Using this as a basis, councils have to make their own judgment on whether your care needs are having a significant impact on your wellbeing and daily life.

The wellbeing principles are also part of the eligibility criteria. For example, local authorities have to consider the impact of your role as a carer on your wellbeing. Similarly, they have to consider the impact of a disabled person's needs on their wellbeing. If the impact is significant then the eligibility criteria are likely to be met.

In April 2016 the second part of the Act will come into effect, including how local authorities should charge for both residential care and community care, and the introduction of the 'care cap'.

Most local authorities, even though they can, don't charge carers for services, including services which give them a break from caring. They recognise that charging carers for services is not in the best interest of carers, the disabled person or the local authority. **MSA**

To find out more about the changes visit gov.uk/careandsupport. We would be very keen on finding out more about people's experiences of getting support so please contact us on 020 7940 4666 or support@msatrust.org.uk.

WIN-WIN GIVING

BOOST THE **FEEL GOOD** FACTOR

Make a tax efficient donation to the Trust today.

By leaving a gift in your will, you can reduce inheritance tax or by donating through payroll giving, HMRC will give us the taxable amount you would have paid.

A GIFT IN YOUR WILL & INHERITANCE TAX (IHT)

This type of gift is currently exempt from Inheritance Tax (IHT). A gift of 10% of your estate to us has the additional benefit of reducing the IHT rate payable on the estate from 40% to 36%.

So, where an estate is liable for IHT, every £100 left to charity

will typically reduce IHT on the estate by £40. So for every £100 given to us, the effective cost to other beneficiaries is only £60.

PAYROLL GIVING – GIVE AS YOU EARN (GAYE)

An easy way to donate monthly to the Trust. Your donation is made before tax is deducted from your salary, so it actually costs you less!

A small gift each month will help our research into finding a cause and ultimately a cure for MSA.

As a basic rate UK tax payer, if you pledge £10 per month from your pre-taxed income this reduces your income tax by £2. The actual cost to you is just £8 and MSA Trust gets £10! For higher rate tax payers it's even more. **MSA**

For more information on how you can use the above methods or for more information please contact us on 020 7940 4134 or email fundraising@msatrust.org.uk.

In Memory

Georgina Jarman
Marjorie Hardy
Margaret Kirkaldy
Ken Benfell
Janet Carr
David Duncan
Alexander Kennedy
Eric Armitage
Mushtaq Kazi
Barry Felton

John Foster
Michael Ball
Valerie Hetzel
Gordon Smith
Phillip Hart
Linda Falkingham
Alan Spratt
David Abra
John Chudley
Sheila White

Barbara Upton
Ann Phillips
Doreen Hodges
Michael Simmonds
Henry Armstrong
Martin Shuttlewood
John Chudleigh
Jean Parker
Beryl Williams
Susan Lippett

Janet Wright
Peter Jackson
John Mitchell
Brian Nisbet
Alan Gibbs
Barbara Porter
Colin Hoyer
Peter Lane
Pam Watson
Phillip Parker

THE PROSPECT RESEARCH STUDY

COULD YOU VOLUNTEER FOR RESEARCH?

With support from the MSA Trust, Professors Henry Houlden and Huw Morris, the co-chief investigators of the PROSPECT research study, explain some of their plans for an MSA Network.

“We are delighted to have started the PROSPECT study. The rarity of MSA necessitates collaboration, we hope this will be addressed through our new study.

The network involves seven core centres across the UK – London, Oxford, Cambridge, Manchester, Brighton, Newport and Newcastle – which have a strong history of MSA research and care. We are very fortunate that this study is being co-ordinated and organised by Dr John Woodside who joined us in September 2014.

Through this UK-wide collaborative approach, we will have access to a larger number of patients enabling us to share common datasets and samples. We hope that our research will lead to improved methods for earlier diagnosis of the disease and better tracking of progression.

We also want to identify biomarkers which can track the effectiveness of new interventions that can aid future drug trials.

We are keen that our research is ‘all-inclusive’ for those who wish to participate – including those who live outside of our core seven centres. The MSA Trust and its supporters have emphasised the importance of this approach. Therefore, we have included two linked studies within PROSPECT – a detailed clinic based study (PROSPECT Longitudinal study) and a UK-wide remote patient study (PROSPECT Cross-sectional study) involving patients in their own home, local hospital and local general practice.

The longitudinal study involves several clinical and biomarker assessments which include brain scans, blood samples and, for some patients, spinal fluid samples. This will be followed by a ‘lighter touch’ follow up over the phone or during a clinic visit.

The UK wide, cross-sectional study involves donating a one-off blood sample at your local GP or hospital, together with filling

in questionnaires at home. We would like to include people with MSA and people unaffected by neurological diseases.

Ultimately, we believe that our research will aid the development of new and improved treatments for MSA and raise the profile of MSA research in the UK. We are optimistic that that this research will lead to new clinical treatment trials and hope to work with pharmaceutical companies in this research.”

MSA

If you are interested in participating in this MSA research project, please contact Dr John Woodside at prospect@ucl.ac.uk or call 020 7679 4272.

WHEN A CHANGE IS AS GOOD AS A REST



With the weather getting better, many people start to think about getting away for a break or a holiday. Katie Rigg, one of our MSA Nurse Specialists, suggests some practical tips to make a break relaxing and memorable. We also hear from members who have made their ideas a reality.

After the dark evenings and cool damp winter everybody benefits from a change of scene and something to look forward to; and this is equally true for those supporting someone with MSA and for people with MSA.

Thinking about where to go and how to make it enjoyable for all is particularly important. Trying to do anything off the cuff and spontaneously can be problematic and if it does

not go well may damage your confidence in trying something similar again.

Few people can honestly say that they can just 'up and go' anywhere, we all have things we have to consider and make contingencies for. Most people have their best experiences when they have thought things through and planned well – this is certainly the key to a successful break for people with MSA.

WHERE TO START?

Think about the sort of holiday you would enjoy and that may offer something of interest for all of you that are going away. Most things are possible if you are realistic about your abilities and plan well.

Do you want to go abroad or stay somewhere different on home soil?

Once you have answered that question think about the practicalities such as how you will get to your chosen destination, and whether you need to be able to travel around once there.

Remember this is a holiday so you and any family carer need to make things as easy and manageable as possible – be realistic, if it means you can explore the area better and not worry about falling or fatigue then take a wheelchair (ideally with a battery pack) or enquire if there will be access to a wheelchair or motorised scooter when you get to the destination.

If you are booking somewhere to stay **always** go for the disabled option as it will give you more space, and if you have particular needs ensure these can be met – eg hoist, commode chair, profile bed, wet-room etc.

Ensure that you have appropriate travel insurance – see MSA website or our factsheet for companies others with MSA have used successfully.

If you are thinking of going to a warm climate area remember to avoid sitting in direct sunlight or getting overheated as this can drop your blood pressure, and drink plenty of water, add extra salt to your diet, or take salt tablets.

TRANSPORT AND TRAVEL

Further useful details for different modes of travel and contact details can be found in our ‘Travelling and MSA’ factsheet.

Whichever form of transport you need to use there are key

things you should mention to the airline, ferry, cruise company or rail company when booking your seats:

Do you need extra leg room for the seat?

Do you need to be close to the aisle, exits and toilets?

What assistance can they offer? – Take **any** assistance offered, even if you think you won’t need it, it will make your journey easier.

Don’t assume ‘disabled facility’ will meet your needs – ask explicitly what this means.

CAR

If you are planning to hire a car whilst on holiday, consider booking a more spacious one that is easier to get in and out of. It may help to pack a ‘turntable’ seat and a slide sheet in your main luggage.

Some vehicle hire companies have wheelchair accessible vehicles for hire. If going overseas, check with the resort or tour operator.

PRIOR TO DEPARTURE

Request a review by your therapy team about a month in advance of departure to pick up on any snags they may spot and any tips they might give you to manage potential scenarios whilst away.

Ask your consultant or GP for a letter to carry with you in your hand luggage about your current health status and medication and add useful contact telephone numbers eg GP, consultant, MSA Nurse Specialist in case you need to call someone about a medical problem.

Ensure you have enough medication for the time you are away plus one week, and that the bottles are labelled correctly with your current doses on them. Keep your medications and a current list of all you are taking in your hand luggage if possible (or at least two days supply)

If you use a Conveen or catheter, ensure you have spares with you; and you may find using a leg bag for the journey reduces the need to find and access toilets.

Having a couple of ‘Guides to MSA’ can be useful as anyone trying to help you with a medical problem may not have heard of MSA.

If there are everyday aids that you use eg, modified cup, plate, cutlery; – then pack these (though knives won’t be able to go in hand luggage on flights) and if you use thickeners make sure these are also packed.

If you have a RADAR key for disabled toilet access take this with you.

Finally if you are going to hot countries with questionable water supply then take water purification tablets and salt tablets with you.

If you prepare in advance there is no reason why you can’t have a great time, but don’t take our word for it, read what some of our members who have been there and done it have to say overleaf... **MSA**

MEMBERS HOLIDAYS

Henry James said about travel “One’s destination is never a place, but a new way of seeing things”. Our members below would agree and share some of their experiences...



Ken and Shirley Forster jetted off to New Zealand and Australia at the beginning of the year for an action-packed six week holiday. Ken is from New Zealand and with careful planning the trip enabled them to spend time catching up with family and friends. Shirley gives some important tips for people hoping to get away including:

Booking a fully flexible airline fare so that no loss would be made if the trip needed to be changed or cancelled at the last minute.

Taking medication for the full period plus a week extra just in case.

Factoring in plenty of time to get organised eg, spending a night at an airport hotel before the flight. **MSA**



Andrew Aldridge makes sure he gets away regularly and explains that this doesn’t need to be somewhere exotic. “There are plenty of good locations close to home and just getting away from the usual routine and worries can be good for everyone, and can provide space and time to talk about things.” Andrew also gives some useful tips including; Making sure your villa or hotel has a shower cubicle (ideally without a lip) rather than a bath. Keeping some spare medication and catheters etc. in your hand luggage when flying in case of delays. Also remember to take your Blue Badge parking scheme permit with you as this applies in European countries. **MSA**



Joy Roach and her mother Janet, who is diagnosed with MSA, recently took a trip across the channel to Paris. Joy explains that on the whole everybody they came across was incredibly helpful so don’t be put off going on holiday, it just needs some extra planning. Some of the things Joy and Janet found to be helpful were:

Emailing or calling the hotels before booking to ask specifically about disabled access as many advertise about being wheelchair friendly but aren’t.

If you need to take lots of equipment there are companies such as mobilityequipmentdirect.co.uk that will loan hoists, beds or mattresses and can deliver these directly to the hotel whether in the UK or abroad. **MSA**

RESEARCH ROUND-UP



Dr Lucia Schottlaender

In the last issue of MSA News we looked at one of the two research projects that the Trust is currently funding. This article focusses on the second, based at UCL Institute of Neurology.

The MSA Trust has granted funding to Dr Lucia Schottlaender, a research fellow at the University College Institute of Neurology in London. Lucia's PhD supervisor, Professor Houlden, had also received funding from the Trust for earlier work mapping the genes of people with MSA. This grant will allow Lucia to build on this, by looking for genes and molecules that are particularly active in MSA.

Lucia and her team are collecting blood samples from people diagnosed with suspected MSA, and brain tissue samples from people who have died from the disease. They will compare these to samples from people with Parkinson's disease and people who do not have neurological conditions. By looking for differences, the team hope to find variations that are specific to MSA.

The researchers will test the samples using a process called expression profiling. This measures all the 'messenger molecules' that are produced when a

gene is active. These messenger molecules tell the body to make the protein that the gene codes for. So, expression profiling is a way of finding out which genes were active when each sample was taken, and how active they are in producing specific proteins.

Proteins are the building blocks of the body – enzymes, hormones and cells are all made of protein. Each gene carries the code for making an individual protein and mistakes in genes can lead to too much, too little or an abnormal form of a protein being made.

The potential of the research is enormous – for example, finding genes that are over-active in MSA could be the first step in developing drugs to block the proteins they make and so treat the disease.

Earlier research has already highlighted two genes called SNCA and COQ2 that are suspected of being involved in MSA. But as Lucia points out "The beauty of this type of research is that it is completely

unbiased, because it gives us information about all the active genes in MSA. We will of course investigate the two that were previously linked to MSA, but we may also find highly active genes that we weren't aware of."

The project will continue for around 18 months and it is hoped that it could be the first step towards developing a reliable blood test for MSA. As a doctor attending clinics, Lucia sees the anguish caused to people with MSA and their families by the current difficulty in diagnosing MSA, and understands what a difference a reliable test could make.

By finding genes that could be targets for potential treatments, the research could also eventually lead to clinical trials of drugs to try and slow down or stop the disease progressing. As Lucia says "Unfortunately finding an effective treatment is still some way off, but our research could be important in beginning that process." **MSA**

FUNDRAISING ROUND-UP

We would like to thank all our fundraisers who again showed their commitment to the Trust, by giving so generously. Whether they made a one-off donation or regular monthly gifts; strapped themselves to an aeroplane or covered themselves in mud; baked cakes or washed cars or by remembering a loved one's passing – we really appreciate your hard work and commitment to supporting everyone affected by MSA.

Here is just a taste of what's been happening:

MARCH

Well done to Catherine Hinton, who was our top fundraiser during MSA Awareness Month. Catherine and her team at Nuffield Health, Fitness and Wellbeing Centre in Surrey, raised **£3,800**.

Heather Buckel and Nick Humphries both took on the Saharan Desert and returned to tell the tale. An amazing feat which raised just shy of **£6,000**.

The MSA Trust hosted two Service of Light events during March with over **£7,000** donated to us to help fund our Research. Thanks to those who attended and those who couldn't make it but sent donations, you've all contributed to what is becoming our flagship event.



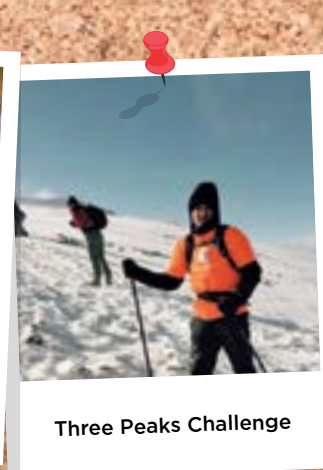
Nuffield Fundraising Day -
Catherine & Mum



esl Cake Sale



Service of Light



Three Peaks Challenge

APRIL

Staff from our corporate partner Mask-arade, got downright dirty for MSA by completing the Wolf Run and raised over **£600**.

Julie Payne bravely strapped herself to the wings of a plane in aid of the Trust and raised over **£2,000** in the process.

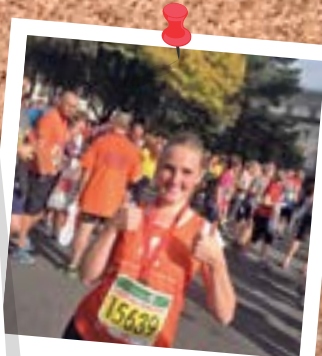
April saw 12 intrepid runners take on the Virgin Money London Marathon, our largest number of runners ever! Collectively they have raised over **£18,000** for the Trust, with more donations expected.



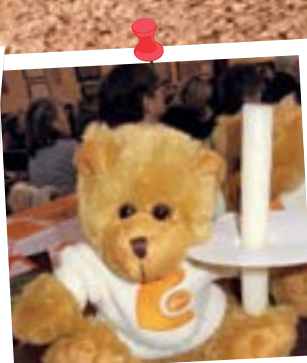
Mask-arade Team Wolf Run



ALLSTATE Corporate Donation



Sarah Running the Cardiff Half Marathon



Service of Light

MAY

Yorkshire's Three Peaks were popular in April. Max Dundas led his band of merry men and women up the Peaks and collectively raised the amazing sum of **£15,000**.

Valerie Arnold and the Charities Committee of Allstate Northern Ireland generously donated £500 towards our work. In addition Investec Bank Plc, London kindly donated **£250** in memory of a much loved employee.

Andrew Hirst and Fiona also conquered the Peaks and raised the outstanding sum of **£1,840** to support the Trust's work.

Chesterton Bowls Club, Cambridge raised the fantastic sum of **£2,100** in memory of their much loved friend and colleague, Richard Griggs.

Would you like to take part in one of our events, or organise your own? Then visit our website www.msatrust.org.uk/get-involved or email fundraising@msatrust.org.uk. If you are happy to do it, then we'll be happy to support you!

Please continue to nominate the MSA Trust at your local Asda Supermarket

The Green Token Scheme by Asda allows their customers to vote for a charity to receive a donation. You can help us become a chosen charity by filling out a "nominate a cause" form either in a local store or through your local store's online page at www.asda.com. We will announce our nominations on our social media pages to let you know when you can vote for us the next time go shopping!

Follow us on Twitter and Facebook to hear exciting news coming up about our national Summer 'Get Together' fundraising event and our activities and events for World MSA Day – Saturday 3rd October 2015.

SUPPORTING & HELPING EACH OTHER

Proving you know best...

With two new support groups starting in Somerset and Worcester and the continuing growth of our network, we are gaining more and more useful insights, tips and hints from our members. Emma Rushton, Support Services Officer takes a look at some of these:

Support groups are a great way of meeting other people who are experiencing life with MSA. Our aim is for groups to be friendly places where people can talk about any difficulties they may be having and share solutions to these. We would encourage you to mention these meetings to any interested health and social care professionals you have contact with and invite them to come along. This way we can raise awareness of MSA and use their knowledge to help others attending the meetings.

Here we feature just a few snippets of the valuable advice that was passed on at support groups held around the country over the past few months:

The Dorset support group discussed the benefits that hydrotherapy can have for people with MSA. It can be difficult to get a referral for this but speak to your GP or ask at your local swimming pool for disabled sessions.

The Turn2us charity has been praised for giving free, informative and helpful advice on benefits, grant applications and local services. Go to their website www.turn2us.org.uk for ways to contact them and access support on any complex benefits questions you may have.

The suggestion of having outward opening

doors in your bathroom is often advocated by our specialist nurses at support groups. This means that if someone has a fall people are still able to easily access the bathroom and help when necessary.

A member at the South Yorkshire support group spoke about a website called www.preloved.co.uk which allows you to buy and sell second-hand furniture and equipment. There is an allocated page for disabled equipment which people have found to be useful when looking for a cheaper alternative to buying something brand new.

At the Somerset support group the use of silk or satin bed sheets or pyjamas (not both at the same time!) was discussed as a good way of helping people to turn or shift over in bed. **MSA**

If you would like to find out more about any of these suggestions, if you have any of your own, or you have any questions about your local support group, please contact me at emma.rushton@msatrust.org.uk or call me on 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.

GROUPS	VENUE	DATE & TIME
Northumberland/Cumbria	Greenholme Court Community Room, Greenholme court, Haltwhistle Hospital, Westgate, Haltwhistle NE49 9AJ	Thur, 9 July - 1.30pm
Dorset	Trinity Methodist Church Hall, Southbourne Road, Bournemouth BH6 5AQ	Mon, 13 July - 11am
Surrey Carer's lunch	Please contact the Trust office for more details	Thur, 16 July - 12.30pm
North Yorkshire	Victoria Hall, 24 Kirkgate, Settle BD24 9DZ	Fri, 17 July - 1.30pm
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 22 July - 1.30pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing BN11 5DR	Tue, 25 August - 2.00pm
Gloucestershire	Whitminster Village Hall, School Lane, Gloucester GL2 7NT	Thur, 3 Sept - 1.30pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 7 Sept - 1.30pm
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	Thur, 10 Sept - 2.00pm
Somerset/Bristol	Locking Castle Church, Jasmine Way, Weston-Super-Mare BS24 7JW	Wed, 16 Sept - 1.00pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 17 Sept - 2.00pm
Greater Manchester	St Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Thur, 17 Sept - 2.00pm
Wiltshire	St Pauls Church Hall, Malmesbury Road, Chippenham SN15 1PS	Mon, 21 Sept - 2.00pm
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Tue, 22 Sept - 2.00pm
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 23 Sept - 1.30pm
West Midlands	Moxley Peoples Centre, 3 Queen Street, Moxley WS10 8TA	Thurs, 24 Sept - 11am
Oxfordshire	The Girl Guide Hall, Southern Road, Thame OX9 2EE	Mon, 28 Sept - 1.00pm
Cornwall	Echo Centre, Barras Place, Liskeard PL14 6AY	Mon, 5 Oct - 1.00pm
Surrey Carer's lunch	Please contact the Trust office for more details	Thur, 8 Oct - 12.30pm
Dorset	Trinity Methodist Church Hall, Southbourne Road, Bournemouth BH6 5AQ	Mon, 12 Oct - 11am
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 14 Oct - 1.30pm
Cambridge	Barton Bowls Pavilion High Street. Barton CB23 7BG	Thur, 15 Oct - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Roah, Roydon, Diss IP22 5RB	Wed, 28 Oct - 2.00pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6 1JQ	Wed, 28 Oct - 2.00pm



RAISING AWARENESS WORKING TOGETHER

“It’s amazing what we can accomplish when we’re in it together.”

Franca Tranza, the Trust’s Head of Communications looks at how we can all promote greater awareness of MSA.

It’s fantastic when newspaper articles or radio and TV broadcasts feature MSA. Each time the media covers MSA means that more people affected by it find out about the Trust and it also means that there is more awareness generally.

But behind each article or broadcast there has often been collaboration between members, the Trust, the corporate sector, other charities and journalists. A special thank you to all the eventers who not only take on sponsored marathons, walks, sky dives, Sahara treks, bake cakes or ask for their wedding donations to go to the Trust, but who also agree to talk to the media about their personal experiences. This can be time consuming but journalists are always interested in real life stories and it’s one of the best ways we can raise awareness.

Our Fundraising team has

been busy trying to set up corporate partnerships. So far our partners tend to be companies with a link to MSA. Maskarade, the original Celebrity and Personalised Mask Company, came on board in 2014 as one of the director’s father-in-law has MSA; the Klondyke Group’s Chairman had MSA, and esl Employer Services formed a link with us after one of their staff members was diagnosed with MSA.

But the journey doesn’t stop at fundraising, all these companies have been brilliant in raising awareness about MSA on social media and helping to grow our online communities.

Working with other charities is also really important as our voice will be much louder if we join forces on specific issues such as hospice care, research or caring. Earlier in the year our Services Team went to meet

staff at Hospice UK. This not only helped build relationships but the charity agreed to publish an article on MSA in their online newsletter.

Recently the Trust was contacted by a PR specialist whose mother-in-law had MSA. He was passionate about ‘wanting to do something’. He used his time and influence to set up a creative thinking session with his colleagues to develop a campaign to raise awareness and funds - so watch this space.

Looking ahead, World MSA Awareness Day 2015 (3 October) is around the corner. Last year one member was instrumental in getting the managers of Blackpool Tower to turn the lights orange on the day.

Let us know how you’re planning to mark the day this year – let’s work together to raise as much awareness as we can. **MSA**

LIFE IS FULL OF SURPRISES

Our guest writer this month, David Murfin shares a wonderful story:

At the last support group I attended with my wife Dorothy in Etton in East Yorkshire, we were asked to report on the status quo and also on positive happenings within the last two weeks. We said that we were enjoying the signs of spring, longer hours of daylight and the emerging spring flowers.

Then we decided to tell the group about my recent confirmation in the faith of the Church of England which meant a great deal to us.

MSA has made getting out and about extremely difficult for me and I was unable to join the other candidates being confirmed at our local church. So I asked Archbishop Sentamu whether a bishop could come to our home to confirm me.

The reply was a wonderful surprise. He said he would come himself having first officiated at the confirmation at church. Last winter His Grace arrived with his Domestic Chaplain, Reverend Richard Carew and with the witnesses of Dorothy, our son, daughter, son-in-law, our two granddaughters, our vicar Reverend Martin Baldock and two very supportive friends the



Archbishop Sentamu

service took place.

It was a joyous occasion. The Archbishop was robed and afterwards led us in singing a hymn. Although the original intention was not to include communion when His Grace spotted a bottle of red wine and homemade bread in the kitchen he suggested he should give us all communion, a real bonus.

We were very grateful. It was a very happy occasion. You never know what's in front of you – happy surprises can be around the corner, whatever your situation. **MSA**

Another one of our members called David Probert, from Surrey, has written a poignant and affectionate account of being evacuated from North London to Airlie in Angus as a child during World War Two. All proceeds from the booklet, "Childhood Memories of Being a 'Sassenach' in Airlie 1940-1953" will go to the MSA Trust. David and his wife Migs, who has MSA, have always supported our work and we are very grateful for this generous offer.

To order the book please write to David Probert at: 22, Lower Weybourne Lane, FARNHAM, Surrey, GU9 9HN enclosing a cheque for £6.00 (£5 for the book and £1 p+p) made payable to D J Probert. For further information please contact David at migs@zeba.fsnet.co.uk.



VOLUNTEERING WITH THE MULTIPLE SYSTEM ATROPHY TRUST

Are you interested in charity volunteering? Could you help spread the word about MSA and the work of the Trust? Maybe you could join us to make some noise cheering at an event? How about making a difference by volunteering at our offices? Is fundraising your forte? Interested? Then volunteer with the Multiple System Atrophy Trust today!

Whether for a couple of hours here and there or a regular commitment over a longer period, whatever time you can give really will matter. You'll be gaining new skills, meeting new people and helping us to support people affected by MSA.

We have volunteering opportunities all over the UK. To find out more about how you could support us in your local area and to find out about opportunities near you please complete and return the form below or email us at volunteer@msatrust.org.uk.

Name:.....

Address:.....

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

Email:.....

I'm interested in volunteering, please contact me to tell me more about:

- ☐ How to organise my own event ☐ Co-ordinating volunteers in my area ☐ Raising awareness of MSA
☐ Helping in our office ☐ Helping at events ☐ Other

If 'Other', please specify:.....

Please return completed forms to:

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